

Preliminary Results*: 2010 National Hemochromatosis Patient Survey

(Hemochromatosis is abbreviated HHC; percentages are rounded up to the nearest whole number)

74% report having received information from a physician on how to treat or control HHC.

Usefulness of Resources

52% report **Health Care Providers** extremely or very useful; **47%** report **Health Care Providers** somewhat or not useful.

48% report **Community-based Groups** extremely or very useful; **15%** report **Community-based Groups** somewhat or not useful; **34%** report never using **Community-based Groups**.

59% report The **Internet** extremely or very useful; **26%** report The **Internet** somewhat or not useful; **12%** report never using The **Internet**.

14% report Medical Centers (Universities) extremely or very useful; **12%** report them somewhat or not useful; **71%** report never used them.

52% report Printed Materials extremely or very useful; **32%** report these somewhat or not useful; **14%** report never used them.

6% report video extremely or very useful; **9%** report video somewhat or not useful; **82%** report never used them.

8% report **Support Groups** extremely or very useful; **6%** report **Support Groups** somewhat or not useful; **83%** report never using **Support Groups**.

7% report **Live Patient Seminars** extremely or very useful; **3%** report **Live Patient Seminars** somewhat or not useful; **88%** report never using **Live Patient Seminars**.

Areas of Interest

60% report extremely or very interested in **Signs & Symptoms** **39%** report somewhat or not interested in **Signs & Symptoms**.

68% report extremely or very interested in **Risk Factors** **30%** report somewhat or not interested in **Risk Factors**.

59% report extremely or very interested in **Diagnosis** **38%** report somewhat or not interested in **Diagnosis**.

71% report extremely or very interested in **Treatment** **26%** report somewhat or not interested in **Treatment**.

65% report extremely or very interested in **Information for Family** **34%** report somewhat or not interested in **Information for Family**.

79% report extremely or very interested in **Self Care Tips** **19%** report somewhat or not interested in **Self Care Tips**.

76% report extremely or very interested in **Diet** **22%** report somewhat or not interested in **Diet**.

85% report extremely or very interested in **Preventing Complications** **13%** report somewhat or not interested in **Preventing Complications**.

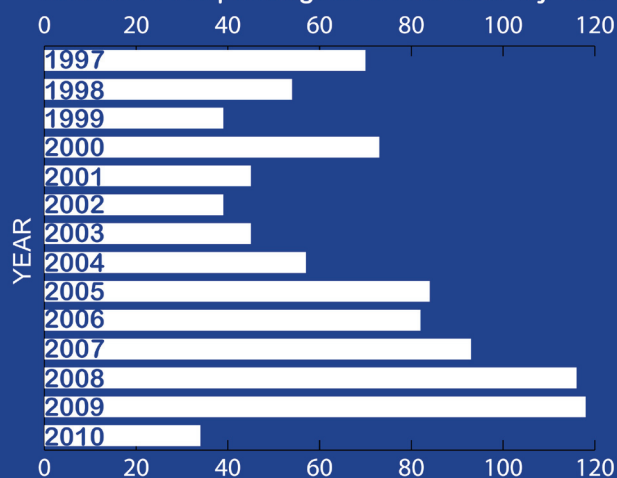
70% report extremely or very interested in **Genetics** **29%** report somewhat or not interested in **Genetics**.

*The final results will be published at a future date.

—The 2010 National Hemochromatosis Patient Survey was a joint effort of the US Centers for Disease Control & Prevention, (CDC) The Medical University of South Carolina (MUSC) and The Iron Disorders Institute (IDI). Preliminary results* based on 949 eligible and completed surveys.

85% of participants had more than a high school education

Number of People Diagnosed with HHC* by Year



*Hereditary Hemochromatosis
Source: 2010 National Hemochromatosis Patient Survey

54 selected to take the survey, died of complications of hemochromatosis. These loved ones will be acknowledged—with permission from the family—in the Memoriam Section of our web sites.

These results* provide IDI with helpful information about hemochromatosis patient opinion, the effectiveness of our outreach and health care provider education programs and emphasize the critical need to continue these efforts. We thank every one on the outreach team and every one who took time to respond to the survey.

—C. Garrison, Executive Director, Iron Disorders Institute (IDI)