

GENETIC ALLIANCE
MONOGRAPH
SERIES #4

COMMUNITY CENTERED FAMILY HEALTH HISTORY Collaboration Across Communities: How Do You Make Research Community-Specific and Universally-Relevant?

PUBLISHED BY GENETIC ALLIANCE

Genetic Alliance: Vaughn Edelson, Sharon Terry, James O'Leary • **American Folklife Center of the Library of Congress:** Ilana Harlow, Margaret Kruesi • **Alpha-1 Foundation:** Dawn McGee, Charlie Strange • **Health Resources and Services Administration:** Penny Kyler • **Institute for Cultural Partnerships:** Claudia Petruccio • **Intermountain Healthcare:** Marc Williams, Janet Williams • **Iona College:** Penelope Moore, William Gratzner, Caroline Lieber • **National Council of La Raza:** Alejandra Gepp • **National Psoriasis Foundation:** Nicora Gardner • **Office of Justice and Peace/St. Mary's Health Wagon:** Karen O'Quinn, Teresa Gardner • **Seattle Indian Health Board:** Meghan Jernigan, Alice Park, Ralph Forquera



Community Centered Family Health History. Collaboration Across Communities: How Do You Make Research Community-Specific and Universally-Relevant?

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COMMUNITY CENTERED FAMILY HEALTH HISTORY

Collaboration Across Communities: How Do You Make Research Community-Specific and Universally-Relevant?



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COMMUNITY CENTERED FAMILY HEALTH HISTORY COLLABORATION ACROSS COMMUNITIES: HOW DO YOU MAKE RESEARCH COMMUNITY-SPECIFIC AND UNIVERSALLY-RELEVANT?

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EXECUTIVE SUMMARY

Evaluation of family health history represents a first step in identifying genetic contributors to health and can serve as an important basis for improving healthcare and encouraging a healthy lifestyle. Though family health history tools abound, neither the premise that they will make a difference in health outcomes nor the analysis of their usefulness along a medical-nonmedical continuum has been validated in a systematic, evidence-based study as measured by changed behavior leading to better personal health. The fundamental purpose of this project was to create and evaluate a customizable, nonmedical family health history toolkit (*Does It Run In the Family?*), informed by oral history and folklore traditions.

With input from partner organizations representing several diverse community types, we modified the toolkit so that it is accessible and applicable across cultures; in disparate environments, from clinics to non-health settings; and within disease-specific communities. We then evaluated the toolkit to answer two questions: Does the *Does It Run In the Family?* toolkit encourage discussion and collection of family health history information, and does the information collected encourage behavioral changes that lead to improved health for individuals, families, and communities? We hypothesized that accessible family health history tools produced by the community, for the community, would promote conversations and increased knowledge about health within the family and translate knowledge of family health history into healthy choices.

All research, engagement, evaluation, and education undertaken in this project were community-based. To start, Genetic Alliance partnered with three community-based nonprofit organizations, two disease-specific communities, a major healthcare delivery system, a faith-based service organization, and a college. Genetic Alliance later added 10 partners, including an employee health and wellness program, a fitness center, hospitals and clinics, a community center, a medical school curriculum, and others. Through these partnerships, we engaged participants representing a wide range of demographic characteristics and ethno-cultural identities.

Throughout the course of the three-year cooperative agreement with the Health Resources and Services Administration, we successfully evaluated the *Does It Run In the Family?* toolkit and found that it increases communication within the family about health and increases awareness about family health history. Furthermore, we funded the successful integration of the toolkit into 10 communities through the CCFHH Program Awards, which now serve as model projects for people interested in launching their own family health history initiative. Finally, we developed an online, customizable version of the *Does It Run In the Family?* toolkit so that people can create unique family health history materials for their families, organizations, and communities. The toolkit itself and the online tool have been disseminated through the local, regional, and national networks of Genetic Alliance and all partners.

BACKGROUND

Family health history is an accessible tool that captures genetic, lifestyle, and environmental factors; allows a healthcare provider to diagnose conditions and understand risk; increases health and genetics knowledge for the individual and the family; and promotes conversations about health in the family and community. The evaluation of an individual's family health history (FHH) represents a first step in identifying genetic contributors to one's health and can serve as an important basis for improving healthcare and encouraging a healthy lifestyle¹⁻⁹. However, many of the tools designed to collect FHH come from a strictly medical perspective¹⁰. Specifically, these family health history tools (FHHTs) translate patient knowledge of their own FHH into a form that is useful to healthcare providers. In most instances, this process involves the creation of a pedigree. Though creating this provider-friendly pedigree is important, the tools that require a thorough knowledge of FHH (medical model tools) at the onset prove inaccessible to many individuals. At the outset of the Community Centered Family Health History project, we hypothesized that the chief reasons for the inaccessibility of medical model tools are: 1) unfamiliar terminology, 2) the hurdle of collecting sensitive health information from relatives, and 3) a lack of culturally appropriate descriptions of family structures and health conditions.

The use of a traditional medical model tool that is not community-based may be problematic for other reasons as well. For example, families may not feel comfortable using a tool that is disseminated through a government portal or a healthcare setting. This can be especially true if the tool does not include images and terminology familiar to the user. Furthermore, because existing FHHTs are frequently offered in either a clinical or an electronic setting, few have studied whether these tools actually improve health outcomes.



Many entities (e.g. AMA, AAFP, the U.S. Surgeon General, and the CDC) have identified a need for FHHTs that can improve healthcare delivery and outcomes^{6,11}. Within the healthcare community is an acknowledged need for proven methods of information collection, archiving, and sharing within families and with healthcare providers. This is a significant unmet need in healthcare and health education nationwide. Though many FHHTs exist, neither the premise that they will make a difference in health outcomes nor the analysis of their usefulness along a medical-nonmedical continuum has been validated in a systematic, evidence-based study measuring changed behavior that leads to improved health outcomes^{12,13}.

In response to these issues, in 2004-2005, through the HRSA/MCHB cooperative agreement *Healthy Choices through Family Health History Awareness* (U33 MC02603), Institute for Cultural Partnership, Genetic Alliance, American Folklife Center of the Library of Congress, and American Society of Human Genetics developed a nonmedical FHHT, *Healthy Choices through Family Health History Awareness Tool*, that incorporates the knowledge and methods of oral historians and folklorists to aid individuals in better describing, archiving, and understanding their own FHH. While the medical community has only recently begun to recognize and appreciate attention to personal story¹⁴, the nonmedical tool was designed with community input and the intention to create modular sections that could be customized to different communities. This adaptability ensures a more accessible tool whose utility can be measured effectively on a community level. In addition, the involvement of established community organizations fuels the sustainability of the initiative.

INTRODUCTION

The *Healthy Choices through Family Health History Awareness Tool* was specific to the Institute for Cultural Partnerships' Harrisburg, PA, community of largely African Americans and Latinos. After completing the *Healthy Choices through Family Health History Awareness* project, Genetic Alliance partnered with a diverse group of eight organizations through another HRSA cooperative agreement (U33 MC06836). The Community Centered Family Health History (CCFHH) Project aimed to create customized family health history tools for each community. Those partners include:

- Alpha-1 Foundation
- Institute for Cultural Partnerships
- Intermountain Healthcare
- Iona College
- National Council of La Raza
- National Psoriasis Foundation
- Office of Justice and Peace/St. Mary's Health Wagon
- Seattle Indian Health Board's Urban Indian Health Institute

In addition to these community partners, American Society of Human Genetics and American Folklife Center advised during the materials-development phase.

The product of CCFHH is the *Does It Run In the Family?* toolkit, a set of two booklets and supplemental materials. *Does It Run In the Family?* contains some content that is static across communities; a gene is always a gene, in Harrisburg, as well as Oakland, Salt Lake City, and New Rochelle, NY. However, the personal health stories, photographs, and specific health conditions presented in each partner's customized version of the toolkit are particular to that community. All eight community partners reviewed the template and helped with the adaptation of the *Healthy Choices through Family Health History Awareness Tool*. "A Guide to Family Health History" explains the importance of family health history and how to collect it, and "A Guide for Understanding Genetics and Health" explains basic genetics concepts and introduces readers to various conditions that can run in families. All partners' customized booklets are available for download on Genetic Alliance's website, www.geneticalliance.org/ccfhh. The toolkit was not designed to replace medical model tools, but as a complementary resource to be used in combination with them.

Like its *Healthy Choices* predecessor, *Does It Run In the Family?* combines family health history, personal health stories, and genetics to help individuals and families gather their health history and use that information to make positive health choices. The key difference is its customizable nature. A tool created for a specific community in Harrisburg, PA, could not simply be reproduced and distributed to communities across the country with the expectation of positive health outcomes based on its use. Instead, we hypothesized that accessible tools produced **by the community, for the community**, would promote conversations about health within the family and translate knowledge of family health history into healthy choices.

Our diverse partner organizations reflect this belief. During the first year of this project, we engaged three racial/ethnic communities (African American, Hispanic, and American Indian/Alaska Native), one large multistate healthcare system, and two virtual communities (genetic condition-specific communities); these are considered Year 1 Partners. At the 18-month mark, we added two more communities—one rural, faith-based Appalachian community and one community and college collaboration project on aging (Year 2 Partners). At the 22-month mark, after a competitive application process, 10 more communities were awarded funding (Year 3 Partners or CCFHH Program Awardees).

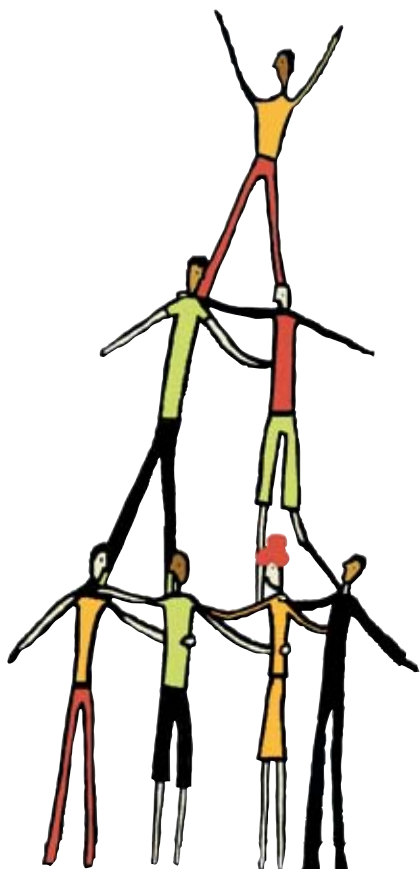
We maintained five project tenets for this national, yet community-based, endeavor: accessibility, community input, sustainability, evaluation, and resource sharing. At the outset, to guide the project according to this maxim, we established basic definitions and laid out key principles for community engagement.

COMMUNITY ENGAGEMENT

Every type of community, and every individual, possesses unique access points to health information. Given this diversity, a flexible approach to customization of materials is required. With a flexible definition of community and a flexible approach, the varied needs of different communities can be met in a culturally appropriate way.

Genetic Alliance and CCFHH partners employ a broad, flexible definition of **community: a population that may be defined by geography, culture, race, ethnicity, age, gender, sexual orientation, disability or other health condition, or groups that have a common interest or cause, such as health or service agencies and organizations, health practitioners, policymakers, or groups with public health concerns.** Over the course of three years, Genetic Alliance partnered with organizations that work closely with each type of community represented in that definition—including American Indians/Alaska Natives, African Americans, Latinos, residents of Appalachia, patients in a healthcare service setting, members of disease-specific support groups, elderly Americans, students in a university setting—and more.

By design, each of the participating communities represents a different set of needs. To develop useful, effective tools that are widely used, it is imperative to engage the audiences that will be the ultimate beneficiaries of the tool.



community: a population that may be defined by geography, culture, race, ethnicity, age, gender, sexual orientation, disability or other health condition, or groups that have a common interest or cause, such as health or service agencies and organizations, health practitioners, policymakers, or groups with public health concerns.

CUSTOMIZATION

Given the diversity of individuals, families, and communities, it is impossible to create a one-size-fits-all family health history tool. Genetic Alliance partnered with a diverse group of communities and organizations, starting with eight and eventually totaling more than 20, to create customized family health history tools. The *Does It Run In the Family?* toolkit consists of two booklets: the first, “A Guide to Family Health History,” provides information to help families collect, organize, and understand their family health history and why it is important. It can be customized with personal health stories, photos, quotes, interview questions, family tree information, and resources.

The second booklet, “A Guide for Understanding Genetics and Health,” modified from the original ICP version and designed with substantial input from the American Society of Human Genetics, explains the basics of how genetics impacts health and how knowledge of family health history can help individuals stay healthy. It also includes information on health conditions that run in the family and who is at risk, as well as hints for health. It can be customized with risk statistics, health conditions that are particularly prevalent in a family or community, and resources. All project partners directly engaged community members to collect the customizable information.

ACCESSIBILITY

Access to resources and services is at the heart of this and all Genetic Alliance projects. Customization ensures that the *Does It Run In the Family?* toolkit is relevant and culturally sensitive, increasing the likelihood that it will be considered credible and engaging and will be effective in diverse communities. This has proved successful, with data showing that the customized booklets increased communication within families.

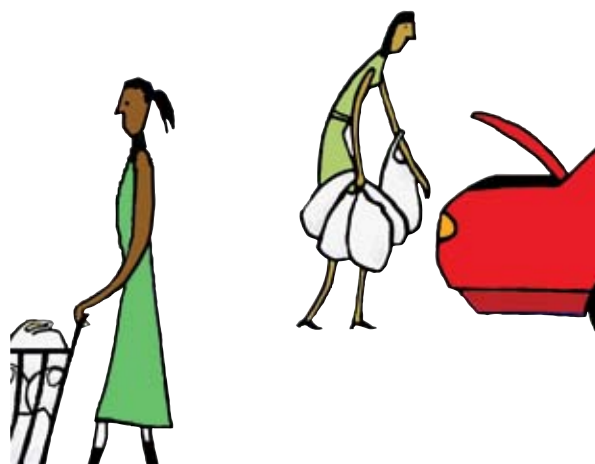
The toolkit is accessible both in terms of the customizable information it contains and the media in which it can be presented—as both a hard copy and a PDF. Modes of communication vary among communities. National Psoriasis Foundation, for example, communicated electronically exclusively, using online registries and email to recruit participants for the project and follow up with them throughout the study. Institute for Cultural Partnerships, on the other hand, used community liaisons: trusted members of the target community who acted as recruiters. Some partners mailed booklets to community members or disseminated them at health fairs and local events; others posted the booklets to a website for download, while still others used both methods to reach diverse populations within single communities. Each partner tailored its recruitment and dissemination using methods known to be successful in that community. (Please refer to *Community-specific Models* on page 16.)

Furthermore, the toolkit is accessible in terms of literacy and language. First, the booklets were kept at or below an eighth-grade reading level. To create culturally and linguistically competent materials when working with the Hispanic community through National Council of La Raza (NCLR), Genetic Alliance hired a professional translator to translate the booklets into Spanish. NCLR made additional modifications to the booklets to make them appeal more to the community, such as including more photographs and modifying the illustrations to look more like the population they serve. In this way, through the project, Genetic Alliance was able to augment the culturally competent, hard copy health educational materials in circulation in Spanish. Genetic Alliance also began translation of the booklets into Mandarin Chinese. A Genetic Alliance intern worked on the translation project throughout her internship in spring 2008. She was able to complete translation of Book 1, “A Guide to Family Health History,” during her tenure at Genetic Alliance.

INTEGRATION

Family health history can be the link between a person’s daily life and his or her health, as well as the bridge between health and genetics. It has applications beyond the confines of a healthcare provider’s office. It can be incorporated into video storytelling, contests, fitness activities, volunteer programs, picnics or house parties, art projects and murals, family events such as birthdays and weddings, workshops and webinars, and provider engagement and training. Family health history information in general, and the *Does It Run In the Family?* toolkit specifically, can be integrated easily into existing programs and initiatives in innovative ways, making it accessible and sustainable in diverse communities.

Family health history should not be a stand-alone intervention. The purpose of this project was ultimately to integrate FHH into ongoing community programs and initiatives so that it became intertwined with and integral to the success of those programs and the health of those communities. Integration is key for sustainability.



RESEARCH QUESTIONS

CCFHH focused on the usability and utility of the toolkit and set out to answer two questions. While a research outline and community challenges are presented below, project results are published separately; this monograph is meant to focus on the community-based nature of the demonstration project rather than the specific outcomes. However, a brief description of and background for the research questions are as follows:

Does the Does It Run In the Family? toolkit encourage discussion and collection of family health history information?

Even when one considers the weaknesses of existing FHHTs, one should not underestimate their value. For example, Sharon Terry, Genetic Alliance president and chief executive officer, conducted two focus groups, held at the Washington, DC, free clinic Bread for the City in late 2005, to discern how individuals perceive their healthcare providers' knowledge of genetics. The 29 participants, all of whom were members of underserved communities, stated—without prompting—that understanding family health history would catalyze significant changes in their lifestyle aimed at improving their health. Furthermore, a 2004 Research! America survey, co-funded by Genetic Alliance and published in *Parade*, reported that 96% of Americans believe that knowing their family health history is important¹⁵.

The Community Centered Family Health History Project used the *Healthy Choices through Family Health History Awareness Tool* as a starting point. To refine and evaluate the tool, which became the *Does It Run In the Family?* toolkit, we wanted to know: How useful are the booklets? Do families like them? Do individuals want to use them in the future with their families and healthcare providers?

Does the information collected encourage behavioral changes that lead to improved health for individuals, families, and communities?

Just as our definition of community is broad, no one agreed-upon concept of health exists. Key to answering this question is taking into account the varying definitions of health among communities. For many, the notion of health goes far beyond the physical; it encompasses mental and spiritual well-being, as well as quality of life. So each community's measure of improved health and satisfaction with the results of a family health history intervention might be very different from the rest.

Nevertheless, a few outcomes can be measured across communities: Do the booklets increase communication within families and with a healthcare provider? Do individuals adjust diet and exercise based on the information they learned? Does the new knowledge influence people's opinion about the importance of family health history?

DEMONSTRATION PROJECT

The following figure provides the complete research structure, including information about project development, recruitment and data collection, and data and publication at both the community-specific and universally-relevant levels.

	Community Specific	Universally Relevant
Project development	<ul style="list-style-type: none"> • Involvement in grant writing • Partner specific goals • Community advisory boards 	<ul style="list-style-type: none"> • Well defined overall project goals • Transparency
Recruitment and data collection	<ul style="list-style-type: none"> • Flexible recruitment models • Additional community-specific research modules • Community institutional review board 	<ul style="list-style-type: none"> • Template framework for methodology • Third party evaluator
Data and publications	<ul style="list-style-type: none"> • Clear data ownerships • Sign-off on aggregate data publications • Individual community data publications 	<ul style="list-style-type: none"> • Clear data use agreements • Aggregate data publications

All research, engagement, evaluation, and education undertaken in this project was community-based. One community, Seattle Indian Health Board, went through an institutional review board (IRB) process for approval prior to recruiting community members for the project, and the University of Washington IRB approved the overall project protocol. During the first phase of the project, the original version of the *Does It Run In the Family?* toolkit was modified to produce a template suitable for customization by various communities. This template was designed with focus group data and community input. Specifically, edits focused on reducing text and literacy level, maintaining collection options, expanding the number of stories, and reorganizing the materials into succinct steps. The development of these steps (Collect, Organize, and Understand) also led to the creation of supplemental materials such as a Family Health History Questionnaire (see page 53) and Healthcare Provider Card (see page 55), which were organized with the two booklets, "A Guide to Family Health History" and "A Guide for Understanding Genetics and Health," into a customizable toolkit.

During the second phase of the project, partners customized the existing toolkit, tailoring the templates to their communities using pictures, stories, quotes, health statistics, local resources, and relevant disease information.

The communities then continued evaluating the booklets through health liaison training, community recruitment, surveys, focus groups, and interviews. Basic evaluation protocol was as follows:

During the project, 25 families, consisting of at least two family members related by blood, were recruited in each community. Each family member was screened for the following requirements:

- 1) At least 18 years old
- 2) Genetically related to enrolled family members
- 3) Not involved in another family health history project

A baseline and follow-up survey were developed from a Centers for Disease Control and Prevention evaluation of a direct-to-consumer marketing campaign by Myriad Genetics. The survey solicits information on health behaviors relevant to family health history such as:

- Trust and decision-making methods with healthcare provider
- Quality of healthcare provider
- Awareness/knowledge of family health history
- Lifestyle and health behaviors

Three months after baseline surveys were collected, follow-up surveys were distributed to determine the utility of family health history and the toolkit. The follow-up survey mirrored the baseline survey, with additional questions regarding intentions to use the tool during future health visits and specific changes in current behaviors that individuals attribute to the information revealed by the tool.

PARTNERSHIP

COLLABORATIVE MODEL

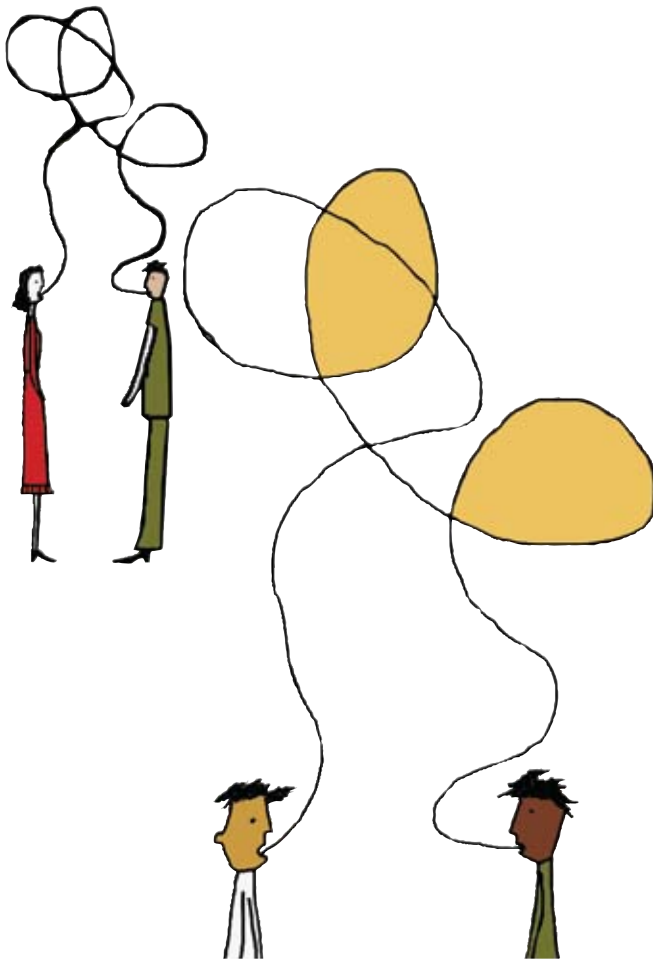
Partnership is a core tenet of Genetic Alliance project work in general—it is part of the Genetic Alliance mission—and the Community Centered Family Health History project in particular. CCFHH is an inherently collaborative project. The coordination among Genetic Alliance, community partners, and HRSA is the foundation of a national, even global, collaboration devoted to family health history. CCFHH partners share methodologies with each other, as well as with local and national audiences at meetings and conferences focused on community, health, and genetics. Community advisory boards spread family health history beyond the 25 families in each community recruited for the project. Furthermore, Genetic Alliance works with its vast network to disseminate family health history information:

collaborating with the National Human Genome Research Institute, National Institutes of Health on DNA Day and working with the HRSA Genetics Collaboratives are just two examples.

Genetic Alliance received many requests for such collaboration throughout the duration of the project. Mini-projects such as use of the toolkit in an occupational therapy class at the University of Texas-Pan American, presentation of the booklets at the U.S. Embassy in Russia, and incorporation of the booklets into a genes and environment presentation at the University of Tennessee Health Science Center provide collaboration opportunities on a smaller scale. Partners have access to valuable family health history materials that they can share with students and colleagues, and Genetic Alliance receives additional evaluations of the CCFHH products. The community-focused nature of the initiative ensures collaboration from the bottom up.

CCFHH began with just eight community partners; we added 10 more through CCFHH Program Awards distributed in Year 3 and worked with many others informally, as mentioned above, throughout the duration of the cooperative agreement. In its own way, each collaboration has created a lasting partnership that will continue to flourish beyond the scope of the project.

Partners were able to meet in person at various conferences where they were participating, presenting, or both, together and individually, including at the Genetic Alliance Annual Conference.



FEEDBACK LOOP

The original project proposal included a summative evaluation at the end of the project. However, we chose to focus more on internal evaluation rather than rely on an outside evaluator to review the process at the end of the cooperative agreement. Genetic Alliance maintained contact with CCFHH partners via:

- Monthly calls
- Monthly e-surveys
- Regular emails

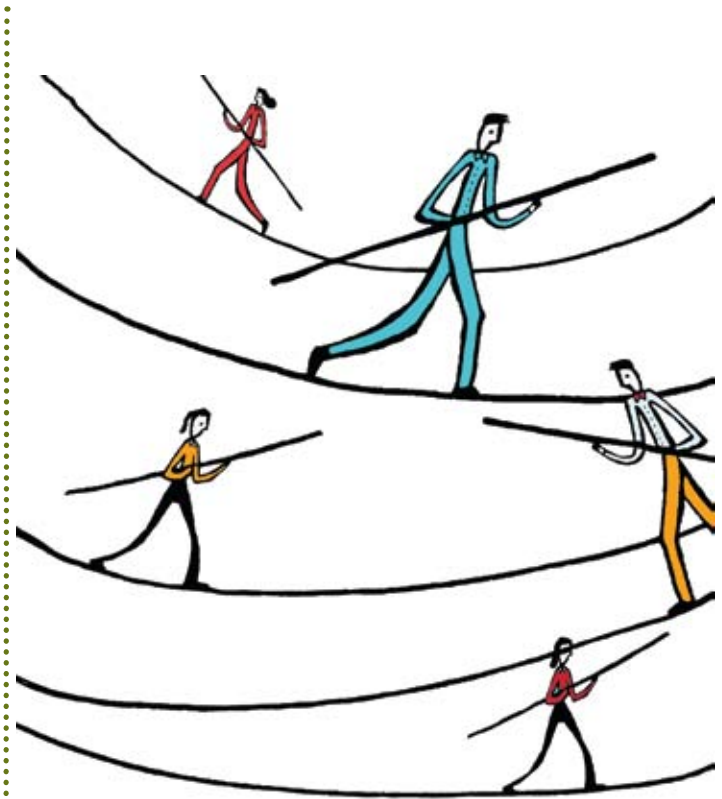
On monthly calls, Genetic Alliance program staff received progress updates from partners and discussed any particular successes, challenges, or needs. Surveys addressed the same accomplishments, milestones, and questions each month:

- How open are project staff to suggestions?
- How many times in the past month have you communicated with your community advisory board (CAB) members?
- How many times in the past month have you convened your entire CAB, spoken about family health history at a meeting or conference, and shared family health history information at a community event?
- If you've had any challenges this month, what were they?
- What has been your greatest success this month?
- What methods have you developed that would be helpful to other communities?
- What resources or guidelines would you find useful in your work on this project?

In addition to monthly surveys, Genetic Alliance collected feedback at critical points throughout the project through e-surveys focused on customization of booklets, recruitment of participants, and evaluation to ascertain successes, challenges, and methods for improvement.

PUBLICATION

With partners across the country, clear, transparent communication and coordination were crucial to this project. The process of writing this monograph was a microcosm for the functioning of the project itself and exemplified both the successes and challenges working under this model. Multiple calls and at least one in-person meeting were conducted to discuss the structure, audience, and publication of the monograph, as well as a paper devoted to the project data. Genetic Alliance drafted an outline and presented it to partners for feedback. With the outline set, each partner contributed text on working with its particular community and provided input on the overall structure and content of the monograph. Genetic Alliance pulled together background from the original grant submission to HRSA, as well as other appropriate materials from the course of the cooperative agreement, and weaved everyone's sections together into the whole. Partners then filled in gaps based on their expertise and experience.



CHALLENGES

Challenges are inevitable in a large project involving multiple partners. For example, university partners frequently encounter internal bureaucratic hurdles, particularly around contracts and copyright. The rigidity of the university contracts and budgets leaves little flexibility to respond to the unpredictable nature of community engagement. Community leaders face different challenges. Limited resources and staff, paired with a desire to have in-depth engagement with community members, can lead to difficulty meeting timelines and objectives. In CCFHH, some community partners were unable to meet recruitment and customization deadlines amidst competing priorities and the challenges of maintaining the provision of primary services to their communities. This inevitably held up all partners involved. Additionally, data privacy and interpretation presented a challenge, despite data-sharing agreements, IRB approval, and proper informed consent. These challenges present a clear need for transparent and thorough systems to help communities, academicians, and other organizations partner effectively.

Genetic Alliance faced its own challenges with this project. For most of the four years, the project had only one full-time staff member equivalent, which sometimes led to delays, and managing a diverse set of remote partners proved difficult. Different work styles, resources, and time zones raised obstacles that required significant time and energy investments to resolve. Furthermore, Genetic Alliance had limited research experience, precipitating the need to engage an external evaluator to handle data analysis.

COMMUNITY-SPECIFIC MODELS

The following figure includes the education structure for the project, including tool development and dissemination, as well as education and community engagement, at both the community-specific and universally-relevant levels:

	Community Specific	Universally Relevant
Tool development	<ul style="list-style-type: none"> • Participation in development • Customizable materials 	<ul style="list-style-type: none"> • Core language • Standard information requirements
Dissemination and education	<ul style="list-style-type: none"> • Shared slides and templates • Customizable multimedia resources 	<ul style="list-style-type: none"> • Overall project and joint presentations • Orgs reaching out to orgs
Community engagement	<ul style="list-style-type: none"> • Funding for community events • Training of health liaisons 	<ul style="list-style-type: none"> • Publication of best practices • Model project development

The general framework for original partners' plans was as follows:

1. Engage community advisory board (CAB).
2. Complete community assessment and submit the data to the Evaluation Team and the National Advisory Committee.
3. Modify the toolkit, to be done in a meeting with the CAB and in collaboration with other communities involved in this project.
4. Develop educational materials using Genetic Alliance and the genetic counselor/information specialist as resources. Materials will be deposited in the Genetic Alliance Resource Repository throughout the grant period.
5. Finalize a community plan for testing the toolkit.
6. Modify the evaluation tools to meet the community and project's needs.
7. Kick off the project with either a teleconference or in-person meeting.
8. Conduct baseline assessment to gather pre-project data on individual participants.
9. Distribute family health history toolkits to 25 families.
10. Conduct follow-up evaluation to measure the toolkit's usefulness and individual and familial behavior changes.
11. Conduct an educational event in the community, to be determined by CAB.
12. Create a sustainability plan.
13. Distribute educational materials to the community.

Each partner modified the plan slightly to accommodate the special needs of its community. The following pages contain details on each partner's work, categorized by partner and addressing the following stages of the project process: Community Need, Community Engagement, Accessibility, Community Evaluation, and Sustainability.

ALPHA-1 FOUNDATION

Community Need

Alpha-1 antitrypsin deficiency (AATD, Alpha-1) is a rare genetic disease that predisposes individuals to chronic obstructive pulmonary disease (COPD) and cirrhosis in infancy and adulthood. Support for individuals and their families affected by AATD has been facilitated by two nonprofit organizations, the Alpha-1 Foundation and the Alpha-1 Association. This community includes over 5,000 diagnosed individuals who have a severe deficiency phenotype and over 50 clinical resource centers representing clinical and research excellence in Alpha-1. The Alpha-1 community also includes over 100 medical and scientific experts who serve on advisory committees and working groups and provide expertise for the development of educational materials and lay information about Alpha-1 for the patient community. Additional resources include an Alpha-1 Research Registry, a cohort of more than 3,000 individuals available for participation in research and clinical trials located at the Medical University of South Carolina, and an Alpha-1 DNA & Tissue Bank located at the University of Florida College of Medicine.

AATD is a co-dominant genetic disease in which each of two alleles produces a serum concentration of alpha-1 antitrypsin (AAT) appropriate for the gene. The most severe deficiency is associated with two severe deficiency alleles named S and Z. The M allele produces normal amounts of AAT. Therefore, the Alpha-1 community is very focused on understanding genetics sufficient to find individuals that are protease inhibitor SZ and ZZ (PiSZ, PiZZ) in affected families.

The Alpha-1 Foundation was an enthusiastic supporter of the family health history initiative for two reasons; first, to see if the genetic education materials would assist families dealing with AATD testing, since individuals with Alpha-1 may remain healthy throughout their lives. Early diagnosis and avoidance of risk factors such as cigarette smoking can help prevent Alpha-1 from causing disease. Furthermore, carriers of one Z allele have some risks and carriers of one S or Z allele may pass the defective allele on to their children. The second reason for joining the study was to determine if the booklets could prompt individuals in the Alpha-1 community to focus on genetic risks independent of Alpha-1.



Engagement

The community advisory board for this study was the Educational Materials Working Group (EMWG) that develops and approves all educational materials produced by the Alpha-1 Foundation. This working group includes educational professionals and individuals with AATD who piloted the final customized booklets. After approval by the EMWG, the booklets were printed and evaluation began.

Recruitment was performed through multiple methods. The Alpha-1 Foundation Research Registry allows members to enroll their families in the Registry. A list of the 100 most recently added families was generated, and all families that had at least three blood-related members listed were used for the first round of recruitment. An invitation letter, the first survey, and a postage-paid envelope were mailed to these individuals. Informed consent was implied by returning a completed first survey. Once the completed first survey was received by the researcher, the two booklets were mailed to the participant. Three months later the participant was contacted to complete the second survey by telephone. This initiative produced 10 families (two or more family members) who completed both surveys.

To get at least two blood relatives in each family, participants already enrolled in the study were contacted and asked to provide the names and addresses of additional blood relatives who might be willing to participate. An invitation letter, the first survey, and a postage-paid envelope were then mailed to these family members. This initiative did not produce any completed families.

Participants were also recruited at two Alpha-1 Association Education Days and the National Conference attended by more than 400 individuals and family members with AATD. Participants who completed the first survey were given the booklets. Those participants who completed the survey and mailed it back to the researchers received the booklets in the mail.

A fourth recruitment method involved sending an invitation letter, the first survey, and a postage-paid envelope to family members that utilized the Alpha-1 Association Genetic Counseling Program. Again, once the completed first survey was received, the booklets were mailed to the participant.

Accessibility

The Alpha-1 Foundation adapted the educational pamphlets about family health history so that they were specific to and appropriate for the Alpha-1 community. Adaptations to the pamphlets included text and terminology specific to those with Alpha-1 and anecdotes and stories about individuals coping with Alpha-1 and communicating about their inherited condition with family members. Stories were compiled based on themes repeatedly heard by Alpha-1 staff and in clinics. Stories were then chosen by organizational leadership at the Alpha-1 Foundation, with input from staff involved in outreach in the community. Although several stories were deemed appropriate, organizational leaders also decided to retain several stories in the generic pamphlet (e.g., about heart disease), as many lung patients are affected by a number of common co-morbidities, and the topic and storyline would have meaning and applicability for those with Alpha-1 and inherited heart conditions.

Evaluation

As of September 2009, a total of 260 invitations to complete the first survey were distributed, which yielded 74 study participants (28.5% completion rate). This cohort of 74 participants was comprised of 22 one-member families, 12 two-member families, and 9 families of three or more members. From the cohort of 74 participants, 35 individuals completed Survey 2. The current data analysis consists of 25 participants (9.6% of the invited cohort) from 10 families in which at least two members completed the second survey.

The only demographic information collected was gender. In the cohort of 74 participants, 50 are female and 24 are male. The gender distribution for the 25 participants in the data analysis is 14 females and 11 males. Race and ethnicity were not collected from participants; however, AATD has its highest frequency in individuals with European ancestry.

No known complications were encountered in performance of this study. Family confidentiality was kept intact since individual participants were not informed of the participation status of other family members. The institutional review board at the Medical University of South Carolina approved this research study.

The comments from nonresponsive members of the study were that they did not read the booklets, forgot what the booklets said, or thought that the actions discussed in the booklets (talking about family health with family members and physicians) were actions that had been occurring in their family for a long time already.

Responsive participants indicated that the booklets reinforced the knowledge and understanding of the significance of family health history and inheritance that participants already had. The booklets also served as another avenue to initiate dialogue about family health issues for family members who may not have been receptive in the past. The booklets were also easy to understand.

Sustainability

An infrastructure existed within the Alpha-1 Foundation to support this project and to disseminate the booklets to the Alpha-1 community on paper or as PDF files on the Web. However, the Alpha-1 community is already rich with high quality, detailed, disease-specific genetic information. The CCFHH booklets proved insufficient to focus families with Alpha-1 on the family health risks that were not Alpha-1 related.

The Alpha-1 community is unique from the other participating communities because it is defined by having a rare genetic disease in the family. Therefore, the main health focus of the individuals in the community is specific to AATD. These families had already learned genetic terms, testing options, and inheritance patterns and already understood the importance of discussing family health diagnoses with one another. Many of the family members not only had to educate their family members, but also had to educate their own physicians about Alpha-1 as a rare genetic disease.

The Alpha-1 community appears less concerned about risks for more common health conditions like heart disease and diabetes and is more likely to focus discussions with physicians on symptoms and complications associated with AATD.

Every population requires testing of educational materials. After reading some of the thoughtful comments from other health communities about how helpful these booklets were to begin the discussion of family health history, we would advocate that they continue to use this tool. The challenge to the Alpha-1 community is to find another educational tool to describe risks for common diseases with a hereditary component.



INSTITUTE FOR CULTURAL PARTNERSHIPS

Community Need

The development and pilot of the first iteration of the toolkit occurred within the African American and Latino communities of Harrisburg, PA, an urban area designated as an Enterprise Community, or a community eligible for federal and state funding due to extreme levels of poverty and unemployment¹⁷. Harrisburg is a diverse city, with year 2000 census bureau data indicating a population that is 55% African American, 32% Caucasian, and 12% Latino. Within the city of Harrisburg, health disparities have been documented relative to county and state levels, including a greater incidence of asthma, diabetes, hypertension, certain cancers, and infant mortality¹⁸. These outcomes mirror ethnic and racial disparities in state level data: for example, 2002 hospital discharge rates in Pennsylvania for uncontrolled diabetes among ages 18-64 were 25.4 for blacks, 10.1 for Hispanics and 5.7 for whites. African Americans in Pennsylvania have the highest age-adjusted death rates across all racial and ethnic groups for coronary artery disease, stroke, lung cancer, and female breast cancer¹⁸. Additionally, the age-adjusted death rate for asthma among black residents of Pennsylvania was 2.6 times higher than that of whites.

While these disease statistics accurately convey the unequal burden of disease across ethnic and racial lines in Harrisburg, they fail to represent the dynamic nature of the South Allison Hill community—specifically, the revitalization efforts centered on the Weed and Seed initiative, a partnership of local grass-roots organizations, law enforcement, and residents. Partnerships with key stakeholders in neighborhood revitalization efforts facilitated an element of trust that was vital to the success of the project.

Institute for Cultural Partnerships' (ICP) participation in this project was greatly informed by the process of developing and piloting the first iteration of *Does It Run In the Family?*, which generated qualitative data regarding common barriers to gathering FHH information and "facilitators" that motivated individuals to overcome barriers. Focus group and survey data revealed multiple barriers to gathering



FHH data, including fear of genetic health risks that may be revealed; anxiety about potential misuse of written family history data; lack of time; lack of interest or perceived benefit; opposition from other family members; and unwillingness or inability to read and comprehend written materials. The pilot also revealed motivators that were useful in recruitment for the CCFHH project, including messaging that conveys the importance of mitigating genetic risk through lifestyle changes and generating a record of family risk that would benefit other family members, particularly children.

Engagement

The community participatory approach utilized in the initial toolkit pilot involved significant investment in building partnerships between the project team and the South Allison Hill community. This prior awareness of the project facilitated the recruitment of community advisory board members and project partners for the CCFHH initiative. A five-member community advisory committee and project partners were recruited from among individuals and agencies who were involved in the development or dissemination phase of the initial project pilot. ICP partnered with faith-based organizations, including Central Pennsylvania United to Fight Cancer (CATALYST), a volunteer-based organization with the mission of improving the cancer survival rates of ethnic and minority persons in the region, and Fountain Gate Church and Ministries, a nondenominational, predominately African American church whose monthly Angel Food Ministry served as a primary venue for project recruitment.

The community advisory board for this project reviewed and provided feedback on all phases of project planning and development, with a particular focus on recruitment and incentives. Committee members reviewed all project materials for cultural competency and literacy levels, including all drafts of the customized toolkit, evaluation survey, and dissemination of results. The committee convened for two in-person meetings in March and April of 2007 and exchanged feedback via telephone and email at critical junctures for the remainder of the two-year grant period.

Recruitment for this project was conducted by lay community researchers, or community liaisons, a model continued from the initial pilot. Liaisons completed a four-hour training on the basics of FHH, use of the toolkit, and survey techniques. Liaisons were rewarded with \$40 in gift cards to a local food store for each family who successfully completed the project. Recruitment was conducted in multiple venues, including several Baptist and nondenominational churches, monthly meetings of cancer survivors, a monthly food ministry, and educational workshops for diabetics at a federally qualified health center in Harrisburg. Community liaisons also recruited participants directly through their personal networks.

Accessibility

Customization of the toolkit for the African American community of Harrisburg occurred over a two-month period in Spring 2007. Qualitative data from the initial project pilot yielded stories and quotes that were used to customize ICP's version of the CCFHH guide. Narratives and quotes in which project participants discussed barriers, benefits, and misconceptions related to gathering family health history were matched with relevant themes from the guide. Although project coordinators at ICP hoped to include verbatim quotes from project participants, it was necessary to strike a balance between quoting the actual words of project participants and thematically pairing the story or quote with content from the guidebook. Composite stories containing elements representing the experiences of two or three toolkit users were drafted to highlight relevant information from the FHH guide.

The community advisory board (CAB) reviewed and commented on stories at three points in the customization process: 1) unedited stories transcribed from focus groups; 2) edited stories prior to placement in the guide; and 3) customized proofs of the guide, including stories and quotes. The CAB also recommended relevant disease data specific to African Americans and the inclusion of sickle cell anemia as a disease of specific interest to the African American community.

Evaluation

Participants were offered incentives of \$10 gift cards at the completion of each project survey. Surveys were completed in person when possible and by telephone when necessary.

Recruitment of first family members was relatively simple: Most people approached were receptive to the project and willing to provide project staff with contact information for a second family member. Recruitment of second family members was more difficult, and recruitment procedures were adapted in response to this difficulty. Project staff reported a loss of momentum from the point of initial contact at recruitment and great difficulty obtaining consent from second family members, despite telephone reminders from project staff at two-week intervals. It is important to note that telephone recruitment of second family members was removed from the context of familiarity and trust afforded by community partnerships; a telephone call from project staff unfamiliar to the potential participant is a qualitatively different type of recruitment than face-to-face contact at a community event sponsored by a familiar and trusted organization. The advisory board and project staff recommended a streamlined recruitment process that allowed screening, informed consent, initial surveys, and incentives to be administered for family health leaders at the point of initial contact. Recruitment and retention rates increased following these changes. Project staff also searched for methods that would allow the recruitment of multiple family members simultaneously: diabetes education workshops typically attended by the patient and a support person; a monthly food ministry where family members often volunteered together and recipients often came as families; and a “survey party” hosted by one community liaison to facilitate the enrollment process for her friends and neighbors. Any method or procedure that removed barriers to enrollment resulted in higher rates of completed enrollment and better completion rates for second surveys.

Social context was crucial to successful recruitment of project participants. **Recruitment worked best when it was conducted within a social network that conferred a degree of trust and a context for continued contact with project staff:** for example, a food ministry where people met monthly as volunteers and recipients of services or recruitment through the personal networks of community liaisons. Without the social context of these methods, follow-through with enrollment of second family members was extremely difficult. More effective recruitment, measured in terms of a low ratio of initial contacts to families who completed the project, occurred in locations where the project coordinator volunteered time to partner organizations: at monthly food ministry events for Fountain Gate Church and monthly meetings and outreach events for CATALYST. Participation as volunteers served to further entrench project staff in the social networks of these organizations, as well as increase the project’s visibility and familiarity within those networks.

Sustainability

The toolkit was disseminated primarily through how-to seminars that highlighted relevant aspects of inheritance and social dynamics of starting family conversations about health and disease history. Presentations integrated the toolkit into health promotion activities at various state, county, and city agencies; local businesses; and nonprofits, including the Pennsylvania State Department of Health, Dauphin County Mental Health and Mental Retardation, South Allison Hill Weed and Seed, Central Pennsylvania Coalition United to Fight Cancer, Highmark Blue Shield, Temple University's Family Reunion Institute, and Clinical Training for the Master of Arts in Marriage and Family Therapy at Louisville Seminary. ICP also partnered with Members First Federal Credit Union to make the toolkit available as part of the credit union's employee wellness program. Furthermore, ICP's customized version of the toolkit is available from the PA Department of Health. It can also be downloaded from ICP's website (www.culturalpartnerships.org).

ICP's outreach efforts for this project built on the toolkit's emphasis on family conversation and oral history by incorporating the toolkit into family reunion and

genealogy workshops. ICP supplied toolkits and technical assistance to over 150 families seeking to incorporate family health history activities into their reunions. Finally, ICP partnered with the Susquecentennial Commission of the City of Harrisburg to offer free genealogy workshops in 2010. Participants receive a copy of the toolkit, as well as an overview of the importance of extending conversations about family history to include health.

Institute for Cultural Partnerships participated in a brown bag lunch series hosted by the Pennsylvania Department of Mental Health and United Concordia, as well as various health fairs and festivals in Harrisburg, PA.



INTERMOUNTAIN HEALTHCARE

Community Need

Intermountain Healthcare (IH) is recognized as a leader in the development and use of electronic health records (EHR). IH is an integrated healthcare system with inpatient, outpatient and health plan coverage within one corporate structure. As a partner, IH, proposed to gather data regarding efforts to encourage employee collection of family health history. Employees would be encouraged to share the history collected with their primary care providers. Ultimately, provider use and employee health changes in response to the family history would be captured. The community was identified as employees and providers in a healthcare system.

Several institutional changes forced a change in the focus of the community served by IH. The major change involved the fact that an outside vendor was contracted to manage health information pertinent to employees. Access to add family health history to the employee health inventory was eliminated. The second important change involved a corporate shift in the method of developing the electronic record. Neither of these was foreseen at the time the grant proposal was submitted.

In preparation for the work of the grant, a literature review was undertaken regarding physician practice related to family health history. Several articles identified what family history is collected by primary care physicians, as well as what barriers existed for collecting family history. However no published data existed regarding how primary care physicians use the information they collect. Perhaps more importantly, no studies explored why physicians collect family history and how it is put to use when they do collect it. IH's community became that of healthcare providers to learn more about the value and utility of family health history within healthcare practice. **Given that other communities must interact with the healthcare community regarding family history, understanding the provider community's attitudes toward family history is essential if the interaction is to go well.**

The principle participants who constituted the IH partnership with Genetic Alliance contributed expertise in

medical genetics, genetic counseling and education, and informatics. While each participant was new to IH, the medical geneticist and genetic counselor have over 50 years' combined experience with family health history and practice within the healthcare industry. The informaticist was new to family health history, but has over 20 years' experience working with physician organizations.

IH's initial contribution included involvement in developing the *Does It Run In the Family?* toolkit on family history collection and understanding genetics concepts. These booklets are posted on IH's website, which is publicly available, and the MyHealth patient portal, which is available to IH patients. Additionally, the group worked developing a tool to record family health history to take to healthcare providers that accompanied the general family history booklets used in each partner community.

Engagement

Intermountain Healthcare is a large, integrated healthcare delivery system that annually cares for more than one million patients throughout Utah and southern Idaho. An integrated electronic health record (EHR) is available to all employed physicians, as well as a substantial number of affiliated physicians. A family history e-form was implemented in the EHR in 2007. In addition, coded family history information can be entered into the problem list and, until recently, chart notes.

Twenty-five primary care physicians (PCPs) who used one of these three methods to record family history were identified. The total number of patients who had family history information entered was determined for each physician. Based on the usage distribution, physicians who entered information on more than 100 patients were defined as high users and the rest as low users. Four physicians declined participation at the onset. Only one female physician was identified in the sample population, and while expressing willingness to participate, was unable to be scheduled for an interview. Thus, 20 physicians representing high and low users were identified to test the hypothesis that the type of experience collecting family history would correlate with the usage. Sixteen physicians, all of whom were male, completed the interviews. The specialties represented included family practice (FP), general internal medicine (GIM), and pediatrics (Peds). No OB/GYNs agreed to participate in the study. The PCPs practiced in a variety of practice sizes and locations.

Accessibility

The booklet templates were changed to include information specific to Intermountain Healthcare. A quote from Dr. Marc Williams, Director, Clinical Genetics Institute, replaced the quote by Sharon Terry. In Booklet 1, one of the example stories was exchanged for a story on collection of genealogy. The story had been shared with the Utah Department of Health and appeals specifically to the Utah population. On the last page of Booklet 1, links specific to Intermountain Healthcare, including links to Genetic Alliance, the Surgeon General's family history tool, and Genetics Home Reference, as well as specific patient education materials located within the Intermountain website, were inserted. In Booklet 2, the condition cystic fibrosis (CF) was substituted because it is the more common autosomal recessive condition in this population. It also coincided with the addition of CF screening as part of newborn screening in the state. In the resources section, links to Intermountain Healthcare and the University of Utah Genetic Science Learning Center were inserted.

Evaluation

Interviews were conducted using open-ended questions. The interviewer encouraged the PCPs to relate their experience regarding family history collection. The content and order of questions varied for each interview, depending on the information related by the PCP. When all content areas had been explored, or one hour had elapsed, the interview was concluded. PCPs gave informed consent and were paid \$200 to participate. The study was approved by the institutional review and privacy boards of Intermountain Healthcare. Money used as physician participation gifts was funded through the cooperative agreement.

Sustainability

The IH partners gave numerous presentations to the community, professional organizations, and the medical community. They also presented at four consecutive Genetic Alliance annual conferences. IH also presented the research of physicians' experiences with the use of family history in their practices at the CDC Family History Workshop in 2008. The complete research was published in full under separate publication. The first paper based on the project is accepted for publication in the journal *Genetics in Medicine*¹⁶.

The customized IH booklets are posted and available for download through the IH patient portal and on the Clinical Genetics Institute's public website. As of September 2009, Booklet 1 was downloaded 786 times and Booklet 2 was downloaded 280 times. The booklets are also associated with a link to the Surgeon General's family health history tool that went live in the fall of 2009. Over 200 patients a month link through to the tool. The partnership with Genetic Alliance has led to participation in several national governmental committees within the Department of Health and Human Services (DHHS) and leadership in national health information professional organizations and within national genetics professional organizations. Several developments highlight the efforts, in part due to the focus allowed IH partners through Genetic Alliance funding, to recognize the inclusion of family health history in national health policymaking. The DHHS added family health history as a necessary component in electronic health record standards. The American Health Information Community added a family health history workgroup that developed a list of required and optional data elements for family health history collection. The HL7 international workgroup, aimed at fostering interoperability of electronic health data, added family health history to a standards workgroup. This standard has been approved by HL7 as the normative standard. NIH sponsored the first-ever State of the Science meeting specific to family health history. IH is not responsible for these events but has actively participated in each, contributed to their creation, and supported their development.

Work to use the results of the knowledge gained regarding the healthcare community continues with ongoing development of just-in-time tools for providers to collect family health history and provide clinical decision support, as well as an internal patient-entered family health history tool that will go live in late 2010.

IONA COLLEGE

Community Need

Iona College takes its name from the island of Iona located in the Inner Hebrides just off the west coast of Scotland. The island of Iona became a center of faith and learning that contributed significantly to the civilization and cultural development of Western Europe. It was in the spirit of this heritage that the religious order of educators, the Edmund Rice Christian Brothers, founded Iona College in New Rochelle, NY, in 1940. The campus is located in New Rochelle, NY, a city/inner-ring suburb of 72,000 people located on the Long Island Sound in Westchester County, in close proximity to New York City.

Each student is provided an educational experience that fosters a love of lifelong learning, a sense of ethical and moral purpose, and an appreciation for art, literature, and culture. The College has remained focused on its educational mission, which embraces the values of justice, peace, and service and welcomes diverse populations into its community. Furthermore, Iona is dedicated to creative teaching and research, emphasizes the spiritual and intellectual aspects of its Catholic traditions, and promotes the integration of its mission into all aspects of college life.

Iona College is a diverse community of learners and scholars dedicated to academic excellence in the tradition of the Christian Brothers and American Catholic higher education. Iona's current undergraduate and graduate student populations total about 4,300. Of that total, 3,246 are undergraduate day students, 96 are undergraduate returning adult (Professional Studies Program) students, and 908 are graduate students. The College is accredited by the Middle States Commission on Higher Education. Its emphasis on the liberal arts seeks to present students with the opportunity to develop their potential to the fullest. The College strives to accomplish this by serving as a center where each area of learning is pursued according to its own principles, with liberty of inquiry. The Iona Social Work Department offers a generalist, student-centered baccalaureate social work program that locates itself and its mission within the context of the college's mission, the principles of Br. Edmund Rice, Catholic Social Teaching (CST), and social work's professional values and ethics.

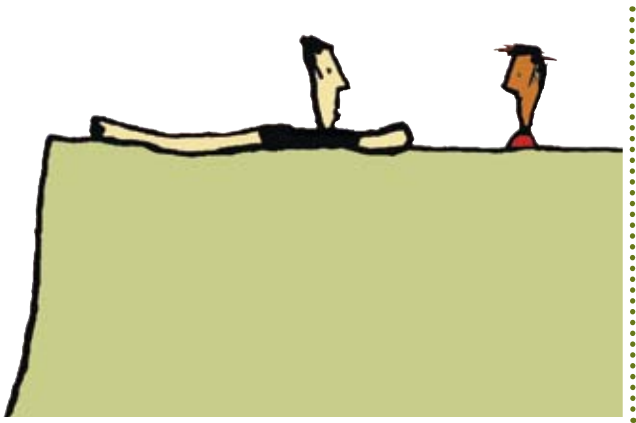
Iona's role in the Community Centered Family Health History project was designed to increase students' knowledge and understanding of family health by promoting interactions with family members of different generations. Two major goals serve to guide the Social Work Department's involvement with this project: 1) It provides an opportunity to include the voices of individuals from groups that are underrepresented in the service system in an in-depth discussion about the meaning and importance of healthcare; and 2) it enables faculty members and students to learn more about assessment, intervention, and intergenerational teaching that is foundational to academicians and this project.

Engagement

Implementation of the Community Centered Family Health History project began in summer 2007 with a thorough presentation of the initiative's goals to college administrators (Vice President of Academic Affairs; Dean of the School of Arts and Science; Chair, Social Work Department; Advancement Officer of Corporations, Foundations and Government Relations) and community stakeholders who agreed with the goals and objectives of the project. However, in the absence of a standing institutional review board at the time, an expedited approval was granted after the project manager completed the CITI Collaborative Institutional Training Initiative (online IRB course) in November 2007.

Garnering community support for this initiative was facilitated by the Social Work Department's longstanding relationships with a range of community and governmental agencies in Westchester County. With input from community stakeholders, a decision was made to recruit seven or eight people who were knowledgeable about the importance of genetics and health, the research process, intergenerational programs, and student recruitment. The group consisted of faculty, college staff, an older adult community advocate, a former teacher and family historian, a graduate student, and a Deputy Commissioner of Health.

Advisory board members met every two months in the first two years and monthly in the third year of the project. They participated in all aspects of customizing the booklets, monitoring the implementation process, and planning the culminating event in May 2009.



In Fall Semester 2007, outreach began with a mass email (GAEL Blitz) to students from the Director of the Gerri Ripp Center for Career Development at Iona. Fliers were posted in academic departments, and news spread through word of mouth. In total, 35 students expressed an interest and 29 completed the study.

Student participants came from a cross section of the student body, including freshmen, sophomores, juniors, seniors, and first- and second-year graduate students. They were majors in psychology, social work, early childhood education, mental health counseling, school psychology administration, finance, general business, marriage and family therapy, healthcare administration, public relations, sports studies, physics, Spanish, and speech pathology. Students (24 females and 5 males) were also from diverse racial/ethnic backgrounds including Caucasian (20), African American (6), Latina/o (2) and Haitian American (1). Orientation sessions were held in December 2007.

Accessibility

Community advisory board members and other colleagues helped customize the booklets in the summer and fall of 2007 by providing quotes, stories, and photographs for Booklet 1, "A Guide to Family Health History." Booklet 2, "A Guide for Understanding Genetics and Health" was primarily edited by the project manager who conducted online research and used the Yellow Pages to identify local health and caregiver resources. The community was uncomfortable with the idea of recommending a specific disease for Booklet 2, since college students represent such a broad cross section of the general population. The customized version of the booklets were thoroughly reviewed and approved by the CAB before being distributed to students and the larger community.

Evaluation

Four aspects were involved in Iona's evaluation process:

- 1) Development of three community-specific questions that were included in the You and Your Family Surveys (Baseline and Follow-Up).
 - How important do you think it is to have a personal knowledge of family health history?
 - Not at all, somewhat, mostly, extremely important
 - Overall, how much did your experience of reading about and discussing family health history change your view about your generation in your family (the people in your family that are close to you in age)?
 - None, somewhat, quite a bit, a great deal
 - Overall, how much did your experience of reading about and discussing family health history change your view about the other generations in your family (family members either younger or older than you)?
 - None, somewhat, quite a bit, a great deal
- 2) Development of an action plan to collect pre- and post-survey data from family members. Students were paid \$200 to recruit three family members and track their progress toward completing the surveys and reading and discussing the booklets within a three-month time frame.
- 3) Development of focus group questions to explore students' thoughts, feelings, and attitudes about family health history as a result of participating in the project. Students were paid an additional \$25 if they volunteered to participate in the focus groups once all survey data was submitted. Focus group findings have been submitted for publication.
- 4) A follow-up study is underway to investigate whether lessons learned and the excitement generated by participation in the project has continued to be practiced and felt by participants.

Sustainability

Multiple venues have been used to sustain a focus on family health history in Westchester County and New York State, including presentations to high school students (“Rx for Success: Dare to be a Doctor,” Building Healthier Lives Together Health Fair), black doctors and allied health professionals (Healthy Weekend Extravaganza Annual Health Symposium), seniors (“What Is Family Health History and Why Is It Important?”), and others. The Iona project was also featured on the Family Health History in Primary Care Webcast, presented by the New York State Department of Health and SUNY Albany School of Public Health on March 18, 2010.

The project culminated with a community event on May 8, 2009. The conference, *Community-Centered Family Health History Project: Learn About the Importance of Health History for your Family and Community*, brought together project advisory board members and partners; Iona College students, faculty, and staff; and interested community members for a day of presentations and discussion about family health history. Prior to the conference, focus group findings were presented to a group of Senior Seminar students in the Sociology Department, thus exposing more students to family health history information and encouraging them to attend and bring their friends to the culminating event.

The range and number of local sponsors and organizational attendees—Iona College, Westchester County Department of Health, Westchester County Department of Senior Programs and Services, Westchester County Public/Private Partnership for Aging Services, The Westchester Alliance of Academic Institutions for Aging Related Services and Workforce Development, Sarah Lawrence Joan H. Marks Graduate Program in Human Genetics, Westchester End of Life Coalition, Lower Hudson Valley Perinatal Network, Mentoring in Medicine, Inc., Mt. Vernon Youth Bureau Intergenerational Choir, Sister to Sister International, Inc.—demonstrate the depth of the project in the community. In addition to faculty members who brought students and relatives, over 63 people preregistered and signed the attendance sheet. The following community organizations sent representatives: Hudson Valley Health Plan, Head Start Family Services of Westchester, Genetic Alliance, Westchester Family Services, St. John’s Hospital, March of

Dimes, Westchester County Department of Probation, Alternatives for Young Mothers, and Weill Medical College of Cornell University.

Through the Westchester Public/Private Partnership for Aging Services, Iona has been cited as a partner on a grant secured through the Andrus Foundation to support the work of the Westchester Alliance on Aging Related Content and Workforce Development. The Iona experience is being assessed to determine its feasibility for other members of the Alliance. Having Alliance representatives serve on the community advisory board not only helped shape the project, but provided a mechanism for ongoing conversations about the project, and has been one way to attain sustainability beyond the grant phase of the project.

Iona College’s membership on the Westchester Alliance and participation in the CCFFH Project presented a fortuitous opportunity for both groups to mutually benefit from previously existing collaborative relationships, thus potentially expanding intergenerational teaching opportunities within college communities.

NATIONAL COUNCIL OF LA RAZA

Community Need

A wide range of studies demonstrate that, compared to non-Hispanics, U.S. Latinos* are disproportionately more likely to experience serious health conditions—hypertension, heart disease, high cholesterol, diabetes, certain cancers, and depression—that may have a genetic component and can run in families. For instance, family members with a history of cardiovascular disease may be at a higher risk of developing the condition compared with those without a family history. However, Latinos are largely uninformed about the importance of tracing their family health history and/or initiating these conversations with their families. A research study conducted by National Council of La Raza (NCLR) revealed that Latinos generally lack knowledge about genetics, genetic testing, and inherited risk factors. In addition, they have very limited access to credible culturally and linguistically competent information about genetics. Demographic data reveal that significant proportions of this population have characteristics that almost certainly undermine

their ability to obtain appropriate information about genetics, downplay the importance of knowing family health history, and/or hinder knowledge of how to act on it. Only about 64% of Hispanics have completed high school, compared to 84% of African Americans and 92% of Caucasians. Nearly 40% of Latinos are foreign-born and an equal number lack full proficiency in English. More than one-third do not have any form of health insurance—the highest of any ethnic group—and, partially as a result, Hispanics are less likely to see a doctor annually than other groups. About one quarter of Latinos live in households with below-poverty level incomes. Each of these categories overlaps, such that between one-fourth and one-third of all Hispanics have two or more characteristics—no high school diploma, limited English proficiency, no health insurance, and low incomes—any one of which may serve as a barrier to the efficacy of traditional social marketing or mainstream media-based public education strategies to increase Hispanics' genetic literacy.

To address the need to provide Latinos with health information in a manner that overcomes the barriers they face, NCLR's Institute for Hispanic Health (IHH) has developed, implemented, and evaluated pilot community-driven projects using *promotores de salud* (lay health educators). Most recently, IHH has applied its proven *promotores de salud* approach to the field of genetics. With initial support from the National Human Genome Research Institute (NHGRI) and Office of Rare Diseases (ORD), NCLR has pioneered the development and testing of training modules and education materials for *promotores de salud* to increase NCLR's target population of low-income, limited-English-proficient Latinos' familiarity with core genomics-related concepts. Specifically, IHH has conducted formative research, created materials, and developed and evaluated *promotores*-driven strategy to educate Hispanic communities about genetics using a family health history approach. **By relying on familiar terms and concepts—in this case, the importance of knowing one's family health history—the project has elevated participants' genetic literacy.**



*The terms "Latino" and "Hispanic" are used interchangeably by the U.S. Census Bureau and throughout this document to identify persons of Mexican, Puerto Rican, Cuban, Central and South American, Dominican, and Spanish descent; they may be of any race.



The next logical step in this process was to expand NCLR's work in this area and begin to help the target population apply this knowledge in specific ways to improve their health, such as promoting prevention efforts, encouraging screenings for early diagnosis, and enhancing treatment. Within this framework, NCLR partnered with Genetic Alliance to further develop and test the *Does It Run In the Family?* toolkit with the goal of finding effective ways to reach Latinos with culturally competent and linguistically appropriate information about family health history and inherited risk of disease using a variation of NCLR's proven community-based *promotores de salud* model.

Promotores de salud are trusted and respected members of their respective communities, who are trained to educate and promote awareness on various health issues in a linguistically and culturally competent manner. They serve as locally-based connectors between healthcare consumers and providers and are committed to improving the health of their communities. The effectiveness of the *promotores* model may be in part attributed to several culturally relevant characteristics. *Promotores* often live in the communities where they work and speak the language of the community residents. Therefore, they can reach many individuals with important health information in a way that is easily understood. Cultural attributes such as *familismo* (supportive family networks) and *confianza* (a strong value in interpersonal trust through warm and friendly relations) also are likely to contribute to their effectiveness and reinforce their work.

Promotores-driven strategies have been well evaluated by NCLR. Interventions using *promotores* have proven very effective in raising awareness, disseminating information, and educating the Latino community about the importance of knowing family health history and genetics. The interventions have also had success relating these concepts to Latino's individual and community health. In pilot testing, evaluation results indicated that the topic of family health history was very important to community members (72%), and the majority of participants (95%) expressed that they intended to look for additional family health information and share this with family and friends.

The family health history approach originated from qualitative research studies conducted by IHH, Genetic Alliance, and Hispanic Communications Network. These studies demonstrated a significant gap in knowledge about concepts related to genetics and genomics and their relevance to health among Latinos, though participants did report a strong interest in learning more and a willingness to act on information related to family history and health. Given the latter, NCLR/IHH inclined to move away from genetics information per se to a family health history approach.

Engagement

NCLR has a network of nearly 300 affiliated community-based organizations (CBOs). These organizations deal on a day-to-day basis with all aspects of serving the Latino population. They are familiar with the practical concerns and policy issues affecting their communities and are actively engaged in developing and implementing innovative solutions to the problems they face. NCLR's active and productive relationships with its CBOs are at the heart of NCLR's work and key to its ability to fulfill its mission. In providing capacity-building assistance, policy analysis, advocacy, and special initiatives that complement the work of its affiliates, NCLR is able to work on the front lines to improve life opportunities for Hispanic Americans throughout the country.

The NHGRI/ORD project served as a conduit for testing the *Does It Run In the Family?* toolkit. Therefore, a customized version of the toolkit was tested with two affiliates, one in Oakland, CA, and another in Washington, D.C., with largely Mexicans and Central Americans, respectively. These affiliates had previously participated in the NHGRI/ORD project.

NCLR created a community advisory board (CAB) comprised of nine members. This included an NCLR representative and four members from each CBO working in the project, two *promotores* and two staff members. The role of the CAB was to provide feedback and comment on how useful the tool was to the community. The inclusion of *promotores* ensured that community members were involved in all stages of the project. The CAB provided significant feedback in the adaptation of the toolkit. CAB members convened for two in-person meetings in July of 2006 and 2007. Additionally, CAB members provided valuable feedback via conference calls and emails.

To ensure proper recruitment of study participants and implementation of the research protocol, *promotores* who had previously been trained in the implementation of the NHGRI/ORD project were recruited to participate in this research project. In addition, preference was given to those *promotores* who were willing to attend one refresher training and were available to conduct follow-up phone calls and interviews with program participants for a period of three months. Training focused on increasing

the capacity of *promotores de salud* to conduct testing of the toolkit in their respective communities and carry out the study's recruitment and evaluation procedures.

Promotores assisted in the process of recruiting families. A total of 30 families were recruited through word of mouth. Each family was contacted in person or via phone call. In most cases, *promotores* were acquainted with the families through their church, school, community health center, or neighborhood. Each family was required to complete a pre-test and post-test questionnaire. *Promotores* worked with the families to ensure effective utilization of the toolkit and proper collection of information.

Accessibility

NCLR followed a three-step process to customize the toolkit. First, CAB members were asked to provide feedback on the original version. To this end, NCLR prepared a pre-testing guide, which included open-ended questions about the amount of text, illustrations/photos, and ease of use, and asked for general feedback. Second, *promotores* tested the original version of the toolkit with their own families. Like CAB members, *promotores* were provided with a pre-testing guide. Third, selected families tested the toolkit and completed evaluation questionnaires.

In Years 1 and 2, NCLR provided technical assistance to Genetic Alliance to refine the two booklets and the evaluation instruments to be tested with Latinos. Furthermore, NCLR trained *promotores de salud* in the use of the toolkit and oversaw its field testing. In Year 3, the two affiliates disseminated the toolkit at community events.

The customization process of the toolkit proved to be a time-consuming, but necessary, process to make it culturally and linguistically competent. As NCLR/IHH anticipated and expressed to Genetic Alliance, the concept of genetics is new to the Latino community, which perceives the topic to be far removed from their day-to-day lives and health-related needs, desires, and challenges. Findings from the formative research confirmed these feelings. The novelty of the concepts required that NCLR/IHH carefully consider how to translate the concept into identifiable, meaningful, and relevant public health concepts.

The initial feedback from both CAB members and the *promotores'* families was not positive. The booklets were deemed “difficult to understand,” “heavy in text,” and “not user-friendly.” These comments, along with information gathered from prior focus groups, were used to make preliminary modifications to the toolkit to ensure its cultural relevance for the Latino community.

To ensure the toolkit’s language competency, all revisions were done in Spanish. Promotores reviewed and provided feedback on all drafts to assess whether the information, literacy level, and word usage were relevant to them and community members. After each review, the toolkit was adjusted according to the feedback received. In addition, community members provided pictures, stories, and quotes to customize NCLR’s version of the toolkit.

Evaluation

For a period of three months, *promotores* implemented testing of the toolkit. During this time, families completed evaluation forms, received the booklets, and read information. Promotores answered questions and conducted follow-up phone calls with the families.

Promotores and CBOs expressed great concern over the length of the evaluation questionnaires. They felt that the technical language and length of the surveys were not appropriate for the community. They also felt that it would be very difficult to commit families for a three-month period and expect them to read the educational materials (booklets). In fact, the CBOs’ final reports to NCLR suggested that families felt somewhat intimidated by the idea of reading a booklet and being asked about it later. Therefore, *promotores* took the booklets with them to show potential families that the materials they needed to read were manageable.

Many of the *promotores* who took part in the initial training for the project were reluctant to participate because of the complexity of the project (e.g., the evaluation forms were too long and/or difficult to understand), and six of them dropped out of the program.

Reports received from CBOs suggest that families liked the booklets and community members showed a great interest in the topic. Families also expressed enjoying the opportunity to talk and share family history.

Sustainability

The use of the *promotores*-based strategies for study recruitment is highly recommended because it is sustainable through CBOs with existing *promotores* programs. In addition, *promotores* provide valuable insights into the challenges of a project by giving their communities’ perspectives and feedback. Developing user-friendly evaluation tools will increase *promotores'* comfort level in implementing initiatives and conveying the message to other community members. Project feedback suggests that community members would benefit from supplementing the information contained in the booklets with *charlas* (small educational sessions) conducted by *promotores de salud*. NCLR-trained *promotores* have demonstrated the ability to reach their communities competently and serve as educators, advocates, and liaisons to enhance and extend the healthcare services that commonly do not reach immigrant Hispanics. NCLR believes this approach is effective in underlining the importance of genetic information and collecting family health history among Latinos.

CBOs and community members have expressed the need and desire for this kind of information. While NCLR’s work to-date represents a positive step in increasing the genetic literacy of Latinos, a large segment of the population still remains largely unaware of the impact of genes on one’s health. Future studies should work to fill this gap. Research is needed to develop and test community-based models that reach underserved populations with culturally-relevant health information. NCLR believes that the family health history approach will be the most successful in stressing the importance of genetic information and collecting family health history.

NATIONAL PSORIASIS FOUNDATION

Community Need

The National Psoriasis Foundation is a national patient advocacy organization head-quartered in Portland, OR. The Foundation's mission is to find a cure for psoriasis and psoriatic arthritis and eliminate their devastating effects through research, advocacy, and education. According to the National Institutes of Health, as many as 7.5 million Americans have psoriasis. Psoriasis is an autoimmune disorder that manifests on the skin. The immune system mistakenly triggers accelerated skin cell growth—the skin cells pile up on the skin's surface, causing raised lesions. Psoriasis can appear on just a few joints or cover the entire body. Psoriasis has no cure.

Recent research has shown that people with severe psoriasis have an elevated risk for psoriatic arthritis, cardiovascular disease, hypertension, obesity, metabolic syndrome, liver disease, diabetes, Crohn's disease, depression, and certain types of cancer¹⁹⁻²¹. The disease is also associated with multiple sclerosis (MS), and research has found that families with MS have higher rates of psoriasis than families without MS²². Additionally, it has been found that people with psoriasis have higher rates of smoking and excessive alcohol use¹⁹. Researchers at UCLA found a correlation between psoriasis and poor diet and exercise habits²³.

With these issues in mind, the National Psoriasis Foundation felt it imperative to incorporate family health history messaging into its core educational programs. Information about the genetic nature of psoriasis had previously been shared with the Foundation's constituent base, but tools for collecting family health history had not been developed or offered.

Engagement

Participants were recruited from the National Psoriasis Foundation's volunteer base of over 500 people located in communities across the United States. All first family members were active volunteers of the Foundation and either had psoriasis and/or psoriatic arthritis or were the parent of a child with psoriasis.

Once a first family member expressed interest, a consent form was mailed and collected, upon which the pre-survey was given by telephone. First family members provided the names of one to two additional family members who could be contacted for participation. All initial contact of first and second family members was done by email; follow-up was primarily done by phone. Recruitment began in August 2007, and the last family was enrolled in January 2008. All post-surveys were collected by April 2008. Thirty families enrolled in the study, and 20 families completed both pre- and post-surveys.

The community advisory board (CAB) was comprised of three long-time Foundation volunteers who each had psoriasis, a student from Portland State University School of Community Health, and a medical professional who specializes in psoriasis. The CAB helped with the customization of the *Does it Run in the Family?* booklets, participant recruitment methods, and identification of avenues for program promotion and dissemination. The CAB met one time in person at the Foundation's National Conference in August 2007. All other interaction was via email and teleconference. The CAB was involved heavily until participant recruitment began and again once all data had been collected.



Accessibility

Customization of the National Psoriasis Foundation booklets began in July 2007. Community advisory board members worked with Foundation staff to review the booklets, identify resources and potential sources for quotes and stories, and decide on information for the specific condition pages. **Because psoriasis patients and contacts of the National Psoriasis Foundation represent a cross section of the general population, many of the quotes and stories in the templates were appropriate for NPF's audience.** The CAB elected to include one psoriasis-specific story from the perspective of a mother and child with psoriasis. This woman also allowed her photograph to be used in the booklets. In choosing the other pictures, the CAB selected ones that represented a variety of cultures and both sexes.

The CAB and Foundation staff chose to include psoriasis-specific information in Booklet 2. Information on psoriasis and psoriatic arthritis was written by staff, medically reviewed by members of the National Psoriasis Foundation volunteer medical board, and finally reviewed by the CAB.

Evaluation

Pre- and post-surveys were collected over the phone by a staff member of the National Psoriasis Foundation. Staff used email to schedule the phone surveys and to send reminders. Because the first family members were existing volunteers of the Foundation, contact with them was usually timely and on schedule. In some families, reaching the second family member for telephone surveys was difficult. Many were not Foundation contacts prior to the project and thus had little connection to the Foundation's staff or work. Foundation staff utilized first family members to ensure that second family members were scheduled for pre- and post-surveys. If Foundation staff were unable to contact the second family members, first family members were asked to assist with scheduling and follow-up.

Family participants were given three months from the date of the pre-survey to read through the two booklets. Foundation staff contacted participants by email at 30-day intervals to check on participation and answer questions.

Because psoriasis patients and contacts of the National Psoriasis Foundation represent a cross section of the general population, many of the quotes and stories in the templates were appropriate for NPF's audience.

Sustainability

The *Does It Run In the Family?* toolkit has been integrated into the National Psoriasis Foundation-affiliated support group program as a packaged presentation that can be given by trained support group leaders.

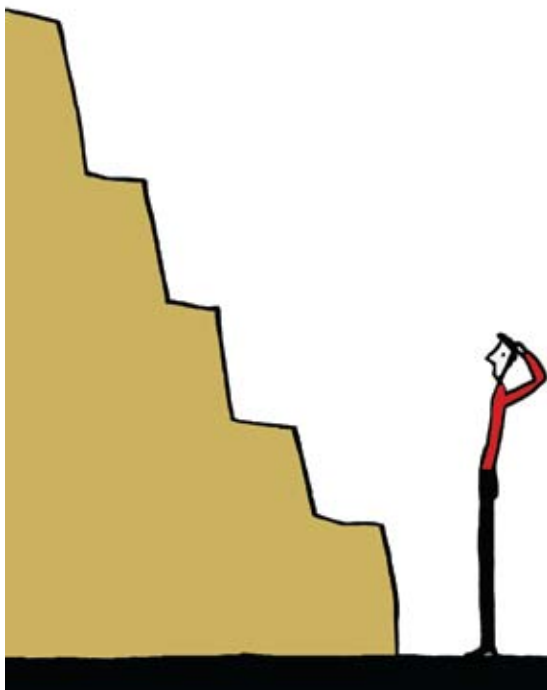
The availability of the toolkit was communicated to Foundation constituents, and project results were discussed in the November/December 2008 issue of *Psoriasis Advance*, the Foundation's quarterly patient magazine.

OFFICE OF JUSTICE AND PEACE ST. MARY'S HEALTH WAGON

Community Need

St. Mary's Health Wagon is a mobile clinic based in Clinchco, VA, in a small, rural, mountainous region with a predominantly Caucasian population. A small community of African Americans reside there, though they are mainly segregated in the locale. Health Wagon provides compassionate, quality healthcare to the medically underserved, uninsured, underinsured, and disenfranchised. Many chronic conditions such as diabetes, lung cancer, and hypertension are prevalent throughout the region. These conditions can be partly attributed to the current lifestyle of the population such as diet, which includes high fat "comfort foods," industry (coal mining), and lack of exercise. Many other cancers also have a higher prevalence in this region, which is thought to be related to the industry and might have a genetic component.

The use of the *Does It Run In the Family?* toolkit was meant to encourage participants to talk to their families, collect their family health histories, and take their findings to their primary care physicians to discuss if they are at increased risk for any health conditions.



Engagement

The community advisory board (CAB) was comprised of area community service agencies and organizations such as community centers, food banks, and women's groups. A patient and a nurse were also recruited for the CAB. The CAB held an organized meeting in the initial stages of the project. After the initial meeting, contact was maintained electronically and through individual in-person meetings. The lack of organized meetings was mainly due to the large geographical region and expenses associated with travel. The CAB provided feedback on all aspects of the project.

Several local community organizations were engaged as collaborative partners for the project. These partners assisted in identifying participants and ensuring data collection occurred in a timely manner. Most CCFHH project participants were recruited from the clinic patient base. Health Wagon recruitment staff queried patients from various mobile clinic sites for willing and able volunteers. Due to the nature of the mobile clinic setup, visiting each site on a monthly basis, recruitment proved to be somewhat tedious. Many patients were asked to participate, but several had reservations about various aspects of the project. Fifty individuals were initially contacted, leading to a total of 24 enrolled families.

Accessibility

The toolkit was customized for the region to engage participants to begin actively thinking about their family health history and how genetics affects current and future health status. Conditions that have a high prevalence in the area such as diabetes and cancer were included. Customization was coordinated by the Health Wagon staff with input from community partners. Although organized monthly meetings did not occur with community partners, participation with the project was immeasurable.

Story collection was completed with ease. Patients readily offered their stories and quotes. However, the process of selecting the narratives and pictures for the booklet was difficult, as many patients had interesting stories to tell. Creating the condition pages was also a simple process because the region is plagued with many chronic diseases, so there are many from which to choose.

Evaluation

When potential participants were identified, they received education about the CCFHH project and were asked if they were willing and able to volunteer as Family Health History Leaders. If the participant agreed to become the Family Health History Leader, the appropriate consent forms were handed out, the pre-survey was completed, and the toolkit was distributed for review and discussion with family. The Family Health History Leader was then tasked with identifying two more participants (blood relatives) for the project.

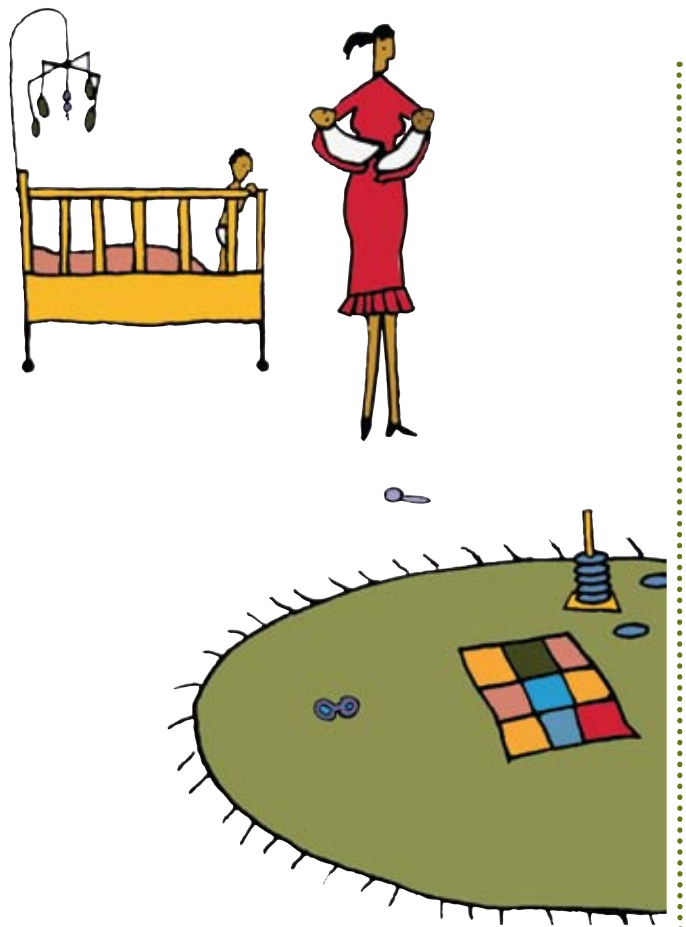
The Family Health Leaders were called at various intervals to determine the progress of getting additional family members to commit. When additional family members were identified, they were given the pre-survey followed by the booklets. Three months after initial contact, the participants were contacted to complete the second survey and were encouraged to discuss their family health history findings with their families and primary care physicians. Keeping the participants' interest in the project was difficult due to the three-month period between pre- and post-surveys.

One suggestion from St. Mary's Health Wagon recruitment staff would be to reduce the amount of time between enrollment and post-survey collection. Three months proved to be too long to wait to complete the second survey. **In the geographical region where the Health Wagon is located, most families spend a considerable amount of time together, providing ample time to discuss their family health history.**

Sustainability

A local presentation about the Family Health History Project was conducted at the Annual Community Health Fair sponsored by St. Mary's Health Wagon. Education and presentations were also conducted at the National Kidney Foundation KEEP Clinic sponsored by the Health Wagon.

Incorporating the information retrieved from the project into electronic health records would prove extremely beneficial for the patient, as well as the physician. It would enable the physician to provide enhanced recommendations and suggestions for lifestyle changes to deter the onset of genetic diseases. The end result would be a more individualized approach to healthcare for the patient. The toolkit has been a useful handout for the Health Wagon's patient base, particularly during chronic disease patient education sessions. The culture of this rural community is one in which communication about family health history is not a priority. It is the hope that education has been offered and will be brought to the forefront about the importance of knowledge of family health history.



URBAN INDIAN HEALTH INSTITUTE, SEATTLE INDIAN HEALTH BOARD

Community Need

In July 2000, the Urban Indian Health Institute (UIHI) was established as a division within the Seattle Indian Health Board, a community health center targeting urban American Indians and Alaska Natives (AI/AN) in Seattle, WA. The mission of the UIHI is to support the health and well-being of Urban Indian communities through information, scientific inquiry, and technology. One of 12 Tribal Epidemiology Centers with core funding from the Indian Health Service, the UIHI focuses on the nationwide urban AI/AN population, while the other 11 serve tribes regionally. A crucial component of the healthcare resources for AI/AN, the Tribal Epidemiology Centers are responsible for:

- Managing public health information systems
- Providing technical support to tribal and urban communities
- Investigating diseases of concern
- Managing disease prevention and control programs
- Responding to public health emergencies
- Collaborating with other public health authorities.

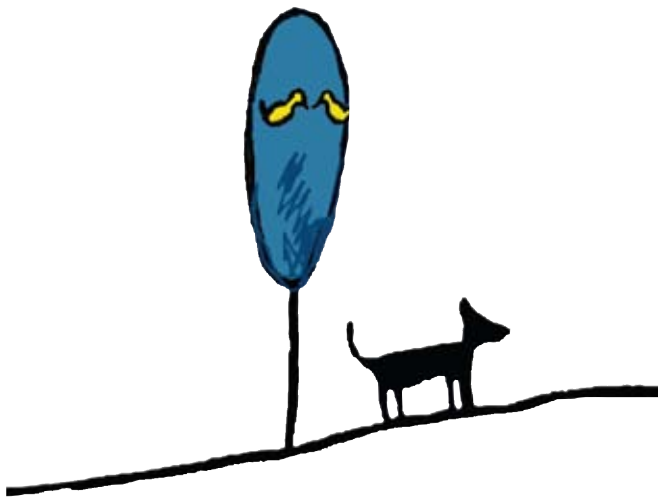
The Urban Indian Health Institute serves the 34 urban Indian health organizations, which are private, nonprofit agencies that provide either direct or referral services to AI/AN living in over 100 select urban counties in 19 states across the country. AI/AN living in urban areas are a diverse and growing population. Over the past half-century, AI/AN have increasingly relocated from rural communities and Indian reservations into urban centers both by choice and by force, through federal policy. Often described as the “invisible population” AI/AN living in urban areas now account for more than half of the overall AI/AN population living in the United States²⁴.

The standard definition of an urban AI/AN is any AI/AN who lives in an urban center. Individuals may travel back and forth between their tribal communities or reservations and urban centers, characterizing the population as mobile. Urban AI/AN are generally spread out within a metropolitan area instead of localized within one or two neighborhoods, thus making it difficult to be seen or recognized by the wider population. Despite this geographical trend, urban AI/AN generally are not included in the Indian health community, nor are they

customarily listed as a minority population in local and national assessment. As a result, they remain invisible and overlooked by the larger society.

While data on the health status of urban AI/AN have limitations, studies have found that urban AI/AN suffer from significant health disparities compared with the general population. These disparities include higher rates of tobacco use, infant mortality, late prenatal care, interpersonal violence, attempted suicide, deaths due to diabetes, accidents, and chronic liver disease²⁴. Added to the health disparities are pronounced socioeconomic disparities among urban AI/AN. When compared with the general population, urban AI/AN are more likely to be unemployed, have lower educational attainment, and be living in poverty²⁵. Work currently taking place at the Urban Indian Health Institute, in collaboration with the network of urban Indian health organizations, is attempting to better understand health risks and strengths of this diffuse population.

The overarching goal of the partnership between the Urban Indian Health Institute and Genetic Alliance was to create a culturally competent health history toolkit that would engage urban AI/AN families to share and discuss health risks and health history. Adapting the toolkit to reflect AI/AN health concerns and distributing this toolkit to the network of urban AI/AN programs was the first of many project-related successes.



Engagement

The recruitment phase of this project lasted approximately four months (March through June) and participants were recruited using the “snowball recruitment” technique. Fliers and consent forms were distributed and posted within Native community-based organizations that the UIHI had an existing partnership with, including: the Seattle Indian Health Board clinic, Chief Seattle Club, Native American Women’s Dialogue on Infant Mortality (NAWDIM), and First Nations at the University of Washington. Project staff hosted “Project Dialogues” at recruitment sites to discuss the project goals and field questions for interested participants. To recruit throughout the Pacific Northwest region, a Native consultant was hired in Year 1, focusing on recruitment in the Portland, OR, area.

Two key methods were utilized for screening and enrolling family members into the study. First, the UIHI hosted a toll-free phone number for all potential participants to call and enroll in the study. Study staff were available during business hours Monday through Friday to field questions and fully screen potential participants. Second, project staff screened potential participants in the field, at the previously-mentioned recruitment locations. In total, 178 individuals were screened, and a total of 25 families (75 individuals) completed the study. The UIHI designed and managed a protected database to house all study-related information, including attrition rates, qualitative notes on recruitment and process, and contact attempts.

Many of the challenges encountered were not unique to this particular study, rather a reflection of common challenges inherent in community-based research within urban AI/AN communities. First, the urban AI/AN community is incredibly mobile, often splitting time between urban areas and rural/reservation-based locations, which had implications for reliable communication. Family needs, medical care, and economic instability are often noted as contributing factors driving the movement between rural and urban areas for many AI/AN. Second, completing the follow-up survey among all participating family members posed a unique scheduling challenge. Many of the responsibilities associated with communication rested with the initial enrollee (the primary family member), including maintaining contact with participating family members. Finally, participants for whom UIHI mailed IRB approved consent forms often required additional follow-up for recruitment documents, which stalled the recruitment process.

In Year 1, the UIHI established a community advisory board (CAB) for the study. Members were selected based on their role as community leaders and key informants. They were asked to advise on the modification of the *Does It Run In the Family?* toolkit and provide overall guidance on the research project. UIHI’s CAB was comprised of six Native community members from a variety of backgrounds, including a traditional/local healer, a PhD graduate student in the field of public health, clinic staff, and counselors.

The CAB met regularly (three times per year) in person and provided significant guidance and feedback throughout the customization process. In addition to this guidance, CAB members were active in the interpretation of preliminary data results produced by UIHI staff. After both baseline and follow-up surveys were collected and analyzed, CAB members were the first to see and discuss the data, providing recommendations for additional analysis and guidance on dissemination and interpretation.

Accessibility

Tool customization built on the unique role of storytelling and oral tradition among many AI/AN cultures. Because the project's overarching goal was the customization of the national family health history tool developed by HRSA, the UIHI collected stories and images from volunteer community members, mainly recruited through CAB members. Personal stories of family health, the importance of communication, and the role of a family disease risk were respectfully collected by project staff; both community photos and stock images were used to accompany stories in Booklet 1.

Language of the booklet included text recommended by Genetic Alliance both before and after customization and original text developed by the UIHI, including the conditions page (developed through an analysis of common diseases that run in AI/AN families) and an overview of the role that historical trauma plays in disease status for many AI/AN. Particular attention was paid to the customization of relevant imagery. Because preliminary analysis showed that only 37% of participants reported that the tool was either very or extremely relevant to their family's health problems, study staff adapted the tool for a second time (Year 3), including updating the imagery and language of Booklet 1. For this phase of customization, the UIHI worked closely with the CAB and, after multiple drafts, proposed final changes to Genetic Alliance in Year 3.



Evaluation

When possible, conducting the participant screening and administering the baseline survey occurred simultaneously. If participant screening occurred over the phone, then the baseline survey was administered after the UIHI received the participant consent form (via U.S. mail). Only then could the UIHI administer the baseline survey. Both the baseline and follow-up surveys were read out loud to each individual while staff completed the paper form, either over the phone or in person. On average, from initial contact to completed follow-up survey, five to eight phone calls were made to eligible participants spanning a four-month period. After all family members completed the second survey, a thank-you note and gift certificate were sent to each family. All completed surveys were on paper, with a randomly-assigned ID number as the identifier, and were stored in a locked file cabinet in a locked room. Participant confidentiality was paramount in this study.

Scheduling and completing both surveys required persistence and dedication. Because of challenges in participant availability (i.e., outside of the 9-5 business hours), the UIHI hired an additional consultant (a public health graduate student) to administer surveys in the evenings or on weekends when necessary.



Sustainability

Dissemination of the adapted tool became a focus of the project in Year 3. Study staff worked first to analyze preliminary data to identify any weaknesses in the tool, and address those weaknesses prior to broad dissemination. Working with the community advisory board, the UIHI made an additional round of edits and revisions to Booklet 1 prior to sending 100 copies to each of the 34 urban Indian health organizations in the nation.

Communication broadcasts (approximately monthly informational emails sent to a listserv) were utilized as a key method of information-sharing between the UIHI and the network of urban Indian health organizations across the country, including:

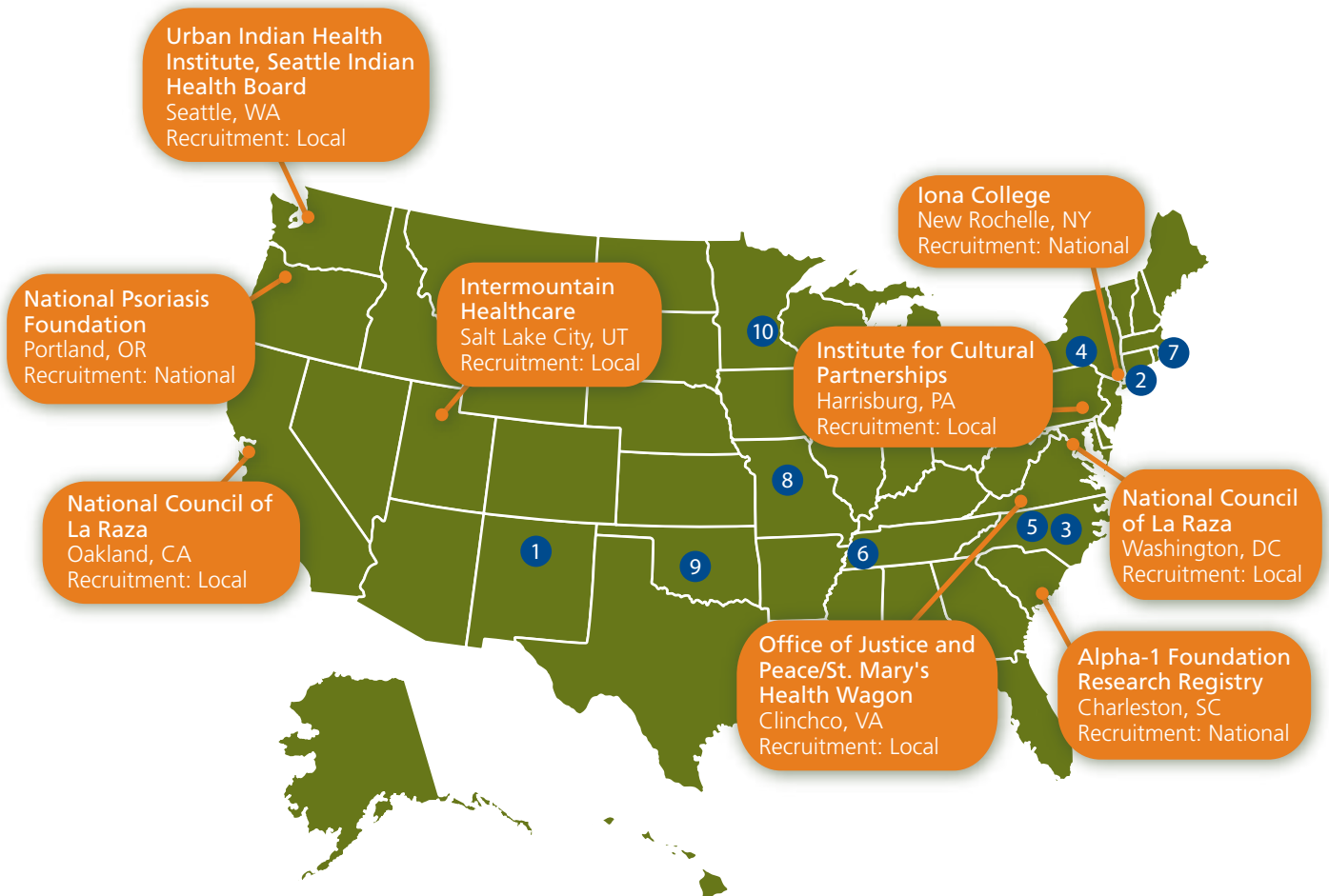
- Family Health History Guidebooks Available (June, 2009)
- Announcing the Customizable Family Health History Tool (September, 2009)

Visit the UIHI website (www.uihi.org) to download copies of the communication broadcasts.

SIHB staff also presented on the process, community input, and evaluation of the project throughout Years 2 and 3 of the project:

- 2009 Washington State Health Care Quality Association (Oral), Bellevue, WA, April 27
- 2009 Seattle Indian Health Board Health Fair (Oral), Seattle, WA, October 28
- 2009 Seattle Indian Health Board Clinic Staff (Oral), Seattle, WA, December 1

COMMUNITY GEOGRAPHICAL OVERVIEW



CCFHH Program Awardees

- 1 Angioma Alliance – Santa Fe, NM
- 2 Brookdale University Hospital and Medical Center – Brooklyn, NY
- 3 Duke Institute for Genome Sciences & Policy – Durham, NC
- 4 Ferre Institute – Binghamton, NY
- 5 The Genomedical Connection – Greensboro, NC
- 6 The Heredity Project – Memphis, TN
- 7 Progreso Latino – Central Falls, RI
- 8 Southern Missouri Telehealth Genetics Services – Columbia, MO
- 9 University of Oklahoma College of Medicine – Oklahoma City, OK
- 10 West Side Community Health Services – St Paul, MN

COMMUNITY SNAPSHOT

Organization	Community Need	Engagement	Accessibility
Alpha-1 Foundation	<ul style="list-style-type: none"> The Alpha-1 community is very focused on understanding genetics Participated to determine if the booklets could prompt individuals in the Alpha-1 community to focus on genetic risks independent of Alpha-1 	Recruitment through: <ul style="list-style-type: none"> Alpha-1 Foundation Research Registry Alpha-1 Association Education Days and National Conference Letter to Alpha-1 Association Genetic Counseling Program participants 	Added to booklets: <ul style="list-style-type: none"> Text and terminology specific to those with Alpha-1 Stories about individuals with Alpha-1 and talking about their inherited condition with family members
Institute for Cultural Partnerships	Barriers to gathering FHH data: <ul style="list-style-type: none"> Privacy and discrimination concerns Lack of time, interest, perceived benefit Opposition from family Unwillingness or inability to read and comprehend written materials 	Recruitment through: <ul style="list-style-type: none"> <i>Community liaisons</i> Messaging that conveys the importance of mitigating genetic risk through lifestyle changes and generating a record of family risk that would benefit family members Prior awareness of the project 	<ul style="list-style-type: none"> Project pilot yielded stories and quotes Narratives and quotes matched with themes from the booklets Composite stories used
Intermountain Healthcare	This Integrated healthcare system has inpatient, outpatient and health plan coverage within one corporate structure.	16 physicians (various types, practice sizes, locations) were interviewed to test whether the type of experience collecting FHH correlates with the usage.	Added to booklets: <ul style="list-style-type: none"> Story on collection of genealogy Page on cystic fibrosis because it is a common autosomal recessive condition in Utah and was added to the state newborn screening panel
Iona College	The project: <ul style="list-style-type: none"> Includes underrepresented individuals in an in-depth discussion about importance of healthcare Teaches faculty and students about assessment, intervention, and intergenerational learning 	Outreach to a cross section of the student body through: <ul style="list-style-type: none"> Mass email Fliers posted in academic departments Word of mouth 	<ul style="list-style-type: none"> CAB provided quotes, stories, and photographs CAB did not recommend a specific disease for Book 2, since college students represent a broad cross section of the general population
National Council of La Raza	Latinos are more likely to experience serious health conditions—hypertension, heart disease, high cholesterol, diabetes, certain cancers, and depression.	Recruitment through: <ul style="list-style-type: none"> Network of ~300 affiliated community-based organizations <i>Promotores de salud</i> 	Three-step customization process: <ol style="list-style-type: none"> 1) CAB provided feedback 2) <i>Promotores</i> tested with their own families 3) Families tested toolkit and completed evaluation questionnaires
National Psoriasis Foundation	People with psoriasis have: <ul style="list-style-type: none"> Elevated risk for psoriatic arthritis, diabetes, cardiovascular, liver, and Crohn's disease and more Higher rates of smoking and excessive alcohol use Poor diet and exercise habits 	<ul style="list-style-type: none"> Recruitment through volunteer base of over 500 people across U.S. All first family members had (or had child with) psoriasis 	Psoriasis patients represent a cross section of the general population, so many quotes and stories in templates were appropriate.
Office of Justice and Peace/St. Mary's Health Wagon	Chronic conditions prevalent throughout rural Virginia, partly attributed to lifestyle ("comfort food", coal mining, lack of exercise).	Most participants were recruited from the clinic patient base.	<ul style="list-style-type: none"> Included conditions with high prevalence in area Selecting stories and pictures was difficult because many patients had interesting stories to tell
Urban Indian Health Institute, Seattle Indian Health Board	Urban AI/AN: <ul style="list-style-type: none"> Are mobile (travel between reservations and urban areas), spread out Suffer from higher rates of tobacco use, infant mortality, late prenatal care, interpersonal violence, attempted suicide, deaths due to diabetes, accidents, and chronic liver disease 	Recruitment through: <ul style="list-style-type: none"> "Snowball" recruitment Fliers distributed "Project Dialogues" with staff Toll-free number for project questions 	<ul style="list-style-type: none"> Unique role of storytelling, oral tradition in AI/AN culture Overview of historical trauma as relates to disease status Particular attention to relevant imagery

Evaluation	Sustainability
<p>Nonresponsive members:</p> <ul style="list-style-type: none"> • Did not read the booklets • Forgot what they said • Thought the actions discussed in the booklets had been occurring in their family for a long time already <p>Responsive participants:</p> <ul style="list-style-type: none"> • Booklets reinforced significance of FHH and inheritance • Initiated dialogue about health issues for family members who were not receptive in the past • Easy to understand 	<ul style="list-style-type: none"> • Dissemination to the Alpha-1 community on paper or as PDF files on the Web • The Alpha-1 community is already rich with high quality, detailed, disease-specific genetic information. The CCFHH booklets proved insufficient to focus families with Alpha-1 on the family health risks that were not Alpha-1 related
<ul style="list-style-type: none"> • \$10 gift card at completion of surveys, completed in person and by phone • Loss of momentum from initial contact and difficulty obtaining consent from second family members 	<p>Dissemination through:</p> <ul style="list-style-type: none"> • How-to seminars highlighting inheritance and starting family conversations about health and disease history • Family reunion and genealogy workshops
<ul style="list-style-type: none"> • Interviews about FHH collection using open-ended questions • PCPs gave informed consent, were paid \$200 to participate • Approved by IH IRB 	<p>Dissemination through:</p> <ul style="list-style-type: none"> • Presentations to the community, professional organizations, and medical community • Paper based on the project accepted for publication • Booklets for download on patient portal and Clinical Genetics Institute's public website
<ul style="list-style-type: none"> • Community-specific questions included in surveys • Students paid \$200 to recruit and track family members • Students paid \$25 for focus group • Follow-up study on focus group results 	<p>Culminating community event brought together CAB members and partners; Iona College students, faculty, and staff; and interested community members for discussion about FHH.</p>
<ul style="list-style-type: none"> • <i>Promotores</i> implemented testing of the toolkit • Concern over length and technical language of evaluation questionnaires 	<ul style="list-style-type: none"> • A large segment of the Latino population is still unaware of the impact of genes on health, but there is a need and desire for this kind of information • Use of <i>promotores</i> is sustainable through community-based organizations with existing programs
<ul style="list-style-type: none"> • Surveys collected by phone by NPF staff member • Used email to schedule phone surveys and send reminders • Used first family members to help contact second family members 	<p>Dissemination through:</p> <ul style="list-style-type: none"> • Booklets in NPF support group program as packaged presentation that can be given by trained support group leaders • Toolkit in quarterly patient magazine
<ul style="list-style-type: none"> • Checked in with Family Health Leaders about recruiting second family members • Three months too long to wait to complete the second survey: families spend lots of time together so could easily discuss FHH 	<ul style="list-style-type: none"> • Communication about FHH not a priority in this culture • Incorporating FHH into EHRs would benefit patient and physician
<ul style="list-style-type: none"> • Baseline and follow-up surveys read out loud (phone or in-person) and staff completed paper form • 5-8 calls to participants over study period • Gift certificate at completion 	<p>Revised booklets:</p> <ul style="list-style-type: none"> • Analyzed preliminary data to identify weaknesses • With CAB made more edits to Book 1 <p>Dissemination through:</p> <ul style="list-style-type: none"> • Communication broadcasts (monthly emails to listserv) • 100 booklets sent to each of 34 urban Indian health organizations in the nation

FAMILY HEALTH HISTORY IN VARIED SETTINGS

FAMILY HEALTH HISTORY WITH HEALTHCARE PROVIDERS

The main outcomes the CCFHH project set out to address were community-based, related to individual and family uptake of the *Does It Run In the Family?* toolkit and its impact on behavior change. However, we assessed communication with a healthcare provider, and Intermountain Healthcare conducted provider interviews to determine how providers use FHH information.

The August 2009 National Institutes of Health (NIH) State of the Science Conference, Family History and Improving Health, concluded that insufficient evidence exists to demonstrate the validity of FHH collection in the primary care setting²⁶. But Intermountain's interviews show that while use of FHH varies among practices and providers, physicians are using the information across specialties. Healthcare provider buy-in to FHH initiatives is essential for FHH promotion. It is important for individuals, families, and communities to take the first steps toward better health on their own, but relationships with providers are also necessary to identify further risk and manage care. Intermountain Healthcare provided several recommendations for working with physicians to implement a FHH initiative such as CCFHH:

- 1) Engage with physicians to understand their needs and concerns.
- 2) Understand if they are currently using a family history tool (even a paper tool) to know what is currently being collected.
- 3) Clarify who is actually reviewing and entering the family history (the physician, the nurse, the assistant, etc.).
- 4) Ask the physicians what FHH information they find to be most useful and how they actually use the information to affect patient care.
- 5) Explore barriers to collection and use of FHH: How could we make it easier?
- 6) Commit to partnering with physicians as new strategies for FHH collection are developed to increase buy-in and usefulness of these strategies.

Another element related to physician use of FHH is the incorporation of FHH information into electronic health records (EHRs). The American Recovery and Reinvestment Act of 2009 provided millions of dollars in incentives for eligible healthcare professionals to adopt EHRs, but these do not necessarily include family health history information. Intermountain Healthcare is a large provider network with an EHR in place, and they are at the forefront of incorporating FHH into EHRs. They will write a paper on barriers to collection and use of FHH in EHRs, which will be published separately, but here they provide some recommendations for incorporating FHH into EHRs:

- 1) Understand how information is currently being captured in the EHR. Is the data structured? In other words, can a computer search and retrieve family history data?
 - a. If yes:
 - i. Is it collected in an electronic form and entered into the problem list, chart form, etc.?
 - ii. Can it be retrieved using a process such as natural language processing?
 - b. If no, confirm that FHH is being entered as text in clinical notes.
- 2) Explore use of FHH within the EHR with physicians.
 - a. How do they (or their designees) enter the data?
 - b. How do they retrieve data when needed?
 - c. How often and under what circumstances are the data updated?
 - d. What barriers to use of FHH in the EHR exist?
 - e. How do physicians circumvent these barriers?
- 3) Partner with physician users as EHR FHH tools are deployed and improved.

Incorporating FHH into EHRs might incentivize physicians to collect and utilize the information and ultimately lead to greater sustainability of FHH initiatives if a good working partnership is in place with healthcare providers.

FAMILY HEALTH HISTORY WITH OTHER CARE PROVIDERS AND THE PUBLIC

Many types of care providers other than primary care physicians and other traditional healthcare professionals exist. An individual is part of family, families are part of a community, and communities are part of society at large. Each level of interaction offers its own mechanisms for care, beginning in the home.

For this reason, family health history should be incorporated and presented as a unifying theme in all public health messaging. FHH is a mix of health, culture, environment, and behavior. It is not just a health concept, but a lifestyle concept, one that will be unique for each family and community. It is accessible across cultures in a way that genetics, as a word and concept, is not. It can therefore be the bridge between health and genetics, showing people the way to connect their daily lives to their health and leading them, engaged and informed, into a world of personalized medicine.

We do not see family health history as a stand-alone intervention; rather, it is imperative that organizations, healthcare providers, health educators, and others tailor their messaging and approach to the relevant access points for their communities. With a flexible definition of community and a flexible approach, the varied needs of different communities can be met in a culturally appropriate way. Individuals, families, communities, and all of their various types of providers, including traditional medical professionals, should work together to make health and healthcare a true partnership.

CCFHH PROGRAM AWARDS

The Community Centered Family Health History Program Awards are a prime example of integrating family health history into varied settings, including use with traditional healthcare providers, as well as other types of care providers and the public. Genetic Alliance distributed 10 CCFHH Program Awards in Year 3. The project period began June 1, 2008, and ended May 31, 2009. These Awards were built into the original cooperative agreement proposal to enhance sustainability of the project products, promote increased use of FHH, and demonstrate the ease with which FHH can be incorporated into diverse programs and communities in innovative ways. Through these 10 programs, FHH has proved to be both applicable and accessible in varied settings.

In March 2008, Genetic Alliance released the Request for Proposals. We received more than 40 letters of intent and almost as many full proposals. We enlisted family health history experts, as well as Genetic Alliance staff, as reviewers. Each proposal was reviewed by at least three individuals (one Genetic Alliance staff member and two external reviewers), and we selected Awardees based on the average of their scores.

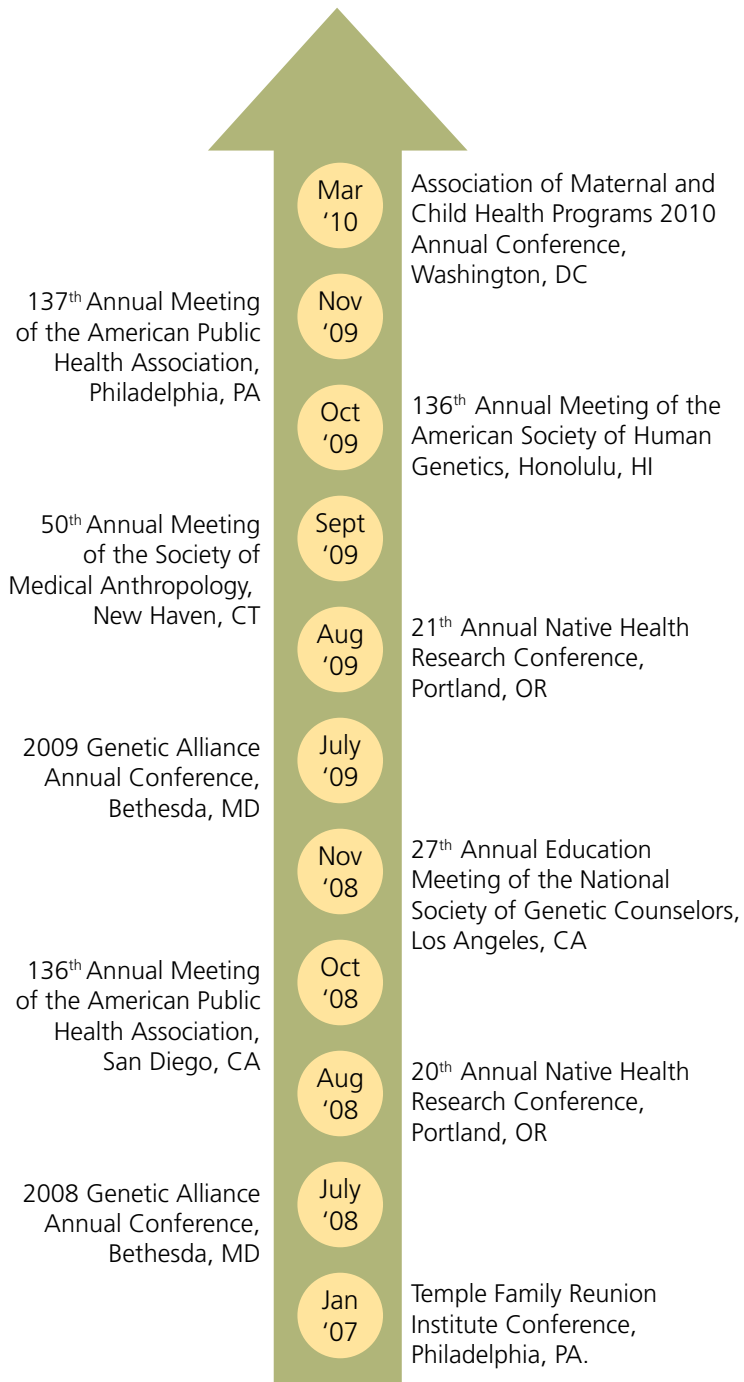
Original CCFHH partners represent a range of community types. Genetic Alliance selected Awardees to fill what proposal reviewers saw as gaps in original CCFHH partners and the field of FHH in general. These additional 10 partners provide further models for successful use of FHH in communities.

Some CCFHH Program Awardees included evaluations as part of their projects, though it was not required based on the amount (\$10,000) and timeframe (one year) of the Awards. While original partners performed a formal evaluation of the toolkit itself, CCFHH Program Awardees further demonstrated its usefulness in different settings. They broadened the scope and reach of the *Does It Run In the Family?* toolkit, as well as FHH interventions in general, becoming model projects for those in need of inspiration for launching their own FHH initiatives. Awardees represent employee health and wellness systems, medical school curricula, military reserve programs, fitness clubs, newborn screening referral programs, and more.

As part of their agreements, Awardees wrote final model project reports, including detailed descriptions of their projects as proposed and as carried out: staff time and budgets, successes and challenges, surprises, lessons learned, and recommendations for replication. These reports are meant to serve as the foundation for DIY family health history initiatives across the country and perhaps even the world. Many individuals and organizations might be interested in starting their own FHH project but lack the resources to know where to begin. Genetic Alliance created a model project database, housed in WikiAdvocacy (wikiadvocacy.org/index.php/Family_Health_History), so that interested parties have easy access to models to work from—varied target audiences, dissemination strategies, evaluation methods, and more, ready to mix-and-match or take whole.

LOCAL AND NATIONAL PRESENTATIONS

Partners spread the word about family health history, the project, and the toolkit at more than 100 local, regional, and national forums. National oral presentations of project results have been made at the following conferences:



Additional national poster presentations were given at the meetings of the National Coalition for Health Professional Education in Genetics, the American Society of Human Genetics, the American College of Medical Genetics, and Community-Campus Partnerships for Health annual meetings.

Partners continue to submit materials about the project for publication and presentation, both formally to journals and conferences and informally through publication of project results in newsletters.

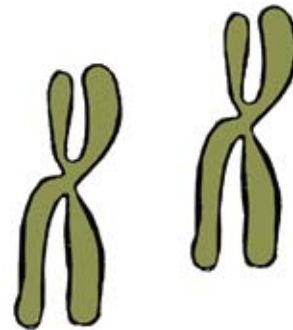
ONLINE TOOL

Another element included in the original project proposal to increase access to and sustainability of the toolkit the online *Does It Run In the Family?* tool. Genetic Alliance developed the online, customizable version of the toolkit to allow any user to create a unique family health history tool for families, organizations, and communities. “A Guide to Family Health History” and “A Guide for Understanding Genetics and Health” are navigable online with the same static content that is found in all of the CCFHH partners’ customized booklets. Then, users can choose from libraries of quotes, personal health stories, photographs, and health condition information, or input their own, to produce a family- or community-specific resource. The current version of the online tool includes more than 30 personal health stories, hundreds of photos, dozens of quotes, and more than 25 health condition pages, including rare and common conditions such as asthma, ALS, and heart disease. This tool, found at www.familyhealthhistory.org, is free and accessible to any user anywhere.

Furthermore, the tool is electronically connected to a printer so that users can order hard copy versions of their unique booklets for the cost of printing and shipping. However, printing costs are a barrier to sustainability – printing is expensive, and many small, community-based and disease-specific organizations do not have funds to print. Still, the Internet is nearing ubiquity, and for free, users can download a high-quality PDF version of their booklets to be posted on a website, emailed, or otherwise shared electronically. While this brings up concerns that the tool might not reach underrepresented and underserved populations who do not have access to a computer or the Internet, our hope is that most, if not all, such populations are engaged in some way with an organization that does have the resources to customize and print booklets that can be disseminated throughout those communities.

Because family health history is such an accessible concept and practice, applicable in diverse community settings, as demonstrated by both the original CCFHH project and by CCFHH Program Awardees, we cast a wide net in our dissemination of the online tool. Via email, we contacted all of the disease-specific organizations in Disease InfoSearch, a Genetic Alliance online resource and database of genetic conditions and support organizations; Family Voices and Parent 2 Parent affiliates; university genetics, genetic counseling, cancer, diabetes, epidemiology, and public health departments; early childhood groups and kid- and family-friendly organizations such as YMCAs, Big Brother Big Sister programs, and Boy Scouts and Girl Scouts; home school organizations; and genealogy groups. To date, more than 600 users are registered in the *Does It Run In the Family?* tool. Booklet 1 has been downloaded more than 300 times, while Booklet 2 has been downloaded 110 times.

We are trying to introduce the tool to a broad audience. However, sometimes it can be valuable to preach to the choir. The tool was submitted to and accepted by CES4Health.info, a peer-review mechanism for products other than journal articles, which focuses on items of community-based scholarship.



RECOMMENDATIONS AND LESSONS LEARNED

Our experience with Year 3 partners emphasized the lessons learned from working with original partners about community differences. Each organization faces its own institutional challenges, and flexibility is an absolute necessity in community work. However, this does not mean a lack of structure. The Program Awardee projects also highlighted the idea that similar materials can be used differently to advance the same goals: increased conversations about health within the family and community and with providers, resulting in healthy lifestyle choices based on increased knowledge of family health history. This diversity can be seen in each partner's customized booklets, all available for download at: www.geneticalliance.org/ccfhh.

Furthermore, the dozens of proposals we received in response to the Request for Proposals underscored the fact that many individuals and organizations are excited about family health history; recognize its potential as a positive health intervention; see the benefits of knowing and sharing this information; want to share it with others; and are willing to find creative ways engage people. Though cliché, in this situation, the possibilities really seem limitless.

In terms of sustainability, both original partners and Awardees have promoted the toolkit beyond the individuals and organizations directly involved in the project. Analysis of our evaluation data, which was submitted for peer review to the journal *Progress in Community Health Partnerships*, found that participants expressed interest in using the toolkit in the future with both family and healthcare providers. This demonstrates promise for sustainability of the *Does It Run In the Family?* toolkit as well as a greater overall sustainability of conversations about health and healthy living. We hope the results of the individuals and families directly involved in the project can be extrapolated to their extended family members, as well as others who have been exposed to the project through various dissemination channels.

Collaboration

Emphasis on collaboration was integral to CCFHH and is crucial to any similar initiative. Genetic Alliance coordinated the activities of partners, but this was not

a Genetic Alliance project. Rather, it was a collaborative endeavor, with a “not about us without us” philosophy. It was important to keep this collaborative mentality throughout the entire project, from planning through evaluation and dissemination.

- The grant application was a collaboration. Genetic Alliance enlisted partners, and each contributed to the shaping of the proposal.
- The CCFHH National Advisory Committee included project partners.
- Each partner organization had its own community advisory board, whose recommendations informed both their specific communities, as well as the overall project.
- Genetic Alliance project staff conducted monthly calls with all partners to discuss the project and the overall process.

All the data belonged to the communities, which made their input absolutely necessary. Responsibility lies not with one party but with every organization involved.

This is an important consideration: All partners must give the project equal priority. CCFHH was only one of many projects that each partner was involved with at any given time. The ability to prioritize and work cooperatively needs to be ubiquitous among partners so that no one is a barrier to the process. CCFHH began with five disease-specific partners, but shortly after the cooperative agreement was awarded, three of those organizations (the National Alopecia Areata Foundation, National Marfan Foundation, and the Colorectal Cancer Coalition) dropped out of the project. Bad timing was the primary deterrent to participation, and financial concerns were also a factor. Personal emergencies, staff transitions, and other unexpected events contributed to the inability of those groups to fulfill their obligations for the project. These issues affected all partners at some point during the project. All communities are different; while they share some things, each community has a unique access point to health information and therefore encountered unique challenges. Fortunately, most were able to work through the obstacles.

The multi-part nature of the project also presented novel challenges that had to be navigated. The project consisted of the following:

- Educational materials development
- Survey of FHH knowledge
- Evaluation of materials with families
- Production of customizable web tool
- Program Awards and model project database
- Publication

The different parts of the project required different working styles. Educational materials development was a collaboration among all partners, while the evaluation of those materials was carried out independently by each partner. Still, coordination was required throughout the evaluation process at a macro level so that all partners proceeded in their work simultaneously with minimal disruption.

Communication

Another critical contributor to both the successes and challenges experienced in this project was communication. Good communication might be a given for collaboration, but in this case it deserves particular emphasis. Clear, open lines of communication were necessary among Genetic Alliance staff, between Genetic Alliance and the HRSA program officer, between Genetic Alliance and partners, among various partner organizations, among staff within each partner organization, and between all parties and the external evaluator. As mentioned above, many partners experienced staff transitions during the project. Open, straightforward dialogue was essential so that incoming staff could efficiently pick up where outgoing staff left off and so that the relationship between Genetic Alliance and the partner organization was maintained with as much continuity as possible.

Specifically, communication around data analysis was not ideal during this project. The evaluator should have talked to each partner organization directly, with a Genetic Alliance representative present. Instead, Genetic Alliance often became the middleman, relaying questions and answers between the evaluator and partners. It should have been made clear from the beginning of the project that partners had access to the evaluator directly. This

might have eliminated some confusion and alleviated some frustrations over the course of the evaluation period.

Flexibility

Finally, the need for a firm yet flexible approach to community work was an important lesson learned. In the work plan that was laid out in the original proposal and approved by all partners, Genetic Alliance expected all evaluation to be completed, with raw data submitted to the evaluator, in month 23 of the project. However, initial recruitment at some sites took longer than expected, and attrition necessitated additional recruitment by some partners late in the evaluation process. In the end, one group, Alpha-1 Foundation, was only able to recruit about half of the required number of families, and Seattle Indian Health Board never submitted their data to the evaluator because of concerns with the analysis plan. Follow-up meetings with SIHB will take place to discuss these concerns, clarify the terms of the project contract, and brainstorm ways the process could have proceeded more smoothly and how to collaborate more effectively in the future.

All of these hiccups in the process are natural, and flexibility was required to accommodate unanticipated events and not to over-burden or stress communities. However, a time comes when it is no longer practical or beneficial to continue waiting and making accommodations. Partners should build extra time into proposed project timelines and should not be hesitant to be strict in upholding timelines when necessary. The nature of community-based work is unpredictable, so cushions should be built into work plans and timelines wherever possible. And when those are exhausted, know that it is time to move on.

FUTURE PLANS AND NEXT STEPS

Genetic Alliance has already started to build on and expand the *Does It Run In the Family?* toolkit for other projects. For example, Genetic Alliance partnered with Genzyme Corporation to produce a booklet on how to share a disease diagnosis with your family, particularly around Gaucher disease. It is not only important to collect family health history information from your relatives; it is similarly important to tell them what you know about your own health. The booklet, appropriately titled “How Do I Talk to My Family about Gaucher?” incorporates information on collecting and sharing information about family health that was first presented in “A Guide to Family Health History.”

Family health history is probably the most widely-accessible focus of any Genetic Alliance program. For this reason, it can be integrated into our other initiatives, just as family health history was integrated into the ongoing programs of CCFHH Program Awardees. In our work with Johns Hopkins/NHGRI genetic counseling students, we combined FHH work with our Access to Credible Genetics Resources Network project so that students work with a condition-specific organization to customize and create new FHH materials using the online tool and help the organization evaluate its existing health education resources.

We also plan to incorporate FHH resources into the Newborn Screening Clearinghouse, as knowledge of family health information is an important gift that children should receive from birth. To wit, the National Coalition for Health Professional Education in Genetics, March of Dimes, Genetic Alliance, and Harvard Partners began a project to develop an electronic tool to gather a woman’s consistent family history information and analyze it immediately to improve patient care. The new tool, to be used in the healthcare provider’s office waiting area, will put family medical history at doctors’ fingertips, alerting them to a patient’s increased risk for birth defects or pregnancy complications. The *Does It Run In the Family?* toolkit will be available to expectant mothers before and after their prenatal visits through a patient and provider website, and might be given to women at the end of their visits by their providers.

Finally, Genetic Alliance will continue to seek opportunities to incorporate the FHH booklets, online tool, and general concepts into all existing and new programs. It offers the perfect opportunity to break silos among projects and topic areas to foster broadly relevant and crosscutting work. Similarly, we will continue to promote the online tool to bolster the user base and encourage customization and printing. No one should have to recreate the wheel when it comes to family health history materials—the *Does It Run In the Family?* online tool puts unique materials at their fingertips.



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Family Health History Questionnaire

Instructions for using the family health history questionnaire:

- 1) Photocopy the questionnaire on the opposite side of this sheet for you and your family members.
- 2) Fill out one copy for yourself.
- 3) Send out the other copies to family members along with a letter explaining why you sent it. Be sure to send out extra copies for any additional people in the same household.
- 4) Tell your family members that they can photocopy blank questionnaires and send them to other family members.
- 5) Try to get all the forms back. Keep in mind that not everyone will fill out all the questions because of the sensitive nature of health information.
- 6) Write each individual's relationship to you at the bottom of the questionnaire after it is returned.
- 7) As time goes on, remember to add any new information that you might learn about your family members to their questionnaire.

Another option: You can send out the questionnaire through email. Go to:
www.geneticalliance.org/familyheathhistory

Optional Family Health History Questionnaire

Instructions: Fill out one of these questionnaires for yourself and make copies for others to fill out. You can also fill out a questionnaire for people who are deceased or cannot do it themselves. *Not all health conditions are listed.* Many other conditions, including many mental health conditions and single gene disorders also run in families.

Name: _____ Today's Date: _____

Place of Birth: _____ Date of Birth: _____

If Deceased
Cause of Death: _____ Date of Death: _____

Ethnicity: _____

<u>Health history</u>	<u>Yes</u>	<u>No</u>	<u>Not sure</u>	<u>Age of onset</u>
High blood pressure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
High cholesterol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Heart disease or heart attack	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Stroke	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Diabetes/sugar disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Types: _____				
Asthma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Alzheimer's disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Birth defects	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Types: _____				
Vision loss/hearing loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Miscarriage/Stillbirth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
How many? _____				

Check one:

_____ Smoker _____ Ex-Smoker _____ Non-Smoker _____ Not Sure

Other Health Concerns:

Healthcare Provider Card

Summary of family health history

I am concerned about my family history of: (check all that apply)

Health Concerns/Risk Factors

- | | |
|--|---|
| <input type="checkbox"/> Heart disease or heart attack | <input type="checkbox"/> Breast cancer |
| <input type="checkbox"/> Stroke | <input type="checkbox"/> Ovarian cancer |
| <input type="checkbox"/> Diabetes/sugar disease | <input type="checkbox"/> Colon cancer |
| <input type="checkbox"/> High blood pressure | <input type="checkbox"/> Endometrial(uterine) cancer |
| <input type="checkbox"/> High cholesterol | <input type="checkbox"/> Other cancer: _____ |
| <input type="checkbox"/> Asthma | <input type="checkbox"/> Mental health: _____ |
| <input type="checkbox"/> Hearing loss at young age | <input type="checkbox"/> Mental retardation/developmental delay |
| <input type="checkbox"/> Vision loss at young age | <input type="checkbox"/> Alzheimer disease/dementia |
| <input type="checkbox"/> Genetic conditions: _____ | |

Prenatal Concerns

- | | |
|--|---|
| <input type="checkbox"/> Birth defects | <input type="checkbox"/> Miscarriage/stillbirth |
| <input type="checkbox"/> Genetic conditions: _____ | |

Identify family members with each condition checked, including age of diagnosis, current age or age at death and cause of death (use extra sheets if needed)

Relationship	Condition	Age of onset	Current age	Age, cause of death
<i>Example:</i>				
<i>Brother</i>	<i>High Blood Pressure</i>	<i>35</i>	<i>45</i>	
<i>Mother</i>	<i>High Blood Pressure</i>	<i>40</i>		<i>65, Stroke</i>

Please include information about your children, your brothers and sisters, mother,(mother's side: aunts, uncles, grandparents), father,(father's side: aunts, uncles, grandparent)

Resources for the Provider

Recognizing Family Risk (Genetic Red Flags)

- Family history of known genetic disorder
- Multiple affected family members with same or related disorders
- Earlier age at onset of disease than expected
 - Breast, ovarian and endometrial cancer < 50 yrs (pre-menopausal)
 - Colon and prostate cancer < 50 yrs
 - Stroke and noninsulin-dependent diabetes < 50 yrs
 - Dementia < 60 yrs
 - Coronary artery disease < 55 yrs males and < 65 yrs in females
- Sudden cardiac death in a person who seemed healthy
- Multifocal or bilateral occurrence in paired organs
- Ethnic predisposition to certain genetic disorders

General Guidelines for Risk Stratification

High Risk

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

Moderate risk:

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

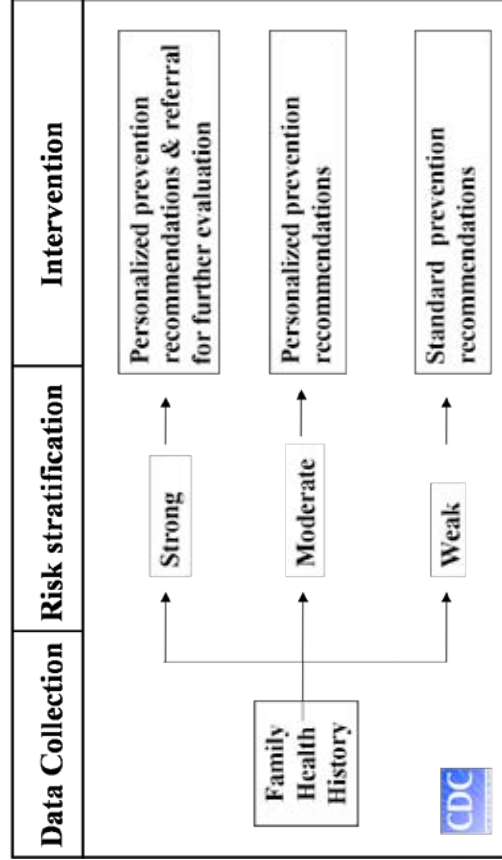
Average risk:

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

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

Family History Website Resources

1. CDC – www.cdc.gov/genomics/famhistory/famhist.htm
2. AAFP Genomics CME – www.aafp.org
3. U.S. Surgeon General – www.hhs.gov/familyhistory/
4. Genetic Alliance – www.geneticalliance.org/familyhealthhistory
5. Recent Literature – www.geneticalliance.org/fhh.literature



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