

In the family

Many common ailments can be passed down from generation to generation

By Markian Hawryluk / Published in the Bend Bulletin Newspaper on 11-24-05

About a year ago, Bruce Shutler lifted a heavy door and felt an excruciating pain in his back. He figured he had pulled a muscle. But when a chiropractor couldn't provide any relief, his doctor sent him for an MRI. The scan showed three compression fractures of his spine.

"You could see the lines of the backbone and then it looked like somebody had taken a dry brush and powdered it," he says. "Very low density. "Shutler was surprised to hear that in his 50s, he was suffering from osteoporosis. It was only after his doctors began treating him that they realized Shutler was the son of another one of their patients, Patricia Petersen, who had been diagnosed with osteoporosis years earlier. Petersen and Shutler learned that their family has a common genetic makeup that puts them at increased risk for osteoporosis. Her son in California is now showing similar symptoms, as did her daughter before she died in a car accident. Petersen's mother was never diagnosed with osteoporosis, but had many of the classic signs. "I didn't realize that was what she had," Petersen says. "You don't look into things when you don't know about them."

Had they known about their predisposition for osteoporosis, they could have taken steps to prevent the deterioration of their bones, and probably avoided their compression fractures. Cases like this are a prime example of why public health officials are urging all Americans to record their family medical history. Surgeon General Richard Carmona has even named Thanksgiving Day the second annual National Family History Day.

"Even with all the high-tech tests, medicines and procedures available in today's modern health care setting, family health history remains the cornerstone of our efforts to prevent

disease and promote personal health,” Carmona said in a written statement on the initiative. “It’s clear that knowing your family history can save your life.”

Family gathering

Public health officials say most families will have at least one disease running through their bloodlines. Yet a recent survey found that fewer than 30 percent of Americans collect any sort of family medical history. Generally, a history of a common chronic disease in a family increases the risk a family member will develop that disease to two-to-five times that of the general population. The more relatives with that condition, the closer the relatives, and the earlier the onset of the disease, the higher the risk.

With families gathering today for Thanksgiving, it may be the perfect time to look into their medical histories and perhaps help identify areas of concern. Petersen and Shutler, who will serve as grand marshals for the Arthritis Foundation's Jingle Bell Run/Walk for Arthritis on Dec. 3, now take injections to increase their bone density. They likely could have avoided or delayed taking those shots had they known their family history earlier.

“Family history of osteoporosis, particularly when a fracture has occurred in a parent, is really a very important indicator,” says Dr. Daniel Fohrman, a rheumatologist with Bend Memorial Clinic. “If somebody's mother fractured her hip tripping, chances are very, very high that is because of osteoporosis, and it puts her at a very large risk of having further fractures. But it also puts her children at risk.” Fohrman says a family history of osteoporosis can warrant earlier screening or lifestyle changes. “What we need to do is pay more attention to the children or even the grandchildren,” he says, “because it’s during the time between puberty and your mid-30s when you build up the majority of your skeletal mass. If you haven’t done so by then, it’s a lot tougher.”

Without mapping out a family history, however, it is often difficult to identify such risks and take the steps to prevent them. Once symptoms appear, it may change treatment options. Dr. Francis Collins, director of the National Human Genome Research Institute, says that despite the advances in genetic research, a detailed family history is still the best

way to identify the glitches we carry in our genes that make us susceptible to particular conditions, “The busy physician, who has 16 minutes or less per patient to see all of the things that need to be looked at in an encounter, now has this as a starting point instead of being expected to collect it, which frankly, rarely happens,” Collins says. Physicians are trained to ask about family history during medical appointments, but they're often under pressure to deal with a lot of issues in a short amount of time. And many patients won't know too much about their family history unless they ask ahead of time. “Knowing your family history can save your life,” Collins says. “It's one of the most powerful ways to personalize your own medical care and best of all, it's free. You don't have to pay anybody to do some fancy laboratory test to get this data.”

Getting it down

Recording a family history can be as simple as writing down each family member's health problems. But there are plenty of ways to make the history a much more valuable tool and plenty of tools available to make the compilation much easier. The surgeon general released an online tool, called My Family Health Portrait, to help users collect information about six common diseases - heart disease, stroke, diabetes, and colorectal, breast and ovarian cancer - for each of their family members. The information is then stored on a secure government Web site containing the same level of security as Internet bank transactions. And no government agency or official can access that data. The six conditions were identified by the Centers for Disease Control and Prevention as those that are most common among Americans and for which a preventive strategy can be developed. The program creates a family tree listing all the medical conditions and other relevant factors that can help doctors and geneticists identify patterns of diseases in families. The most pertinent information will be about those relatives closest to you. Your parents and siblings are a better indicator of your risk for a disease than your grandparents, aunts, uncles or cousins. “Basically, the more specifics you can give your doctor, the more information he or she will have to make further decisions,” says Dr. M. Sean Rogers, an internist with Bend Memorial Clinic. Rogers also stresses that while family history can identify an increased risk, it doesn't guarantee you will develop that problem. “I have patients all the time that I look at family history and say, 'You probably

will develop hypertension. You probably will need medication at some point,” he says. “You can delay that point by exercising, eating healthy and watching your weight.” And even if a condition can't be prevented, early detection can improve treatment options. “A general rule of thumb for really almost any cancer: the earlier you find it, the higher chance you'll be able to cure it,” Rogers says.

Risk management Whether you actually develop a disease is much more involved than merely having a genetic predisposition, says Barbara Pettersen, a genetic counselor in Bend. “The conditions in your family are not just genetic,” she says. “More often, it is a result of a combination of genetic vulnerability plus lifestyle and other environmental factors and culture and behavior. “For example, you may be at greater risk for heart disease if your Aunt Amy had a heart attack at age 45.” That's a warning sign until we realize that Aunt Amy was 300 pounds, didn't exercise, and smoked three packs a day,” Pettersen says. “So we're less concerned about the genetic influence unless there are other family members that have early onset heart disease.” Pettersen helps to counsel people on what their risks for various conditions are, based on a family history. Often times, certain patterns in a family history can suggest a person might have a single genetic mutation that increases his or her risk. Pettersen can help individuals decide whether they want to undergo more involved genetic testing in those cases. She can also identify less obvious risk factors that many individuals will miss.

“Some people have multiple risk factors, but they don't necessarily put them altogether until they talk to someone,” she says. “That's why geneticists always draw the family pedigree or tree. Because we see patterns emerge on the paper. “Pettersen says it's important for people not to delay recording their family history. It's best to get the information before memories fade or elders pass on. Some family members may be reluctant to talk about their past medical conditions and experts warn against pushing too hard. “There are certain cultures that don't like to talk about their medical conditions, so that's a little more difficult for some people,” Pettersen says. “Sometimes the older generations don't talk about the fact that grandma had five miscarriages. But that information could be important to the granddaughter who is now having miscarriages and

wondering why she is having trouble keeping a pregnancy.” Pettersen recommends keeping the history in a safe place and providing a copy for your physician to place in your medical records. Keep the history up to date, perhaps using Thanksgiving as a time to catch up with relatives and update the record.

How to collect your family history:

1. Date the creation of the history and write your name at the top.
2. Create a family tree with at a minimum, your parents, siblings and offspring.
3. The more relatives you can add, the more useful the tree will be.
4. Designate their sex.
5. List siblings from oldest to youngest, going from left to right.
6. Include yourself in the proper order.
7. For every family member, record any diseases that relative developed, the age of onset and other details related to their condition. If you don't know, don't guess. Inaccurate information will minimize the effectiveness of the tool.
8. Be as specific as possible. Instead of writing down cancer, note what type of cancer, the age of onset, and where the cancer started before it spread. For relatives who have died, note the age of death, or an approximation, and the cause of death.
9. For relatives with heart disease, note the number of blockages if possible. Multiple blockages are more likely to have a higher genetic component than a single blockage.
10. Record lifestyle factors, such as height and weight, smoking, alcohol or drug use, fitness level, etc.
11. Record miscarriages and still births, and the ages at which they occurred. Designate whether twins are fraternal or identical, and if a child was adopted.
12. If your family includes half-brothers or half-sisters, designate whether they had a different mother or father.
13. List any allergies or intolerances.
14. If possible, designate the ancestry for branches of your family. Certain ethnic populations have a higher risk for certain conditions.

For more information on creating a family medical history, check the following Web sites:

Surgeon General's Family History Initiative www.hhs.gov

National Society of Genetic Counselors www.nsgc.org

Centers for Disease Control and Prevention www.cdc.gov