

Summary – 2016 Town Hall Meeting

Various Speakers

Welcome and Introductions

Cristy Balcells, RN MSN, Executive Director, MitoAction



This is MitoAction’s fifth annual Town Meeting! “Every year we see the agenda grow,” she said. “It’s exciting to see that this year I had to squeeze just a couple minutes for each speaker. We have so many exciting organizations, individuals, advocates, companies to hear from.”

The meeting is to inform you, get you excited about all the work being done in Mito medicine, help you feel connected and be a part of this important community, and be a part of the activities happening across the world.

Balcells has a daughter with Leigh’s disease. “It’s not easy having a child with mitochondrial disease ... I walk the walk with you. I appreciate how important it is to have this community coming together.”

It is MitoAction’s hope that the Town Meeting helps you feel connected and a part of the Mito community!

For our podcast library of speakers, visit www.mitoaction.org/podcasts.

Building a patient community

Philip Borden, MitoAction Board of Directors President



It’s exciting to see MitoAction’s growth over the years, said Borden, who got involved with MitoAction about seven years ago after his wife was diagnosed with Mito. “We used MitoAction as a great resource when we didn’t know anything about what mitochondrial disease was,” he said.

MitoAction’s focus on the patient is what drew Borden to the organization. “It’s increasingly important to have that patient focus,” he said. “Being a voice and advocate for the patient and families is a powerful resource. It’s always been MitoAction’s strength and we will continue to focus on that.”

MitoAction News & Events

MaryBeth Hollinger RN MSN, Mito 411 coordinator and moderator of the Friday support calls



Mito 411 volunteers offer live, one-to-one support, education, advocacy, and a unique camaraderie that is formed through the ties of Mito. Call 1888-Mito411 or email Mito411@mitoaction.org to request support. In 2015, Mito 411 logged 380 calls and emails. “The calls end with two people finding common ground and moving forward together,” said Hollinger. Volunteers are the heart of Mito 411. For more information on Mito 411, email Hollinger at Mito411@mitoaction.org.



MitoAction’s toll-free teleconference support groups meet on Fridays at noon EST. “We work much like other support groups — except the travel time, parking, traffic, packing up the kids, and germs have been eliminated,” Hollinger said. “We get insights of Mito care from all areas of the county and share how we cope and LIVE with this disease. “

[Click here for more information on the support groups.](#)

Shawney Lamm, Event and Program Manager, MitoAction

This year we are looking for people who are interested in hosting a 5K in their community. A 5K is a great way to spread awareness about mitochondrial disease and engage people within your community who might not know about this rare disease. We will help you with all of the organizing for this event by providing all of the materials, online registration and of course pre and post support. If you are interested in spreading awareness by hosting a 5K or have other ideas for your community please email Shawney at shawney@mitoaction.org.

Ginger DeShaney, Director of Operations & Support, MitoAction



A great way to get in-person support is through a [Mito Patient & Family Social](#). We are always looking for people to host these laid-back, casual gatherings that allow Mito families to meet in person. Hosting is easy and we’ll help every step of the way. Email Ginger at support@mitoaction.org to get started!



A fun way to make an impact in the community is by hosting a Restaurant Night. A portion of the proceeds from your Restaurant Night will be donated to MitoAction. Email Ginger at support@mitoaction.org to book yours today!
Christine Cox, Director of Advocacy & Outreach, MitoAction



MitoAction will be expanding its advocacy section of the website as well as expanding our coverage of insurance and social issues. We'll also be doing more in our advocacy podcast series, continuing what we started in 2015 with Annette Hines, JD, of the Special Needs Law Group of Massachusetts. Cox is continuing work on the Mito Cocktail bill in Massachusetts. If you are a resident of MA and want to work on the bill, or have any other advocacy issues, please email Cox at outreach@mitoaction.org.

Susan Stover, Events & Development Director, MitoAction



MitoAction is planning its two staple fundraising events in Boston. The first up is the Sandra K Russell Derby Day Benefit for Mito on May 7, 2016, at Mandarin Oriental, Boston. "It's the most unique and exciting fundraiser," Stover said. "It's a great time for friends and family to come out and celebrate being supporters of MitoAction and getting to take in the Kentucky Derby."

We are also already working on our family and community walk and 5K awareness event, tentatively scheduled for Sept. 18 in Boston. It's a waterfront family fun day to bring the Mito community together and an opportunity for patients and families to spread awareness, raise funds, and get involved by forming teams. It's also a chance to meet our sponsors, see their support and how they benefit the Mito community.

If you have other ideas and want to connect with us, email Stover at events@Mitoaction.org.

UMDF News & Events

Cliff Gorski, Director of Communications, UMDF



UMDF has upcoming regional meetings for patients, families, and medical personnel:

- Feb. 12-13 at Children's Memorial Hermann Hospital in Houston
- Feb. 19-20 in Raleigh Durham, NC, at Duke University School of Medicine
- May 20-21 at the Mayo Clinic at St. Mary's Campus in Rochester, MN.

[Click here for more information.](#)

The national symposium will be in Seattle with partner Seattle Children's, June 15-18. UMDF will announce scholarship applications and hotel grants. Registration is now open at UMDF.org/symposium.

UMDF continues to bring medical experts around the country to educate physicians and clinicians about Mito. The next Grand Rounds and Family meetings will be at Cook Children's Hospital in Houston with Dr. Bruce Cohen and UT Southwestern Medical Center in Dallas with Dr. Tyler Reimschisel. Last year UMDF held 20 family meetings and 15 Grand Rounds. [Click here for more information:](#)

UMDF has developed "Mito on Call," which is geared toward non-Mito physicians who will have the ability to ask a question or pose an issue about patient care or related issues. Those questions will be sent out to 20 experts in the Mito field who will return a prompt answer. UMDF is working with the Mitochondrial Medicine Society on this endeavor. For more, visit www.umdf.org/mitooncall.

Gorski also mentioned that the [Mito Registry](#) continues to seek people. There are currently 1,100 people signed up.

As a result of June's Day on the Hill Advocacy day in Washington, DC, the group requested to keep mitochondrial disease listed in the Department of Defense Peer-Reviewed Medical Research Program. It has been listed. The agreement provides \$278,700,000 for a peer-reviewed medical research program.

Lastly, 2016 is UMDF's 20th anniversary and they will be rolling out some things in April.

Genetic Metabolic Center for Education

Dr. Mark Korson, Medical Director



Dr. Korson left clinical medicine to address two problems: There are not enough clinicians to treat patients with metabolic and mitochondrial diseases and the lack of training in metabolic and mitochondrial medicine today.

The **Genetic Metabolic Center for Education (GMCE)** was established with the mission to promote the identification, diagnosis, and management of patients with metabolic and mitochondrial disease through the following programs:

- A **Consultation and Clinical Support Service** to assist physicians with the diagnosis and management of their metabolic and mitochondrial patients. Contracts are

established with a medical practice or hospital, and clinical support occurs during scheduled meetings and through emergency access, according to the client's need.

- **Educational programming for specialists, specialty trainees, and medical students**, including live conferences, online training modules, and online electives. A library of patient presentations will give a face and a voice to a wide range of genetic metabolic disorders discussed in GMCE's educational products. In addition, a unique online training module about mitochondrial disease is being developed in conjunction with the Mitochondrial Medicine Society. GMCE's goal is to gain the endorsement of specialty medical societies so that all residents are encouraged to participate in an online "mini-metabolic fellowship" sometime during their training.

To learn about GMCE and find out how you can get involved, visit www.geneticmetabolic.com.

MitoCanada

Maureen Latocki, Executive Director



MitoCanada is Canada's only organization focused on Mito. The organization's highlights from last year include:

- In September, the organization went from a founding board to a skills-based board and has representatives from the pediatric and adult communities, as well as individuals with expertise in health system knowledge, research, and finance. And as of Dec. 1, the staff grew from 1 to 1.6 full-time equivalent.
- MitoCanada received tremendous response from volunteers, so it is looking at how to harness all that talent moving forward.
- The organization forged new partnerships with the Canadian Inherited Metabolic Diseases Research Network and is in the midst of the first study of clinical practice for Mito in Canada; and RelayHealth/McKesson, which will allow Canadian patients to have access to an online portal to manage their disease. This year's [Garrod Symposium](#) will have a Mito thread with Dr. Mark Tarnopolsky presenting on behalf of MitoCanada on the topic of "Mitochondrial Disorders and Innovative Therapies."

Looking ahead to 2016:

- MitoCanada is looking to take advantage of Canadian government opportunities around clinical trials and will seek out opportunities for the Mito community.
- MitoCanada is redesigning its support offerings to be more responsive. "We are looking to try to mirror how MitoAction has provided help and support," Latocki said.
- The organization will be rebooting Team Mito, which is its major fundraising vehicle. It doesn't get any government funding but Team Mito has raised close to \$1 million since it started.
- Latocki is working to make MitoCanada a truly national organization by looking at how best to engage with the regions in Canada and make sure the organization is more effective.
- It will also build on the great response to awareness week last year.

Mito Hope & Help
Cheryl Clow RN

MITO HOPE and HELP

Mito Hope & Help, which provides advocacy and support to upstate New York Mito patients, has a few exciting projects and extends an invitation to others for collaboration.

- Jon Dorflinger, CEO and founder of the Saratoga Film Academy, will do a crowdfunding campaign for a full-length documentary, "This is Mito." His trailer debuted at Mito Hope & Help's 2015 symposium. [Click here to see the trailer](#). Clow is hopeful this film will change the status quo, improve Mito patient care, and raise awareness.
- The organization is finalizing details on a Mito Liaison program. It hopes to offer local Mito patients who either don't have a Primary Care Physician or who have a doctor who can't address Mito a trained healthcare professional to bridge the gap between their Mito specialist, PCP, and other specialists. The liaison, Dr. Toni Sturm, is an internal medicine physician who will be available, with an RN, on a daily basis to coordinate patient care. Dr. Darius Adams and Clow will help train the liaison. Sturm and an RN will make house calls and be available at clinic sites, for consults, coordination of care, hospital stays, and follow-ups.
- Mito Hope & Help will hold its fifth annual symposium this fall; dates to be determined.
- The group also continues to work for passage of legislation to mandate coverage of the Mito Cocktail in New York.

For more information, visit www.mitohopeandhelp.com.

Mito Research Guild

Steve Serex, co-VP with Seattle Children's Hospital Mito Research with his wife, Theresa



In the past year, the Guild has raised \$300,000 through its annual auction, golf tourney and other smaller events. All the money goes to research at the Seattle Research Institute and for grants and equipment at the institute. It also pays for a research assistant and a clinical nurse practitioner to support Dr. Russ Saneto, a salary for a post-doctoral position at the Research Institute that has led to two papers, a one-year salary for a fellowship doctor who will become a Mito child to adult transitional doctor, family grants, and more.

At Seattle Children's Research Institute, Drs. Phil Morgan and Margaret Sendesky are studying mitochondrial function in simple genetic organisms. They've discovered a possible pathway that links mitochondrial inhibition by anesthetics to damaging effects of anesthetics exposure in early childhood. They are also working on a mouse model.

At Seattle Children's Hospital, Saneto is the principal investigator (PI) for the

- Alpers Huchting Blocker Syndrome Natural History Study supported by the NIH;
- NIH natural history study of patients with mitochondrial disease;
- Leigh's Syndrome study by Edison Pharma for EPI-743;
- Edison's Compassionate Use of EPI-743 in patients with ETC abnormalities;
- Collaborative study of the NIH and FDA looking at PDH deficiencies.

He's also on the data safety monitoring board for the mitochondrial disease study being run by Reata Pharma looking at NRF2 in Friedreich's Ataxia patients. Saneto is also the scientific director for UMDF's upcoming symposium in Seattle.

Saneto has published a case studies book called "Mitochondrial Case Studies: Underlying Mechanisms and Diagnosis," with Dr. Sumit Parikh of the Cleveland Clinic. The book is available [here](#). This book is meant to attract doctors and students to mitochondrial medicine.

For more information, visit <http://www.nwmito-research.org/>.

Foundation for Mitochondrial Medicine

Laura Stanley, Executive Director



2015 was an exciting year for FMM. In addition to [furthering research partnerships](#) with the Michael J. Fox Foundation and the Alzheimer's Drug Discovery Foundation, FMM, The University of Alabama Birmingham, and Seahorse Bioscience have embarked upon [The Foundation for Mitochondrial Medicine](#), the first academic medical institution-biotech industry-philanthropic partnership for mitochondrial clinical care and research advancements.

The [Foundation for Mitochondrial Medicine Clinical Program at UAB](#) will open in 2016 and:

- Respond to the unmet clinical, diagnostic, and therapeutic needs of the patient community impacted by mitochondrial disorders;
- Leverage UAB mitochondrial research in the field of translational bioenergetics;
- Address the growing scientific and clinical market of testing instruments for the field of metabolomics and bioenergetics.

Two components will be developed in parallel:

- A clinic for adult and pediatric mitochondrial patients
- A CLIA* certified mitochondrial clinical laboratory (*Clinical Laboratory Improvement Amendments -- Congressional quality standards.)

The expected outcome is to have an integrated clinic with the objective of serving the patients' needs and providing the clinical testing protocols necessary for precision diagnostics and the basis to monitor therapeutic interventions for mitochondrial dysfunction.

The clinic:

- A monthly multidisciplinary clinic to evaluate and care for adult and pediatric patients with established disease, staffed by specialist physicians (adult and pediatric neurologist, geneticist, coordinated consultations from a pain management specialist and gastroenterologist, among others as relevant), a nurse coordinator, physical therapist, occupational therapist and dietitian.
- The nurse coordinator will play a key role with objectives to: coordinate, schedule, and manage patient care; liaise with the multiple specialists to form a comprehensive view and treatment plan of the patient; hold monthly case management discussions with Clinic staff to highlight shared learnings and important observations impacting the various functional areas; centralize reporting for Bioenergetics Health Index testing and other tests.

The CLIA laboratory:

- Establish the protocols using Seahorse extracellular flux technology for the evaluation of the activity of mitochondrial enzymes and complexes to complement and support histological evaluation.
- Obtain CLIA certification for these standard tests using the Seahorse platform.
- Develop state-of-the-art non-invasive blood tests for bioenergetic health from the UAB Mitochondrial Medicine Laboratories Bioenergetic Health Index and cellular bioenergetic parameters.
- Validate new approaches with current diagnostic tests and a comparison of evaluations using muscle biopsies. Address the question whether bioenergetics tests in cells from blood can serve as a surrogate for muscle biopsies.

Learn more about FMM at www.hopeflies.org!

ThriveRx

Abby Brogan, Outreach Coordinator



ThriveRx, a division of Diplomat, is a national nutrition support company for individuals on TPN and/or enteral feeds at home. ThriveRx is presenting two new research projects at the American Society of Parenteral and Enteral Nutrition (ASPEN) Clinical Nutrition Week:

- Created by its consumer advocate team, the project concentrated on what is non-adherence and why consumers may be non-adherent.

- Created by the ThriveRx nursing team, this one looked at swimming and central venous lines. This exciting topic was awarded Poster of Distinction.

ThriveRx Consumer Education topics for 2016 include:

- **March:** 2 webinars; Dysmotility Diet Overview and Central Venous Line Care
- **May:** Coping Techniques
- **August:** Alternate Therapies for Dysmotility
- **September:** Managing the Day-to-Day of Mitochondrial Disease (with guest speaker, Cristy Balcells of MitoAction)
- **November:** Navigating the Holidays

To learn more about ThriveRx and its consumer education program, visit: <http://www.thriverx.net/>, email Info@ThriveRx.net, or call [888-684-7483](tel:888-684-7483).

Edison Pharma

Dr. Guy Miller, CEO; **Dr. Matthew Klein**, Chief Medical Officer



With the key positive findings from the first wave of EPI-743 clinical trials demonstrating target engagement, safety, tolerability, and objective signs of efficacy, Edison will be launching a set of Phase 3 trials to continue their effort to advance EPI-743 for the treatment of mitochondrial diseases. In addition, Edison will initiate new EPI-743 exploratory trials in other indications. Over the next several months, Edison will be launching a Phase 3 trial that will include children and adults with various inherited mitochondrial disease as well as trials in pediatric Friedreich's Ataxia, Friedreich's Ataxia Point Mutations, Dominant Optic Atrophy, Wolfram syndrome, and others. Updates will be available on clinicaltrials.gov and on the [Edison website](#).

In addition, Edison's second-generation compound EPI-589 has successfully completed nonclinical, safety pharmacology and CMC work for initiation of its first clinical trials in adult neurodegenerative diseases. The FDA has approved the INDs for EPI-589 Phase 2 trials in ALS and Parkinson's disease, which will be launched by Edison in partnership with Sumitomo Dainippon Pharma, Ltd in the first part of 2016.

Courtagen Life Sciences

Dr. Richard Boles, Medical Director



Courtagen combines state-of-the-art DNA sequencing with expert interpretation to determine genetic causes or factors underlying illness so that your physicians will be able to better treat complex diseases. Some of our tests that can apply to families with a known or possible diagnosis of mitochondrial disease include:

- **nucSEEK:** Sequences the nuclear-encoded genes that often underlie mitochondrial disease/dysfunction, as well as many genes involved in peroxisomal disease, ion channels, neurotransmitters, and other conditions that can look like mitochondrial disease.

- **mtSEEK:** Sequences the entire mitochondrial DNA (mtDNA).
- **epiSEEK:** Sequences genes identified to cause seizures and other kinds of non-epileptic "spells," including hypoglycemia.
- **rxSEEK Epilepsy:** Pharmacogenomic test to characterize a patient's metabolism of antiepileptic drugs and show drug-drug interactions.
- **devACT and devSEEK:** Sequences genes identified to cause autism and intellectual disabilities, including an extensive number of treatable metabolic disorders including neurotransmitter-related conditions.
- **lysoSEEK:** Sequences genes identified to cause lysosomal storage disorders and peroxisomal biogenesis disorders.

The nucSEEK, mtSEEK and devACT tests are favorites with many physicians treating functional disease, such as chronic pain, fatigue, GI symptoms, dysautonomia, anxiety and depression, whereas treatable results that make a difference are common.

With all of Courtagen's tests, the primary goal is to identify treatable factors. When applicable, Courtagen reports include suggestions for consideration for further testing or treatment options. Your healthcare provider can also request a telephone consultation regarding the meaning of the sequence results and potential options with Boles (mitochondrial and functional disorders) or Dr. Minh Le (neurological disease/epilepsy). All testing can be done on a saliva sample sent through the mail. Results are available in weeks, not months.

For more information, visit www.courtagen.com.

Gene DX

Mandy Balog, MS, CGC, Team lead and genetic counselor



Last year was a big year for GeneDx. In November, the company expanded its comprehensive Mito panel, going from 139 to 319 genes. It added new genes that were just discovered, increasing the diagnostic rate. The update included deletion and duplication testing.

The company also added another director and genetic counselor. For more information, visit <https://www.genedx.com/>.

Reata Pharma

Erin Collins, Clinical Study Manager



Reata is conducting a Phase 2 mitochondrial myopathy clinical trial with eight sites in the US and one site in Denmark. The study is testing Reata's investigational drug RTA 408 vs. placebo in a trial called MOTOR, and is designed to assess the safety and efficacy of RTA 408 in patients who have genetically confirmed mitochondrial myopathy with a history of exercise intolerance. There are currently 24 patients enrolled in the study and Reata is working to enroll the next group of 8 patients.

If you or someone you know are interested in participating in the study, you can contact one of the 8 participating US study centers to discuss your eligibility. Site contact information and the major eligibility criteria can be found on [here](#). Eligible patients will receive study drug (RTA 408 or placebo) for 12 weeks and will complete a safety follow-up visit four weeks later. A total of 5 one-day visits and 2 two-day visits are required. One component of the study is exercise testing, completed through two tests on a recumbent exercise bike. One of the tests takes about 8-12 minutes to complete and the other test takes about 30 minutes to complete. Each site has a trained team to work with patients to help them complete these tests.

If you are interested in participating but do not live close to one of the centers, Reata is providing for some travel reimbursement to help cover the cost of travel expenses.

For more information, visit <http://reatapharma.com/> or email info@reatapharma.com.

Miracles for Mito

Maria Hopfgarten, President, **Heather Schichtel**, Director



Miracles for Mito[™] Miracles for Mito, located in Colorado, started five years ago. It's the voice for Mito awareness and support in the Rocky Mountain Region. The group holds several support meetings a year and has now turned them into parties, such as for Easter, Halloween, and the holidays. "We've built a community for families in the regional," Maria said.

The group also offers a family assistance program for things insurance doesn't cover, such as iPads, therapy, respite, and funeral expenses. Miracles for Mito also sends four people to the UMDF symposium; and Maria and Heather and will be presenting "Finding Joy" at this year's UMDF meeting in Seattle.

The organization will be updating its website, www.miraclesformito.org, with upcoming events, including its walk in May and a silent auction/dinner in October.

E

mail Maria at mhopfgarten@gmail.com and Heather at heather.schichtel@gmail.com.

Camp Korey, Shivani Gogna, Camper Liaison

Double H Ranch, Jacqui Royael, Director of Operations

Victory Junction, Mark Schumacher, Chief Development Officer



a seriousfun camp



a seriousfun camp



Double H Ranch

a seriousfun camp

MitoAction's Matthew Harty Camper Fun was established a few years ago to support our camp partnerships. MitoAction has created special partnerships with these camps as part of our mission to make summer camp a possibility for every child who suffers from mitochondrial disease.

These three camps offer camp traditional experiences for children with life-threatening illnesses. Each camp has a medical staff and dieticians. Activities, which are all universally accessible, run the gamut from arts & crafts and drama to rope courses, zip lines, and rock climbing.

Dates for each camp's Mito sessions are set for 2016:

- Camp Korey, Carnation, WA: June 27-July 1, July 4-8, July 18-22. [Click here for the Camp Korey application page.](#)
- Double H Ranch, Lake Luzerne, NY: June 23-28; July 26-31. [Click here for the Double H application page.](#)
- Victory Junction, Randleman, NC: July 3-6; July 31-Aug. 3. [Click here for the Victory Junction application page.](#)

NAMDC/Massachusetts General Hospital

Dr. Amel Karaa, Mitochondrial disease program at MGH



There's a new initiative to create a Complex Disease Diagnostic and Care Program to help diagnose, treat, and coordinate care for patients with complex disease. The project is in the fundraising stage. Money will be used to hire clinical support staff.

Clinical trials for mitochondrial myopathy are actively enrolling.

Visit www.clinicaltrials.gov to get information on how to contact sites for enrollment.

NAMDC is actively enrolling for the mitochondrial disease registry and biorepository. To enroll, visit <http://www.rarediseasesnetwork.org/namdc/>.

MitoQ

Greg Macpherson, CEO



MitoQ is excited to be working with MitoAction and to be able to make MitoQ available to the mitochondrial disease community as a non-prescription alternative to existing Mito Cocktail formulas

MitoQ is a brand new type of CoQ10 that is able to target and reach mitochondria between 800 and 1,200 times more than other forms of CoQ10. MitoQ is a patented antioxidant that targets the mitochondria to support optimal cell function and heart, liver, and brain health. MitoQ also boosts energy and lowers oxidative stress in the mitochondria as well as supports mitochondrial membrane function along with all of the processes that occur in the membrane.

MitoQ has been the subject of over 200 published papers as researchers evaluate its effect in various disease models as well as using it as a probe to better understand mitochondrial involvement in common health conditions. Based on this research, MitoQ is most suitable for those with mitochondrial dysfunction where the mitochondrial membrane is impacted due to oxidative stress.

MitoQ has been evaluated through Phase II clinical trial level and is currently being studied in humans for Chronic Fatigue and Fibromyalgia, Vascular Function and Frailty in older adults, and in Kidney and Lung conditions associated with mitochondrial dysfunction.

MitoQ received some exciting news at the end of 2015. MitoQ was accepted into the NIH's Interventions Testing Program. This is a fully government-funded, fully independent research program that evaluates compounds with anti-aging properties. Due to the link between mitochondria and aging they believe a supplement like MitoQ may have a significant impact on both health-span and lifespan.

Discount for Mito patients! [Click here and use the code "MitoAction" at checkout.](#) For more information, visit <http://www.mitoq.com/>. Physicians wishing to offer samples to their patients, please email gmacpherson@mitoq.com.

Australian Mitochondrial Disease Foundation (AMDF)

Sean Murray, CEO



AUSTRALIAN
MITOCHONDRIAL
DISEASE FOUNDATION

The AMDF was started in 2009, growing from an all-volunteer staff to five full-time staffers. Its mission is threefold:

- To fund **research** into mitochondrial disease
- To **support** sufferers of mitochondrial disease & their families

- To **educate** the general public & the medical profession about mitochondrial disease
Last year the group raised \$1 million to support Australia's patient community and fund research. There are about 5,000 Mito patients in the country.
AMDf has launched the first [Australian Mitochondrial Disease Patient Registry](#) (Mito Registry) and is encouraging people to join.
Murray is looking to attract clinical trials to Australia, urging pharma reps to keep Australia in mind.

For more information, visit www.amdf.org.au.

Closing Comments

Cristy Balcells, RN MSN, Executive Director, MitoAction

"The patient voice is so important in determining the field of mitochondrial medicine, such as what works and what doesn't," Balcells said. "Be involved.

"I look forward to a wonderful year!"