

Internet Resources for Chronic Illness Management

www.childfoundation.us (for diagnosis of Interstitial Lung Disease)

The Mission of this non-for-profit organization is to provide support, education and hope to families affected with a pediatric interstitial lung disease and to advocate and raise funds for scientific research.

<http://www.medicalhomeinfo.org/CareNoteBook/>

Provides a list of downloadable forms with which you can build your own Care Notebook (available in Word or Adobe format). The National Center provides support to physicians, families, and other medical and non-medical providers who care for children and youth with special needs. Click on “State Pages” and select a state for more specific resource information pertinent to your community.

www.nichcy.org

National Dissemination Center for Children with Disabilities (You can search by state for a list of state-level offices. Even if an office is not close to your home, they can usually put you in touch with resources in your community, as well as provide you with information and assistance about disability issues in your state)

www.ibsgroup.org/chronickids

Information on school issues for children with chronic illness

www. chtop.org

Information on respite care (can search by age, state, and condition, such as “chronic illness” category)

www.familyvoices.org

Provides families tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care.

<http://www.familyvoices.org/states.php>

To find the Family Voices page for your state. At the bottom of your state’s page, other state-specific resources will be listed with links to other websites.

www.nationalhealthcouncil.org

The National Health Council (NHC) provides a voice for the millions of people with chronic diseases and disabilities and their family caregivers. Information about advocacy and links to find your local government representatives.

<http://depts.washington.edu/healthtr/>

A resource for adolescents with special health care needs, chronic illnesses, physical or developmental disabilities; focused on helping adolescents take more responsibility for their own health care in preparation for transitioning to adulthood.