

Bibliography and Resources

Mitochondrial Disease

Mitochondrial Disease Action Commission www.mitoaction.org Education, Advocacy, and Support for people with Mitochondrial Diseases, their families, caregivers, educators, etc.

United Mitochondrial Disease Foundation www.umdf.org “To promote research and education for the diagnosis, treatment, and cure of mitochondrial disorders and to provide support to affected individuals and families”

Treatment of Mitochondrial Cytopathies; Cohen 2007 <http://www.medscape.com/viewarticle/410871>

Adult Presentations of Mitochondrial Disease, Naviaux 2000. http://www.adultmito.net/wp-content/uploads/2010/05/Adult_Presentations_of_Mito_Disease_Naviaux.pdf

Mitochondrial Dysautonomia and Functional Disorders Alliance www.curemito.org

General information for adults with Mitochondrial Disease <http://www.adultmito.net>

Coming Soon! Online, self-paced Continuing Education course for professionals working with infants and young children with Mitochondrial Disease and their families. Visit <http://www.mitoaction.org/> for updates.

Disability Awareness

A Course on Chronic Illness: Learning the Patient’s Perspective” <http://www.ajpe.org/aj6701/aj670109/aj670109.pdf>

MA Office on Disability <http://www.mass.gov/Eaof/docs/mod/InteractingBraille.doc>

United Cerebral Palsy http://www.ucp.org/ucp_generalsub.cfm/1/9/6573

Easter Seals http://www.easterseals.com/site/PageServer?pagename=ntl_etiquette

The United Spinal Association <http://www.unitedspinal.org/disability-etiquette/>

<http://www.familyvillage.wisc.edu/General/Disability-awareness.html> Disability Awareness resources suitable for children

Americans with Disabilities Act

<http://www.disability.gov>

<http://www.ada.gov/hospcombr.htm> ADA Business Brief

http://www.unitedspinal.org/pdf/understanding_the_ada.pdf Easy-to-read explanation of the ADA

Family Resources (general)

<http://www.nichcy.org/Pages/StateSpecificInfo.aspx?State=MA> National Dissemination Center for Children with Disabilities: List of resources available in MA

www.familyvillage.wisc.edu Very large site with information about most disabilities in a variety of situations.

www.disabilityresources.org Another clearinghouse site, disabilities are arranged alphabetically and it is quite easy to navigate.

http://www.jointcommission.org/GeneralPublic/Speak+Up/about_speakup.htm Patient Safety Campaign; includes information for decreasing errors when patients are unable to speak for themselves.

<http://eeo.gsfc.nasa.gov/disability/publications.html> NASA’s Equal Opportunity Program Office. The info sheets, booklets, and other publications relate to general disability issues.

Palliative Care, Hospice, Sibling Support

Please refer to "Caring For the Whole Family"

Parents with Disabilities or Chronic Illnesses

Please refer to "Mommies Can't Get Sick"

"Accessories;" medical devices, equipment, support services

For an extensive discussion of medical devices that EI clinicians may encounter in homes, please visit www.mitoaction.org and enter "accessories" into the search box.

www.oley.org A non-profit organization dedicated to improving the quality of life of individuals who use home enteral and parenteral nutrition, through education, research, and emotional support.

<http://complexchild.com> This e-zine is written by parents of children with special health care needs for parents of children with special needs. The articles provide important information for parents and caregivers as well as providing an inside perspective of life as a parent of children who are medically fragile and/or have mild to profound disabilities

<http://www.makoa.org/vent/index.html> Vent User's Support Page a HUGE list of resources related to trachs, vents, medical conditions that lead to trach/vent use, parent, family, and patient support.

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