



PRESS RELEASE

For immediate release

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MitoAction's director receives DIA scholarship

BOSTON – MitoAction Executive Director Cristy Balcells is one of just 19 people to be named a Drug Information Association (DIA) Patient Advocate Fellow. These competitive scholarships go to nationally recognized patient organizations.

As a nurse, public health professional, nationwide patient advocate, published author, and mother of a child with mitochondrial disease, Balcells is known within the Mito community as a leader and liaison to patients and physicians alike. She is often the “voice” of the mitochondrial disease patient community, advocating for resources, improvements in diagnostic testing, and collaboration with biotech on treatment and science, and sharing the full spectrum of the patient and family experience.

“I am excited to be able to share multiple perspectives and experiences during the DIA patient advocate meeting,” Balcells said. “I feel that given my unique position in the community, I would be of great value representing not only mitochondrial disorders but also the field of rare disease advocacy and patient education.”

The Fellows will attend the intensive DIA annual meeting, “Advancing Therapeutic Innovation and Regulatory Science,” in Boston in June and focus on the discovery, development, and lifecycle management of pharmaceuticals, biotechnology, medical devices and related products, which is DIA’s mission. “We are ramping up our work with patient advocates to educate them on how to most effectively work on behalf of their organizations,” said Donna Mayer, manager of stakeholder engagement at DIA. “The patient voice is vital and DIA continues to teach advocates how to use theirs.”

Balcells is excited about the opportunity to participate in the meeting. “I am optimistic that the future is poised to shift toward more innovative approaches to drug development, and that rare disorders and patient advocacy organizations like MitoAction will lead the charge in creative thinking about how to serve patients and bring viable treatments to market as quickly and safely as possible.

“Gone are the days when just a few stakeholders had a say in drug development. Today, given the impact of the collective voices of patients and families via social media, we can harness the actual needs of the disease community and leverage those stories to influence how new therapies are developed,” Balcells continued.

“I look forward to learning more about the process and see the DIA meeting as an opportunity to build a solid foundation in drug development knowledge in order to better serve as an advocate for the mitochondrial disease patient community.”

Mitochondrial disease is an inherited chronic illness that causes debilitating physical, developmental, and mental disabilities. You can be born with it or it can develop later in life. It's progressive and there is no cure. About 1 in 2,000 people has Mito. MitoAction is a 501(c)(3) charity formally incorporated in 2005 to provide programs and resources centered on support, education, and advocacy for patients and families affected by mitochondrial disease. For more information, visit www.mitoaction.org.