The Pursuit of Answers

You've been part of WHI for years now, and the routines for the different programs are pretty familiar—you complete all those forms that come in the mail, get your mammograms, give blood samples, record what you eat, etc. Most women are clear about their reasons for being in the study, whether it's helping future generations or paying more attention to their own health.

We talk about "being part of the answer," but it's easy to lose sight of what answers we're seeking. This article looks at the original questions, or hypotheses, of WHI and how they're answered through tracking the health events, or outcomes, of women in WHI.

The WHI Clinical Trial (which includes the Hormone, Dietary, and Calcium/Vitamin D studies) was designed to look at some of the major causes of illness and death in postmenopausal women. Researchers hope that the various study interventions (or treatments) will reduce the risk of getting sick or dying from the main diseases common in older women, thereby improving the health of women over 50.

For the Hormone Program, researchers are looking at whether hormones (now estrogen alone, since women taking estrogen plus progesterin were asked to stop their study pills) reduce the rate of heart disease and hip fractures. The study also assesses if estrogen increases the risk of breast cancer.

In the Dietary Study, researchers want to see if a low-fat dietary pattern reduces the rate of breast cancer, colorectal cancer, and heart disease. The low-fat dietary pattern involves reducing total fat, while increasing intake of fruits, vegetables, and grains.

The health of Calcium/Vitamin D Study participants is being followed to see if these supplements reduce the risk of hip fractures and colorectal cancer.

Many women are involved in more than one part of the Clinical Trial. Information

Continued on page 2
The Pursuit of Answers

Continued from cover

from smaller subgroups of participants—many of whom are in both the Hormone and another WHI program—will help us learn about the effect:

- hormones and a low-fat dietary pattern have on the rate of breast cancer in women at high or low risk for the disease;
- hormones and a low-fat dietary pattern have on the rate of heart disease and breast cancer, compared to each intervention alone;
- hormones and calcium/vitamin D have on the rate of fractures, compared to each intervention alone;
- hormones, a low-fat dietary pattern, and calcium/vitamin D have on smaller groups of women, such as age groups and racial/ethnic groups.

How do we find out, over time, what impact the different parts of the Clinical Trial are having on health? WHI researchers track the health of participants, through study forms and clinic visit procedures, to find out about health events, or outcomes. Every WHI Clinical Center has staff members who follow up when participants report a health event or hospitalization. They often ask the doctor or hospital involved for X-rays, lab test results, etc. All of this confidential information is entered into the WHI database without any information that identifies the participant. The information is reviewed regularly by the WHI Data & Safety Monitoring Board to ensure participant safety and will give researchers concrete evidence of the benefits and risks of the different parts of the study.

Your clinic visits are especially important, both for your safety and for contributing to our knowledge about women's health. Mammograms, blood pressure checks, blood draws, and bone density screenings provide a tremendous amount of information and help fill in the picture. We wouldn't see the whole picture of your health through forms alone, nor through clinic visits only. By doing both, we're able to carefully track every participant's health.

This quest for answers requires a great commitment from every woman involved with WHI. We appreciate your efforts to keep us updated on your health—in person and through study forms—so we can someday answer these important questions for all women.

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Letters

We'd love to hear feedback on the newsletter and your story ideas. We regret that we cannot answer questions about individual medical conditions. Published letters may be edited. Send a letter to:

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An Unexpected Route to Friendship

In early September 2001, Shirley Brooks-Jones sat in Denmark across from her good friend from Poland. She was pondering a tough question he had just posed: What are you most grateful for? While many things like health and education came to mind, Shirley finally pinned it down to two. “The first thing I’m most grateful for is that as a woman, I’ve had the good fortune of being born in the United States, because regardless of how wealthy or intelligent or anything else I am, had I been born in a lot of other countries, I wouldn’t have been able to do the things I’ve done,” she said. “The second thing,” she added, thinking about what she’d seen in Poland as the result of war, “is that at least in modern times, the shores of my country have never been invaded.”

Two days later was September 11. Shirley was flying home from Germany, the last leg of a trip she took to attend a board meeting of People To People International, an organization that enhances international understanding and friendship. About five hours into the flight, the captain announced they were having a problem with an indicator light and they were going to land in Gander, Newfoundland. As they landed, Shirley saw planes from all over the world crammed on the airfield, nose to tail, wing to wing. “Something’s not right here,” she thought.

A few minutes later, the captain came on the loudspeaker again, apologizing for the ruse and explained that there was a national emergency and the U.S. borders were closed. The very thing for which Shirley had been grateful—no invasion—had been dashed by the terrorist attacks. For the first time in history, American airspace closed and 252 international flights carrying nearly 44,000 passengers were rerouted to Canadian airports, including the one where Shirley sat.

A day later, Shirley and her fellow passengers were finally allowed to get off the plane, and they were taken to the nearby community of Lewisporte. The residents of this remote, sparsely populated area rallied to make the stranded passengers feel welcome. The dazed and heartick travelers were offered shelter in homes, service clubs, churches, and schools. They were given home-cooked meals, and had all of their immediate needs—from prescription drugs to Internet access to an understanding ear—taken care of. “They were ready for us. They had thought of everything possible that we might need,” recalls Shirley. “They wouldn’t let us pay a penny for anything.”

“We fell in love with those people and they fell in love with us,” says this Dietary and Calcium/Vitamin D participant at the Columbus Clinical Center. Three days later when the passengers were finally en route to the U.S., Shirley and several others brainstormed how to thank the Lewisporte residents for their generosity and safe haven. They decided to start a scholarship fund for the Lewisporte high school students. Shirley announced the idea over the plane’s intercom, and a pledge sheet was circulated through the aisles. By the time they landed, $15,000 had been pledged. With matching funds and corporate contributions, the fund grew to $50,000. Shirley was honored to return

(Continued on page 4)
to Lewisporte for the 2002 high school graduation ceremony. She surprised 14 students with college scholarships. "I'll never forget the looks and smiles," she says.

"Lewisporte has become my second home," Shirley remarks.

"They really made a wonderful experience out of a terrible situation. It's become my life's mission to grow that scholarship fund and continue helping that community."

The story of the Flight 15 Fund hasn't gone unnoticed. Magazines like *Family Circle, Reader's Digest, Kiplinger's* and *People* featured the story, as well as *The Boston Globe* and *The New York Times*. A public television documentary, "Stranded Yanks: A Diary Between Friends," took Shirley to Lewisporte again to help tell the tale, and several books chronicling the events have been published.

The whole experience has been a little overwhelming to the ever-humble Shirley. "For a kid who grew up with no running water or toilets, this is a miracle," she says. "I sometimes hear people complain that they're bored. With so many problems, so many opportunities, how can you be bored when there are so many good things you could be doing?"

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### FOR YOUR HEALTH

- Drinking enough water is important to maintaining good health, but most people actually get about as much water from foods as they do from drinks. One apple, orange, or raw tomato contains almost four ounces of water.

- While driver-side air bags are an important safety feature, they can be dangerous if you're sitting too close to the steering wheel (where the air bag is stored). Make sure to leave at least 10 inches between your breastbone and the center of the wheel; double-check that distance with a tape measure, as research has shown that most people misjudge it. If you're too close, try reclining your seat slightly or sliding it back. If possible, tilt your steering wheel down, away from your head and neck.

- If your feet are cold, it may take you longer to fall asleep. To speed up slumber, try wearing socks or placing a hot-water bottle (wrapped in cloth) at the bottom of your bed. (But don't use heat if you have diabetes or another reason for poor blood flow to the feet.)

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- Each year, about one in three people over age 65 falls. Try these steps to reduce your risk of falling:
  - Use bright-colored adhesive strips to call attention to stumbling points, such as the edges of steps.
  - Make sure stairs and hallways are well-lit and turn on lights if you get up at night.
  - Move unstable furniture out of the main traffic areas of your home.
  - Tack down or toss out throw rugs.
  - Get regular exercise to maintain strength and balance.
  - Make sure all stairways have railings and install grab bars around the shower and toilet—preferably in colors that stand out from the surroundings.

- Need help creating a living will, advance directive, or durable power of attorney for health care? Visit www.caregiver.org on the Internet for free access to planning tools. At the website, click on "Fact Sheets" in the "Clearinghouse" section, then select "End-of-Life Decision Making" from the alphabetized list of fact sheets. You can also send $1.00 for the fact sheets to Family Caregiver Alliance, 690 Market Street, Suite 600, San Francisco, CA 94104.
Many women exercise to maintain good health, but what type of workout is best? In this ongoing column, we feature WHI research results. The focus in this issue is on a scientific paper written by JoAnn Manson, MD, PhD, Principal Investigator at the Boston WHI Clinical Center, and other WHI scientists. Their findings were published in the New England Journal of Medicine. Regular physical activity protects the heart, but scientists were uncertain whether the benefits of walking are similar to more vigorous exercise. Research on this subject has been limited, particularly among women of color.

The researchers examined the links between total physical activity, walking, and vigorous exercise and the risk of coronary heart disease (CHD) and total cardiovascular events. Data from 73,743 women aged 50 to 79 participating in the Women's Health Initiative Observational Study was used. These participants had no diagnosed cardiovascular disease or cancer at the beginning of the study when they completed detailed physical activity questionnaires. During the next 5.9 years of the study, there were 345 newly diagnosed cases of CHD (nonfatal heart attack or death related to heart disease) and 1,551 total cardiovascular events.

Researchers found that increased physical activity was strongly related to a lower risk of CHD and total cardiovascular disease. Both white and black women (there were not enough women of other races to be analyzed separately) had similar decreases in risk (30-40 percent) with increasing activity. Strenuous exercise and walking produced similar decreases in risk. Ethnicity, age, or body mass index (an estimate of total body fat) did not affect the benefits.

If walking is how you choose to exercise, this research showed that it can be as beneficial as more strenuous exercise in helping protect the heart.


WHI Word Scramble

Some of the words in this newsletter have been scrambled below. Solve each word scramble and use the shaded letters to solve the puzzle at the bottom. (Answers on page 7)

1. A clinical trial is a type of:
   
   D T Y S U

2. A friend to the north:
   
   A A C D N A

3. A healthy habit:
   
   L A W G I N K

4. WHI in the news:
   
   M O R E H O N S

5. Our main concern for you:
   
   F A S T E Y

6. Fill in the shaded letters below and then unscramble to reveal a message from us to you
   … our V.I.P. (very important participant)!

   Our message: _______ _______ _______ _______ _______ _______ _______ _______ _______
Dear WHI

Q: When the Estrogen plus Progestin study was stopped, I was told to stop taking my study pills. If I'm not taking pills anymore, why should I stay in the study?

A: We now have a new, equally important question to answer—how long do the risks and benefits of taking estrogen plus progestin persist? This question can only be answered if you continue to participate, whether you were taking placebo (inactive) pills or active estrogen plus progestin. We would like you to continue having your yearly mammograms and other health exams and to continue filling out the health updates so that we can monitor your health on a regular basis. With this health information, we will know about any changes that occur after you stopped taking your estrogen plus progestin study pills. We will continue to also monitor all participants' health through the end of WHI.

Q: My health is not as good as it was when I first joined WHI. Since WHI is studying healthy women, am I still important?

A: You're correct that when women joined WHI, they did not have certain medical conditions; however, we expect to see changes in our participants' health as they age. This is a natural part of aging. An important aspect of WHI is collecting information about how your health changes over time. In fact, conditions you may experience during the study are probably some of the very health issues WHI is interested in learning about. Your participation is just as important now as it was when you joined the study. When problems or challenges come up over the years, we will work with you to try and resolve them and make sure that your participation in WHI is as manageable and flexible as possible.

Q: What should I tell my proxy about my participation in WHI?

A: How much you want to share about your part in WHI is up to you, but it's a great idea to keep your proxy—the person you've designated to give information about your health if you are unable to—informed about your study participation. Consider letting your proxy know that WHI has been an important part of your life for many years and that you are committed to providing information and participating to the fullest extent possible. You might want to share this newsletter or other information you receive from your Clinical Center with your proxy. Make sure your proxy has received the letter provided by your WHI site that describes your participation and the important role of a proxy.
Q: I'm a very busy caregiver. I'm not sure that I have time to participate or attend my annual Clinical Center visits.

A: If you're in a caregiving situation, staying in WHI may seem hard. But you are irreplaceable to us. We understand that life situations change, and want to work with you if that happens. If the person you care for is physically able to leave the house, ask your Clinical Center about bringing him or her along on your clinic visit. If you need help, perhaps a trusted family member, friend, or neighbor could care for your loved one on the day of your visit. If you don't know anyone who can help, your Clinical Center may be able to put you in touch with community resources to assist you. Caregivers often put their own needs last during challenging times; you can use your clinic visit as a well-deserved break from your caregiving routine. If you are simply unable to attend a clinic visit, please let us know. We'd be happy to talk with you about ways you can temporarily change your participation to meet your current needs.

Q: The annual clinic visits are not very long. I don't feel that I am getting much out of participating in WHI anymore.

A: Many participants lead busy lives, so we try to make the visits efficient. That's why we often ask you to fill out your study forms before your clinic visit. Talk to your Clinical Center staff about your concerns or ideas for making your participation more meaningful. Sometimes it's helpful to think back to why you first joined the study and explore whether those reasons are still there. Was it to be part of a national effort to improve women's health? To help future generations? To honor the memory of a loved one? Maybe there are new reasons — ongoing opportunities to contribute to medical knowledge, personal growth, a chance to meet new people or see old friends.

Q: WHI asks me the same questions over and over again. Nothing has changed in my life. How am I contributing?

A: WHI is a long study. Sometimes participants feel less enthusiastic about the forms after awhile. But that's part of what makes WHI so important—more years will bring more information, which we hope will lead to more answers! Even knowing that nothing has changed in your life is important information. You are asked a lot of questions over time so that we know when and how your health changes. Since none of us knows when our health might change, tracking this information during the whole study makes good sense. If you need assistance completing the forms, your Clinical Center can help. Taken together, the information we get from the women in WHI will paint a broader picture of women's health than has ever been seen before. This information will help us look at many questions for years after the study ends.

KEY TO SCRAPPABLE (page 5)
Stay In Touch

Don’t forget to call your local Clinical Center if your address or phone number change!

Albert Einstein College of Medicine
Bronx, New York • (718) 931-1010

Arizona Prevention Center
Phoenix, Arizona • (602) 241-9216
Tucson, Arizona • (520) 321-7440

Baylor College of Medicine
Houston, Texas • (713) 793-1866

Berman Center for Clinical Research
Minneapolis, Minnesota • (612) 341-7900

Brigham and Women’s Hospital
Chestnut Hill, MA • (617) 278-0782

Center for Health Research
Portland, Oregon • (503) 355-6759

Charlton Memorial Hospital
Fall River, Massachusetts • (800) 742-3446

Detroit Clinical Center
Detroit, Michigan • (313) 965-8000

Emory University
Decatur, Georgia • (404) 370-7355

Evanston Hospital
Evanston, Illinois • (847) 570-1130

Fred Hutchinson Cancer Research Center
Seattle, Washington • (206) 875-4580

The George Washington University
Washington, DC • (202) 872-3700

Kaiser Permanente—Bay Area Clinic
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Medical College of Wisconsin
Milwaukee, Wisconsin • (414) 805-7040

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Nevada Clinical Center
Reno, Nevada • (775) 784-4906

New Jersey Medical School
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New Brunswick, New Jersey • (732) 235-6546

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Ohio State University
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Rush-Presbyterian St. Luke’s Medical Center
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UAB Preventive Medicine
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UCLA Women’s Health Initiative
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Cincinnati, Ohio • (513) 584-6061

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University of Iowa
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University of Miami School of Medicine
Miami, Florida • (305) 243-4800

University of North Carolina
Chapel Hill, North Carolina • (919) 547-5600

University of Pittsburgh
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University of Wisconsin
Madison, Wisconsin • (608) 282-1600

UTHSC
San Antonio, Texas • (210) 567-1850

UT Prevention Center
Germantown, Tennessee • (901) 347-8300

WHI of the Nation’s Capital
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WHI of the Triad
Greensboro, North Carolina • (336) 272-0455

Women’s Health Initiative
Hawaii, Honolulu, Hawaii • (808) 441-5555

If you have questions, use the telephone number listed above to contact your Clinical Center.