

Press Release

Advocacy group urges genetic self testing for 2004 Awareness Month

Until the CDC institutes population screening for Hereditary Hemochromatosis, the American Hemochromatosis Society urges the American public to “test themselves” for hemochromatosis during its annual “National Hereditary Hemochromatosis Genetic Screening and Awareness Month”(May 2004)

Topic: Health, Genetic Screening, Blood Donation, Genetic Disease, Iron poisoning

Who: American Hemochromatosis Society (AHS) non-profit 501c3

What: “National Hereditary Hemochromatosis Genetic Screening and Awareness Month”

Where: U.S.A.

When: May 2004 (May is the month that AHS founder, Sandra Thomas’, mother died in 1999 from Hereditary Hemochromatosis/iron overload disease, the most common genetic disease in the USA)

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Josephine Bogie Thomas, left, a founding board member of the American Hemochromatosis Society, and her daughter, Sandra Thomas, founder and president of the non profit society, at their former summer home in Pittsburgh, Pennsylvania in 1998. Together, they worked to increase public awareness of hereditary Hemochromatosis since Josephine’s diagnosis in 1983. After Josephine’s death due to Hemochromatosis on May 13, 1999, Sandra has carried on the work that her mother inspired her to do. “My mother’s dying wish was to have everyone genetically tested so that they could get an early diagnosis and prevent the complications of the disease. She didn’t want anyone to have to go through what she did”, says Sandra. “We all have to die of something, but it doesn’t have to be Hereditary Hemochromatosis”.

“Self testing easier than brushing your teeth”

If only she had known about genetic testing for hemochromatosis decades ago, ponders Sandra Thomas, President and Founder of the American Hemochromatosis Society based near Orlando, Florida. She could have saved her mother’s life. However, Thomas’ mother, Josephine, died from hereditary hemochromatosis (HH) on May 13th, 1999. It was a needless, avoidable death.

Although too late for Thomas’ mother, it’s not too late for the American public. Sandra, a nationally recognized advocate for victims of hereditary hemochromatosis, has vowed to do all she can in memory of her mother to alert the public to the dangers of hereditary hemochromatosis (HH). HH, also known as “genetic iron poisoning” is the most common genetic disease in the USA according to the Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia, creating such symptoms as arthritis, chronic fatigue, fibromyalgia, diabetes, infertility, sterility, impotence, premature menopause, heart arrhythmia,

heart attack, and liver disease and cirrhosis. “Knowledge is power”, states Thomas, “but knowledge is not enough, you must get tested.” Sounds easy enough, but Thomas has found through personal experience as well as dealing with the public for years that getting tested for hemochromatosis is not as easy as it may seem. Not because testing is difficult, but because doctors are reluctant to test for it. “Making the do-it-yourself genetic home test kit for hemochromatosis accessible to the public is my top priority”, Thomas adds, “Everyone should know their genetic risk for this disease and take preventive measures to protect themselves, including donating blood”. Bloodletting, identical to blood donation, is the treatment of choice for hemochromatosis. Therefore, frequent blood donors often escape the major illnesses and premature death that hemochromatosis can cause. People who are at high genetic risk for the disease can ward off high iron storage levels by preventively donating blood. The FDA approved the use of HH blood as donor blood in 1999.

Hemochromatosis affects an estimated 43 million Americans as carriers of the gene mutation, and another 2 million Americans who have the disease but most do not know it. People of European ancestry, particularly those with Celtic and Nordic ancestry, are at the highest risk of having the gene mutations for the disease, however, it can also affect African Americans and Hispanics. Because hemochromatosis is potentially a deadly, but highly treatable, and even preventable, genetic disease, Thomas wants to see preventive genetic testing done. In fact, the motto of the American Hemochromatosis Society is “Prevention through Genetic Testing”. Anyone concerned about genetic discrimination can rest easy knowing that DAT (direct access testing) is available through several labs in the USA which carry a do-it-yourself DNA genetic home test kit. The results are confidential and sent only to the patient. No doctor is needed to order the test or to receive the results. “We are not advocating removing the doctor from the medical equation; what we are advocating is getting a correct diagnosis to the patient in the first place,” says Thomas. “Until the CDC institutes population screening for hereditary hemochromatosis, the American Hemochromatosis Society will urge the American public to ‘test themselves’ for hemochromatosis during its annual ‘National Hereditary Hemochromatosis Genetic Screening and Awareness Month’ (May 2004). I selected May because it is the month that my mother died, and there is no excuse for anyone to become ill, or die, from hemochromatosis.”

With a few swabs of your cheek with a mascara-type wand, you can mail in your “cheek cells” to be analyzed for the hemochromatosis gene mutation. You can also test your own iron storage levels using the blood tests, serum iron, TIBC, and serum ferritin. Basically, you can find out whether or not you have hemochromatosis, or are at genetic risk for it. If you find that the results are positive, then you should seek the advice of a specialist in hemochromatosis.

For more information on hemochromatosis, please contact the American Hemochromatosis Society, 4044 W. Lake Mary Blvd., #104, PMB 416, Lake Mary, Florida 32746-2012 U.S.A. or call the information line toll free: 1-888-655-IRON (4766) or visit the web site at: www.americanhs.org or email: mail@americanhs.org

To direct order a DNA genetic test kit for hereditary hemochromatosis, go to: www.healthcheckusa.com or call toll free: 1-800-929-2044.