



MitoAction's Statement on Nationwide Closures of Mitochondrial Disease Clinics

In the past year, the mitochondrial disease community has witnessed the closing of five clinics specializing in the treatment of mitochondrial disorders. While these clinic closures all have occurred for slightly different reasons, it has become clear that treatment of mitochondrial disorders, with their varied presentations, diagnostic difficulties, and limited available treatments, is not considered a priority at academic centers across the country. This reality has emerged at one of the most exciting times in mitochondrial medicine, during which advances in genetic testing are making diagnostic processes less invasive and new therapies for mitochondrial disease are on the brink of starting clinical trials or seeking FDA approval.

The loss of five specialists is a massive blow to the mitochondrial disease community, representing nearly 15 percent of the active clinicians available for patient care. Mitochondrial medicine has never been a big field, and the number of clinicians has always been few and far between. Patients often have to travel a great distance for care as not every state has a mitochondrial disease specialist available. With the numbers of specialists available for patient care now even further reduced, the mitochondrial disease community is facing a nationwide care crisis that must be addressed in a thoughtful and deliberate manner.

With its mission to serve as the voice of the patient, MitoAction is taking this crisis in patient care very seriously. MitoAction is collaborating with the members of its Medical Advisory Board and Advocacy Task Force to explore the systemic reasons for these clinic closures on a national level. MitoAction also is concentrating on finding viable solutions to this care crisis and is currently investigating possible options through conversations with clinicians, patients, and families. In the meantime, MitoAction will continue to educate primary care physicians and non-Mito specialists on the clinical management of mitochondrial disease patients through its clinical conference CME offerings, the next of which will be held on March 21 in Atlanta, GA.

MitoAction's Mito411 line is available to help patients with specific physician referrals, and MitoAction's updated mitochondrial disease specialist list can be found at www.mitoaction.org/doctors. If you have additional physicians to add to this list or know of non-Mito specialists who are well-versed in mitochondrial disease care, please contact Christine Cox at outreach@mitoaction.org.

Mitochondrial medicine is a complex field that deserves the best and the brightest. Together, we will encourage physicians to practice in this field, hospitals to staff clinics with a mitochondrial disease focus, and researchers to continue to search for a cure.

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