

Family Support Organizations: Including Trainings & Conferences

The following is a list of family support organizations, some that offer trainings and host conferences for families. They provide great opportunities for parents to make connections and learn advocacy skills needed to care for children with trachs.

TrachCare, Inc.

www.trachcare.org

The Massachusetts-based non-profit, that has developed this guide, and is dedicated to helping provide support, education, and awareness to families with children and young adults who have, or previously had a tracheostomy. We host family gatherings twice a year, often collaborative with medical professionals working to improve tracheostomy care through educational forums, maintain a website and informational guide. You may join our e-mailing list to stay contacted and visit our website to register.

Aaron's Tracheostomy Page

www.tracheostomy.com

An excellent and comprehensive Internet resource on tracheostomies created by a mother and a registered nurse of children with special needs.

The mission of Aaron's Tracheostomy Page is:

To help assure the highest quality home care for children with tracheostomies; provide needed tracheostomy information in order to ease some of the anxiety related to caring for a child with a trach; and to facilitate parent-to-parent networking and support.

Global Tracheostomy Collaborative (GTC)

www.globaltrach.org

A multidisciplinary team of physicians, medical professionals, patients, and families around the world working to improve the quality of global tracheostomy care. Patients and families are invited to visit the website, sign up for a free patient-family membership to follow the ongoing GTC efforts, and are welcome to submit their tracheostomy story to help spread awareness.

Federation for Children with Special Needs (FCSN)

1-800-331-0688|www.fcsn.org

A center for parents and parent organizations to work together on behalf of children with special needs and their families. The FCSN comprises of several family advocacy, education, and training organizations. Some of these are Family TIES, Mass Family Voices, Parent Training and Information Center, and many more.

FCSN Annual Conference (*March*)

A statewide annual conference attracts over 500 parents and professionals.

Family TIES of Massachusetts: Together In Enhancing Support

1-800-905-8437|www.massfamilyties.org

A statewide information and support network provided by and for families of children with special needs. It offers a "parent-to-parent" program where a coordinator matches a parent to an appropriate support parent. A "support parent" is someone who is trained to listen, share concerns, offer information and support, with respect for confidentiality, cultural and individual differences. Family TIES also publishes a "pink" resource directory annually to help parents locate services and resources for their children with special needs. The directory is available at the above website. Family Ties also offers skill-building workshops to support families of children and youth.

Massachusetts Family Voices

1-800-331-0688 |www.fcsn.org/mfv

The state chapter of a national organization of parents and professionals who are committed to improving systems of care for children with special healthcare needs. Mass Family Voices has an excellent website and a "Listserv" where parents and professionals can share information and resources easily and efficiently. Mass Family Voices have also hosted a series of topical conference calls that may be helpful resources for families stored on their website.

MASSTART: Massachusetts Technology Assistance Resource Team

978-851-7261 x4022

<http://www.mass.gov/eohhs/docs/dph/com-health/special-needs/masstart-brochure.pdf>

An important consultation service for families of children with trachs or other technology-dependent healthcare needs. The program, sponsored by DPH, helps families and schools work together to develop individualized healthcare and emergency plans and provides training for school staff members.

Parent Training and Information Center (PTI)

1-800-331-0688/www.fcsn.org

A program that offers parental training to develop advocacy skills necessary for improving the quality of special education services for your children.

PTI Educational Trainings (Ongoing)

“Turning Three” A workshop to help prepare for the transition from Early Intervention to the public special education process at age three.

“Basic Rights” An introductory workshop on special education law and student rights.

“An IEP for My Child” A workshop to learn how to write an appropriate “Individualized Education Plan” for your child.

DEVELOPMENTAL DISABILITIES COUNCIL

617-770-7676 www.mass.gov/mddc

Consumer Empowerment Funds

A funding resource to provide individuals with developmental disabilities or their family members to attend conferences or trainings. The goal is to promote empowerment by assisting training efforts for families. Each family can receive up to \$500 per event per year.

Early Intervention Parent Leadership Project (EI PLP) 1-800-353-4757/www.eiplp.org

An organization for parents of children who receive Early Intervention services from birth to age 3. Our TrachCare project evolved out of a parent grant from the EI PLP. The PLP is sponsored by the Department of Public Health (DPH).

Massachusetts Families Organizing for Change 1-508-824-6946 www.mfofc.org

A grassroots organization that provides leadership training to help inform and educate individuals, families, and the community about advocacy, services, and resources for individuals with disabilities.

Mass Families Organizing for Change Annual Training: (Regionally based)

“Mass Families Organizing for Change Leadership Series”

A leadership series to connect with other families and learn lifelong advocacy skills. The training is held over three weekends.