

Consumer Resources

The Centers for Medicare & Medicaid Services Center for Consumer Information and Insurance Oversight (CCIIO), part of the Department of Health and Human Services (DHHS), provides national leadership in setting and enforcing standards for health insurance that promote fair and reasonable practices to ensure that affordable, quality health coverage is available to all Americans. The center also provides consumers with comprehensive information on coverage options currently available so they may make informed choices on the best health insurance for their family. Visit CCIIO at: <http://cciio.cms.gov>.

The Centers for Disease Control and Prevention National Center on Birth Defects and Developmental Disabilities Hemophilia Homepage provides consumers with access to the most up-to-date resources including the complete hemophilia treatment center (HTC) directory, videos, brochures, fact sheets and numerous other health education and outreach resources. The HTC directory provides the names and contact information of treatment center staff who are part of the federally funded HTC network. For a comprehensive listing of programs and resources visit: <http://www.cdc.gov/ncbddd/hemophilia/index.html>.

Families USA is a national nonprofit, nonpartisan organization dedicated to achieving high-quality, affordable healthcare for all Americans. For more than 30 years, it has been a highly effective consumer advocate organization at the national, state and community levels. In addition to providing user-friendly consumer resources, it offers extensive tools for state and local advocates, including state budget, healthcare-related legislation and implementation efforts. For access to the complete list of resources visit: <http://www.familiesusa.org>.

Healthcare.gov is the website managed by the U.S. Department of Health and Human Services that educates Americans about the Affordable Care Act (ACA). The website has a tool to find individual state's Consumer Assistance Programs, which states have established them, and other helpful sources for health insurance. Visit: www.healthcare.gov.

The Health Resources and Services Administration National Hemophilia Program Homepage assists people with hemophilia and other bleeding disorders and their families by coordinating activities and care at the national network of 130 hemophilia treatment centers (HTCs) located throughout the country. The program existed since 1975, and with HRSA support, HTCs provide diagnostic and educational services for individuals with bleeding disorders. The website is: <http://mchb.hrsa.gov/programs/hemophilia/index.html>.

Kaiser Family Foundation website provides access to reports, surveys, issue briefs, charts, slides and fact sheets about health policy-related issues such as the number of uninsured, Medicare, Medicaid, healthcare costs, and health reform. Through the main site one can access the Health Reform Source, a site devoted entirely to health reform implementation, including explanations of the health reform law, public policy issues and easy access to relevant data, studies and developments. The main website is: www.kff.org.

HANDI, the National Hemophilia Foundation’s Information Resource Center HANDI’s mission is centered on service—answering specific questions, fulfilling information requests, providing quality educational publications, making referrals to additional sources of assistance and immediately responding to the needs of the bleeding disorders community. HANDI’s collection of more than 13,000 articles, textbooks, and educational publications is the definitive source for information about hemophilia and other inherited bleeding disorders. Call 1.800.42.HANDI or email: handi@hemophilia.org.

The National Hemophilia Foundation’s Steps for Living website is a one-stop resource for information on bleeding disorders for kids, adolescents, parents and health educators to promote healthy living for the whole family. The site provides information and resources to help consumers, family members and caretakers adjust to life with a bleeding disorder as a child grows and matures. There is information and activities for all age groups, including insurance and treatment guidelines. For further information visit: www.stepsforliving.hemophilia.org.

National Hemophilia Foundation’s website advocacy section includes information to help the community stay informed. It enables consumers to respond to emerging issues through such resources as links to response letters to state and federal policymakers on preferred drug lists (PDLs), sole source provider contracts, Medicaid managed care and other health reform regulations. There are also resources available to assist consumers with healthcare coverage options in their state, a downloadable Personal Health Insurance Toolkit, information about state hemophilia programs, and A-PLUS webinars. Visit NHF’s website: www.hemophilia.org and select “Advocacy.”

Navigators:

For states with a Federally Facilitated Marketplace or State Partnership Marketplace, the federal government awarded Navigator grants to the following entities in August: <http://www.cms.gov/CCIIO/Programs-and-Initiatives/Health-Insurance-Marketplaces/Downloads/navigator-list-8-15-2013.pdf>.

For states with a State-Based Marketplace, a list of Navigators must be obtained from the state’s Marketplace website. The following are links to State-Based Marketplace websites:

- California – Covered California – www.coveredca.com
- Colorado – Connect for Health Colorado – www.connectforhealthco.com
- Connecticut – Access Health Connecticut – www.accesshealthct.com
- D.C. – DC Health Link – www.dchealthlink.com
- Hawaii – Hawaii Health Connector – www.hawaiihealthconnector.com
- Idaho – Your Health Idaho – www.yourhealthidaho.org

- Kentucky – Kentucky’s Health Connection – www.kynect.ky.gov
- Maryland – Maryland Health Connection – www.marylandhealthconnection.gov
- Massachusetts – Mass Health Connector – www.mahealthconnector.org
- Minnesota – MN Sure – www.mn.gov/hix
- Nevada – Nevada Health Link – www.nevadahealthlink.com
- New York – New York State of Health – www.healthbenefitexchange.ny.gov
- Oregon – Cover Oregon – www.coveroregon.com
- Rhode Island – Health Source Rhode Island – www.healthsourceri.com
- Vermont – Vermont Health Connector – www.healthconnect.vermont.gov
- Washington – Washington Health Plan Finder – www.wahealthplanfinder.org

Patient Services Incorporated (PSI) evaluates an individual’s financial, medical and insurance situation to determine who is eligible for premium or co-payment assistance including COBRA. It provides help for many illnesses and offer many types of financial assistance. For more information, call: 800.366.7741 or visit: www.patientservicesinc.org.

**Many manufacturer or therapy providers have a division or third party group that is designed to assist you with insurance questions/concerns. Please check with your provider.*

State Specific Resources

Every state has a bureau/agency that may be contacted for assistance. The name of the agency may differ from state to state. *Examples are:* Department of Insurance; Insurance Commission’s Office; Office of Insurance Regulation, etc.

In addition, local consumer advocacy organizations dedicated to serving the bleeding disorders community exist in most states. (See www.hemophilia.org for a listing of local hemophilia advocacy organizations.)

Additional Helpful Links

Hemophilia Federation of America: <http://hemophiliafed.org>.

LA Kelley Communications: www.kelleycom.com.

Hemophilia Treatment Center Network: to find the one closest to you visit: www.cdc.gov/ncbddd/hemophilia/HTC.html.