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Living Well With Mitochondrial Disease: A Handbook for Patients, Parents, and Families

Cristy Balcells
Woodbine House (March 2012)
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As many as one in every four thousand children born in the United States develops mitochondrial disease by the time they turn ten. It's roughly the same number of children with cystic fibrosis—an often-devastating, but well-known condition that affects the lungs and digestive system. Yet few have ever heard of mitochondrial disease, a metabolic disorder that prohibits cells from producing the energy needed for organs, and the body overall, to effectively function. Even fewer know where to turn for help with mitochondrial disease.

Cristy Balcells, a registered nurse whose five-year-old daughter, Eva, suffers from a serious and progressive form of the condition, said she wrote *Living Well with Mitochondrial Disease: A Handbook for Patients, Parents, and Families* to help provide the kind of education and support that was not available when doctors began the long process of diagnosing Eva. She does this effectively, weaving compelling, first-person patient and parent stories into the comprehensive medical information that makes up most of this 350-page book. No doubt she found many of these stories through her job as executive director of MitoAction.org, a Boston-based nonprofit dedicated to mitochondrial disease education, support, and advocacy.

As a guide like this should, *Living Well with Mitochondrial Disease* tackles this genetic disorder in layman's terms, without dumbing it down. Complex topics like "mitochondrial biochemistry," "electron transport chain complexes," and "oxidative phosphorylation" are written about in detail, but explained in sentences that are simple, straightforward, and easy to understand. Charts and graphs add to the book's depth and usefulness, as do the various viewpoints Balcells includes, such as "A Dad & Husband's Perspective" or the story of Kelly, a young woman who was diagnosed when she was twenty-four and poignantly shares her fear of the unknown: "There are a lot of scary words used to describe this diagnosis, and I have endured and seen others go through scary stuff."

It's clear that mitochondrial disease is a scary disorder. Doctors don't fully understand how it occurs or how best to treat it. There is no known cure, and most young children diagnosed with the condition do not live beyond their teen-age years. In rare cases, like Kelly's, the condition can also affect adults. Treatment varies from person to person and is focused on alleviating symptoms and slowing the disease's progression.

Balcells acknowledges the fears related to these and all aspects of mitochondrial disease, so much of which is uncontrollable. However, sections like "Reacting to the Diagnosis" help alleviate those fears by providing reliable expertise and helpful how-tos on those aspects that *can* be controlled, such as language choices, exercise for stress relief, and school day modifications.

As Balcells explains in her Author's Note, she stumbled on MitoAction.org shortly after Eva was diagnosed, when it was just a newly formed organization. At the time, there were just a handful of members, but Balcells felt instantly connected and, she said, compelled by their desire for answers and "action right now." Readers dealing with mitochondrial disease who need tools for answers and action will find them here.

CINDY WOLFE BOYNTON (February 9, 2012)

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