

Media Release

FOR IMMEDIATE RELEASE

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IRON: ESSENTIAL FOR LIFE BUT TOO MUCH CAN KILL YOU

July 20, 2004 ROCHESTER, N.Y. - July is National Hemochromatosis Awareness Month and the Mary M. Gooley Hemophilia Center, along with the Iron Disorders Institute is mounting an outreach campaign in public libraries this month to bring hereditary hemochromatosis, or Iron Overload as it is commonly called, to the forefront of awareness. Books donated by the Mary M. Gooley Hemophilia Center are being placed in 16 local libraries which have agreed to showcase the disease as a public service. "The Guide to Hemochromatosis," published by the Iron Disorders Institute, along with pamphlets and brochures describing hemochromatosis will be available to library patrons.

People need iron to live! Some take vitamins with iron to feel better. For others, too much iron can kill them! A condition called Hereditary Hemochromatosis (HH) is a very common, but rarely diagnosed genetic disorder, which does not allow for the normal processing of dietary iron. Although normal bodily functions provide for eliminating excess dietary iron, this process does not occur in a person with HH. Here, iron builds up in the body and deposits in joints and vital organs such as the liver, pancreas, heart and brain. This may lead to conditions such as cirrhosis, diabetes, arthritis, heart failure, impotence and emotional problems.

Genetic mutations which result in HH are most prevalent in people of Northern European descent. HH is believed to be the most common genetically transmitted disease, and is equally present in both genders. Ironically, women generally experience an onset of the disease later in life, because the loss of blood during their menstrual cycles and during pregnancy and childbirth, also removes excess iron stores, thereby delaying the course of the disease.

Early warning signs of HH include: Weakness or chronic fatigue, joint pain, pain in hands or feet, leg cramps or

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HEMOCHROMATOSIS -2222-

abdominal pain, loss of libido (sex drive), heart arrhythmia or a bronze or gray discoloration of the skin. Elevated iron levels can be confirmed by running specialized blood tests or a liver biopsy.

The treatment normally prescribed is a series of weekly therapeutic phlebotomies (blood draws), which will deplete the body of its iron stores over a period of time. If there has been no organ damage at the time of diagnosis, it is likely that the patient after being successfully “de-ironed” will experience a normal life expectancy and only have to be phlebotomized occasionally.

Patients diagnosed with this disorder in the Rochester area are often referred to the Mary M. Gooley Hemophilia Center for treatment, where a staff of highly trained doctors and nurses treat approximately 300 patients with this condition. The Center is internationally recognized for its clinical research in the field of HH.

Outreach campaigns are extremely important, since we know statistically that thousands more people in the Rochester Area may be affected by HH than have been diagnosed to date.

The Mary M. Gooley Hemophilia Center, founded in 1959 was the first free-standing treatment center for hemophilia in the United States. The mission of the Mary M. Gooley Hemophilia Center is to improve the lives of people affected by bleeding disorders and iron overload. This is done using a comprehensive model of care in which quality of life issues are closely monitored. In addition to its extensive research projects, Center staff treats patients with Hemophilia, Hemochromatosis (iron overload), von Willebrand Disease and Gaucher Disease.

For more information on Hereditary Hemochromatosis please contact the Mary Gooley Center: 1415 Portland Ave., Suite 425, Rochester, New York 14621, www.hemocenter.org (585)-922-5700 or visit the Iron Disorders Institute website at www.irondisorders.org.