



Help Is On The Way

Resources For Those Affected By Mitochondrial Disease

Mary Castro Summers

Marcel's Way Family Fund and
Franciscan Children's, Brighton, MA

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Mary is the parent of 3 adult sons, and her young was born with complex health needs. For the past 30 years, she has relied on research skills honed as a paralegal with her personal and then professional work experience with the New England Regional Genetics Group, the FIRST Project at the University of Massachusetts Medical School, Family TIES of Massachusetts, and now Franciscan Children's in Brighton, Mass.

As a member of the committee that reviews applications for Marcel's Way Family Fund at MitoAction for the past 5 years, Mary has learned of the impact of Mitochondrial Disease and has assisted many families in finding local community resources to address their needs.

Mary is passionate about community resource information-sharing and making connections among families supporting children and adults who have special health care needs. She was personally supported by others and enjoys paying back those acts of kindness. Her motto in this work is, "you may be caring for your loved one by yourself, but you should never feel alone."

How Might Mitochondrial Disease Affect You or Your Loved One?

- Poor growth
- Loss of muscle coordination
- Muscle weakness
- Seizures
- Autism
- Problems with vision and/or hearing
- Developmental delay
- Learning disabilities
- Heart, liver, and/or kidney disease
- Gastrointestinal disorders
- Diabetes
- Increased risk of infection
- Thyroid and/or adrenal abnormalities
- Autonomic dysfunction
- Dementia

**Genetic and Rare Disease Information
Center: 888-205-2311**

What *Types of Help* Matter?



- Health care needs
- Emotional support
- Basic needs
- Community services



Health Care Needs

- Health insurance
- Medical services
- Pharmaceuticals
- In-home services
- Durable medical equipment
- Outpatient therapies
- Alternatives to prescription medications
- Home accessibility equipment/devices

Emotional Support

❖ For an affected child or adult

❖ For the caring family and friends

– Consider your options:

- Peer support: I know you like myself...
- Talk therapy: find the words to express yourself
- Introspection: meditation, yoga, exercise
- Tap your creative self: visual arts, music, writing, gardening
- Find peace in nature: breathe in the blessings

– Find meaning in your life, bring joy to others.

Basic Needs

- Financial Assistance: How can I make ends meet?
- Food: Feed my body, nurture my soul
- Housing: Everybody needs a roof over their heads
- Transportation: Getting around town

Community Services

- Education
- Job training and supports
- Socialization
- Recreation
- Charities for funding supports

Questions?

Please turn to your state's Parent to Parent Program or Family Voices chapter to find communities of support:

www.p2pusa.org

www.familyvoices.org

Thank you for your time!