Helpful Links

Virtual Event: June 26-27, 2020

Watch Power Surge
Register NOW to watch Power Surge 2020 LIVE - beginning Friday, June 26, 2020 at 10:00amE/7:00p
Registrants will receive e-communications with instructions how to watch online.
If you do not receive something before Friday morning, please check your spam prior to contacting us at helpdesk@umdf.org.
www.umdf.org/powersurge

The Big Pitch
Read the accelerators finalists’ presentations prior to the Big Pitch on Saturday, June 27 at 12:30pE/9:30aP
Become an accelerator now to participate in the Big Pitch voting!
www.umdf.org/accelerators

Speakers
2020 Power Surge moderators, speakers and panelists (in order of presentation). Click speaker’s name for full biographical and institutional information.
www.umdf.org/powersurge/speakers

Sponsor Goody Bag
Download a virtual goody bag of information from the sponsors and partners of Power Surge 2020!
www.umdf.org/powersurge/goodybag

Event Program
Download the Power Surge 2020 Event Program, featuring daily agenda and list of speakers and panelists.
Also featuring our 2020 UMDF Award winners! (pdf)
www.umdf.org/powersurge/program
Day 1: Friday, June 26 – Clinical Trials Program - Scientific/Clinical/Patients

(All times are U.S. Eastern)

10:00 am  UMDF Welcome
Brian Harman, UMDF President & CEO

10:10 am  Clinical Trials – Nuts, Bolts and the Importance of Trials for Therapies
Frank J. Sasinowski, MS, MPH, JD, Hyman, Phelps & McNamara, Washington DC

10:40 am  Overview of the Day - Panel Discussion of our Learnings
Philip Yeske, PhD, UMDF Science & Alliance Officer

10:45 am  Panel 1 – FDA Workshop and Other Regulatory Learnings
Moderator: Philip Yeske, PhD, UMDF Science & Alliance Officer
Panelists: Amel Karaa, MD, Massachusetts General Hospital/Harvard Medical School, Boston, MA; Patroula Smpokou, MD, Food and Drug Administration (FDA) - Division of Rare Diseases & Medical Genetics (DRDMG), Washington DC; and Frank J. Sasinowski, MS, MPH, JD, Hyman, Phelps & McNamara, Washington DC

11:20 am  Panel 2 – Patient Perspectives: Patient and Clinical Study Coordinator Panel
Moderator: Philip Yeske, PhD, UMDF Science & Alliance Officer
Panelists: Monica Chulewicz, Adult Patient; Michael Hall, Parent/Caregiver; Lilly Lee, Clinical Research Coordinator, University of California San Diego, La Jolla, CA; Jessica Reit, MPH, Clinical Research Coordinator, University of California San Diego, La Jolla, CA; and Kristin Engelstad, MS, CGC, Clinical Study Coordinator, Columbia University, New York, NY

11:55 am  Panel 3 – Lessons Learned: Industry Panel
Moderators: Amel Karaa, MD, Massachusetts General Hospital/Harvard Medical School, Boston, MA, and Philip Yeske, PhD, UMDF Science & Alliance Officer
Panelists: Jim Carr, PharmD, Stealth BioTherapeutics; Colin Meyer, MD, Reata Pharmaceuticals; Matthew Klein, MD, MS, FACS, PTC Therapeutics; and Patrice Rioux, PhD, formerly Raptor

12:55 pm  Break
Day 1: Friday, June 26 – Clinical Trials Program - Scientific/Clinical/Patients (cont’d)

1:15 pm  Clinical Trial Updates  
Speakers:  Joanne Quan, MD, Modis/Zogenix; Tolga Uz, MD, PhD, Astellas Pharma; Chad Glasser, PharmD, MPH, Cyclerion; and Alex Dorenbaum, MD, Reneo Pharmaceutical  
Speakers:  Michio Hirano, MD, Columbia University, New York, NY (Entrada Therapeutics MNGIE Natural History Study Lead Investigator); Magnus Hansson, MD, PhD, Abliva (formerly NeuroVive); Matthew Klein, MD, PhD, PTC Therapeutics; Noa Sher, PhD, Minovia Therapeutics; Magali Taiel, MD, Gensight-Biologics; Peter W. Stacpoole, PhD, MD, University of Florida, Gainesville, FL; and Fernando Scaglia, MD, Baylor College of Medicine, Houston, TX

2:50 pm Panel 4 – Current Trials and Moving Forward – Primary Mitochondrial Myopathy Case Study  
Moderators:  Amel Karaa, MD, Massachusetts General Hospital/Harvard Medical School, Boston, MA, and Philip Yeske, PhD, UMDF Science & Alliance Officer  
Panelists:  Industry Representatives – Niall O’Donnell, Reneo Pharmaceutical; Magnus Hansson, MD, PhD, Abliva (formerly NeuroVive); and Tolga Uz, MD, PhD, Astellas Pharma

3:35 pm Impact of COVID-19 and Mitochondrial Medicine  
Peter McGuire, MS, MD, The National Institute of Health, National Human Genome Research Institute, Bethesda, MD, and Eliza Gordon-Lipkin, MD, The National Institute of Health, National Human Genome Research Institute, Bethesda, MD

4:20 pm UMDF Collaborative Initiatives - North American Mitochondrial Disease Consortium (NAMDC), Mitochondrial Care Network (MCN), Mitochondrial Sequence Data Resource (MSeqDR), and Mitochondrial Disease Community Registry (MDCR)  
NAMDC - Michio Hirano, MD, Columbia University, New York, NY; MCN - Sumit Parikh, MD, Cleveland Clinic, Cleveland, OH; MSeqDR - Marni Falk, MD, Children’s Hospital of Philadelphia, Philadelphia, PA; and MDCR - Philip Yeske, PhD, UMDF Science & Alliance Officer

5:20 pm Closing Remarks
Day 2: Saturday, June 27 – Patient/Family Program

(All times are U.S. Eastern)

10:00 am   Welcome: UMDF and the Mitochondrial Medicine Community
            Brian Harman, UMDF President & CEO

10:20 am   COVID-19: Managed Care and Urgent Care for Mitochondrial Patients
            Speaker: Austin Larson, MD, Children’s Hospital Colorado, Aurora, CO

11:30 am   Medications for Primary vs. Secondary Mitochondrial Disease in the Era of COVID-19
            Speakers: Amel Karaa, MD, Massachusetts General Hospital/Harvard Medical School, Boston, MA; Amy Goldstein, MD, Children’s Hospital of Philadelphia, Philadelphia, PA; and Sumit Parikh, MD, Cleveland Clinic, Cleveland, OH

12:30 pm   accelerators Brown Bag Big Pitch
            Speakers: Kinsley Christopher Belle, Stanford University, Stanford, CA, and Lia Mayorga, Instituto de Histologia y Embriologia de Mendoza, Mendoza, Argentina

1:30 pm   Riding Out the COVID-19 Storm – Navigating the “New Normal”
            Speakers: Margaret Moore, UMDF Support/Education Associate, and Jaclyn Leit, LCSW, BC-TMH, Denville, NJ

2:30 pm   Telehealth – Before, During and After COVID-19
            Speakers: Amel Karaa, MD, Massachusetts General Hospital/Harvard Medical School, Boston, MA; Bruce Cohen, MD, Akron Children’s Hospital, Akron, OH; and Sumit Parikh, MD, Cleveland Clinic, Cleveland, OH

3:30 pm   Closing Remarks
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Friday, June 26
Moderators and Speakers

- Brian Harman
  UMDF President & CEO
- Philip E. Yeske, PhD
  UMDF Science & Alliance Department
- Frank J. Sasinowski, MS, MPH, JD
  Hyman, Phelps & McNamara, Washington, DC
- Amel Karaa, MD
  Massachusetts General Hospital/ Harvard Medical School, Boston, MA
- Patroula Smpokou, MD
  Food and Drug Administration – Division of Rare Diseases & Medical Genetics (DRDMG), Washington, DC
- Lilly Lee
  University of California San Diego, La Jolla, CA
- Jessica Reit, MPH
  University of California San Diego, La Jolla, CA
- Kris Engelstad, MS, CGC
  Columbia University, New York, NY
- Michael Hall
  Parent of child with Leighs, Boulder, CO
- Monica Chulewicz
  Patient with Mitochondrial Disease, Seafood, NY
- Jim Carr, PharmD
  Stealth BioTherapeutics
- Colin Meyer, MD
  Reata Pharmaceuticals
- Matthew Klein, MD, MS, FACS
  PTC Therapeutics
- Patrice Rioux, PhD
  formerly Raptor
- Joanne Quan, MD
  Modis/Zogenix
- Tolga Uz, MD, PhD
  Astellas Pharma
- Chad Glasser, PharmD, MPH
  Cyclerion
- Alex Dorenbaum, MD
  Reneo Pharmaceutical
- Michio Hirano, MD
  Columbia University, New York, NY
- Magnus Hansson, MD, PhD
  Abliva (formerly NeuroVive)
- Matthew Klein, MD, PhD
  PTC Therapeutics
- Noa Sher, PhD
  Minovia Therapeutics
- Magali Taiel, MD
  Gensight-Biologics
- Peter W. Stacpoole, PhD, MD
  University of Florida, Gainesville, FL
- Fernando Scaglia, MD
  Baylor College of Medicine, Houston, TX
- Niall O’Donnell
  Reneo Pharmaceutical
- Peter McGuire, MD
  NIH, National Human Genome Research Institute, Bethesda, MD
- Eliza Gordon-Lipkin, MD
  NIH, National Human Genome Research Institute, Bethesda, MD
- Sumit Parikh, MD
  The Cleveland Clinic, Cleveland, OH
- Marni Falk, MD
  Children’s Hospital of Philadelphia, Philadelphia, PA

Saturday, June 27
Moderators and Speakers

- Brian Harman
  UMDF President & CEO
- Austin Larson, MD
  Children's Hospital Colorado, Aurora, CO
- Cliff Gorski
  UMDF Director of Communications
- Amy Goldstein, MD
  Children's Hospital of Philadelphia, Philadelphia, PA
- Sumit Parikh, MD
  The Cleveland Clinic, Cleveland, OH
- Amel Karaa, MD
  Massachusetts General Hospital/ Harvard Medical School, Boston, MA
- Margaret Moore
  UMDF Support/Education Associate
- Jaclyn Leit, LCSW, BC-TMH
  Denville, NJ
- Bruce Cohen, MD
  Akron Children's Hospital, Akron, OH
Renéo Pharmaceuticals is a clinical stage company dedicated to developing therapies for people with genetic mitochondrial diseases. Our focus is finding a treatment for mitochondrial myopathy to improve daily function and quality of life.

Renéo is a proud supporter of UMDF Power Surge 2020

To learn more about us, please visit reneopharma.com

In the fight against TK2 deficiency, you are not alone.

Thymidine kinase 2 deficiency, called TK2 deficiency or TK2d, is a very rare genetic disease. Tk2d is a form of mitochondrial DNA depletion syndrome.

Because the genetic testing that finds TK2d is so new, and there are many other mitochondrial depletion syndromes (MDS) with symptoms like those of TK2d, it is thought that there are many more people with TK2d who have not been diagnosed.

Let’s work together.
Whether you’re living with an MDS, have been diagnosed with TK2d, or are a parent, caregiver, or healthcare professional (HCP) who wants to learn more about MDS and TK2d, join the registry so we can all take on TK2d together. Join us, and together we’ll take on TK2 deficiency.

Visit www.tk2d.com to learn more.
Project:
Investigating intrinsic and extrinsic factors influencing mitochondrial heteroplasmy in mt-tRNA mutation-linked disease

The work represented in this grant utilizes a two pronged approach to further our understanding of the role heteroplasmy and mutations play in mitochondrial disease; first a basic science approach to expand our knowledge of heteroplasmy and what influences its dissemination across tissue types, secondly we use high-throughput techniques to screen for conditions and compounds which could alleviate heteroplasmy and its resultant cellular dysfunction. In the future, this work will serve as a template for investigating and treating mitochondrial disease.

**READ**
Read breakdowns of the finalist projects
[umd.org/accelerators](umd.org/accelerators)

**WATCH**
Tune in to the Big Pitch on Saturday, June 27, 2020 at 12:00pm EDT
[umd.org/BigPitch2020](umd.org/BigPitch2020)
There are thousands of mitochondrial diseases and zero cures. We’d like to change that fact.

At Akron Children’s Hospital, our world-renowned pediatric neurologists are helping to lead the industry in mitochondrial research and treatment. Until a cure is discovered, we continue to offer integrated care for children suffering from these and other neurological diseases.

For more information, visit us at akronchildrens.org/neurology

Astellas is committed to turning innovative science into medical solutions that bring value and hope to patients worldwide. Every day, we work together to address unmet medical needs and help people living with cancer, overactive bladder, heart disease and transplants, among other conditions. We remain dedicated to meeting patients’ needs, and our support for them will never waver.

At Astellas, we’re focused on making changing tomorrow a reality.

Our mission is to deliver life-changing therapies by treating the root cause of mitochondrial diseases. Working hand in hand with patient advocacy groups, from our beginning, was much more than an aspiration. This is the place where our science transforms into meaningful therapies.

Visit our site for more info: www.minoviatrix.com

Contact us with any question: info@minoviatrix.com

*MAT is an investigational drug, currently undergoing a clinical trial for Pearson Syndrome.
The **Stanley A. Davis Leadership Award** is presented annually to a UMDF leader who exemplifies dedication to the UMDF. The award was created to honor the work and dedication to the organization shown by the late UMDF Board Chairman, Stanley A. Davis.

We are proud to recognize **Joy Krumdiack** as the 2020 Stanley A. Davis Leadership Award recipient.

“When I was diagnosed, UMDF was there on the Internet for me with descriptions of the various types of mito. It was a great way to learn what was happening, help educate my physicians locally and realize that I was not alone in this. That is why I volunteer for UMDF: to encourage and educate others who are looking for answers. When I could no longer work as a Certified Medical Assistant because of mito, I began to get more involved with volunteering. I wanted to help in any way possible.

“Receiving the Stanley A. Davis Leadership Award is such an honor! I count it a privilege to be able to support, educate and raise awareness for the mito community through UMDF.

“Thank you to all who made this possible!”
SAVE THE DATE!

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The UMDF Heartstrings Award recognizes a child or teen that has donated or raised funds for the UMDF, enabling the UMDF to continue its mission. The winner is chosen based on related criteria of age, time invested, talents demonstrated, effectiveness, and generosity and how the individual has “tugged at the heartstrings.”

We are proud to recognize Nathaniel Pakuris as the 2020 Heartstrings Award recipient.

Nathaniel became involved with the UMDF because of his very best friend, Michael LoPresti. They met each other in the third grade at school. Michael is affected with mitochondrial disease. Nathaniel says he met Michael through a program at school called the “Next Steps” program. The program was available to children with disabilities and illnesses. “At first, I pictured it as just a really good learning experience, but then it turned into a beautiful friendship,” Nathaniel said. The program arranges for various activities for the children along with their ‘peer pals’. Nathaniel, who is a ‘peer pal’, would go above and beyond the program to spend recess and lunch with Michael. Their friendship blossomed outside of the classroom, too. Nathaniel has been to every birthday party for Michael since the pair became friends. They also visit through Facetime.

A few years ago, Nathaniel had an idea to have a lemonade stand to fundraise in honor of Michael. “I thought I would make $25,” Nathaniel said. “I was wrong, I was very wrong.” The stand raised several hundred dollars. Dozens upon dozens of people showed up to buy lemonade or to just make a donation.

Nathaniel also loves to spread awareness about mitochondrial disease and how it impacts his friend. Even though the COVID-19 restrictions have only allowed them to see each other online right now, Nathaniel and Michael talk with each other most days and they continue sharing with and learning from each other. They look forward to a time when they can be together again, in person.
Check out our schedule of upcoming virtual walks!

www.energyforlifewalk.org

The Delta Gamma Foundation is a proud supporter of UMDF’s Power Surge 2020.

What first started as an inspiration in 1936, Delta Gamma’s philanthropy Service for Sight has now grown into a powerful movement to promote access and advocacy for people who are blind or visually impaired and to encourage sight preservation.

Throughout North America, Delta Gammas engage in service and fundraising to support Service for Sight. Last year, the Delta Gamma Foundation awarded close to one million dollars in grants to non-profit organizations that share the Service for Sight mission, including five schools founded by Delta Gammas for children who are blind or visually impaired.
The Energy Award is designed to recognize an individual who embodies the spirit of the UMDF and its Mission: promoting research and education for the diagnosis, treatment and cure of mitochondrial disorders and providing support to those affected.

We are proud to recognize Ryan Eberly as the 2020 Energy Award recipient.

“It is an honor to be recognized as the recipient of the UMDF Energy Award when there are so many volunteers working tirelessly to fulfill the mission of the UMDF. I have enjoyed the past few years as an UMDF Adult Ambassador connecting with people newly diagnosed with CPEO and providing them with credible information from the UMDF website or the Mitochondrial Medicine Society (MMS) to learn about mitochondrial disease. I urge people to participate in mitochondrial disease registries such as the Mitochondrial Disease Community Registry or RDCRN and NAMDC to help scientists and doctor’s advance treatment and find a cure for mitochondrial disease. I encourage people to share the same resources with their non-mito specialists to help educate more doctors about mitochondrial disease and I inform them of a valuable resource for their health care professional, UMDF’s “Mito On Call”. I continuously share UMDF events and information across many mito specific private Facebook groups to spread awareness of mitochondrial disease.

“I have been fortunate to help the MMS with projects such as the guide written for the Mitochondrial Care Network “Mitochondrial Disease: A Guide for the Newly Diagnosed” and an exciting yearlong collaboration that is still in development. The UMDF has also trusted me to edit their online Resource Guide and keep the Mito Physicians list up to date which helps our community find specialists in their area. I was able share ideas and ways to improve usability of the upcoming redesigned UMDF website. I was able to assist other volunteers to prepare polling questions for the Externally-Led Patient-Focused Drug Development Meeting so the FDA could hear directly from the mito community.”
LEAP stands for Living, Encouraging, Achieving and Persisting. The award is presented to an individual who is age 14 or older living positively with mitochondrial disease. The Awardee overcomes daily challenges to achieve goals in career, family, and volunteer service. The individual demonstrates a positive attitude, hope for a brighter future, and an enthusiasm that inspires others.

We are proud to recognize the Holmes Family as the 2020 LEAP Award recipients.

Thank you for recognizing our family as the recipients of the 2020 LEAP Award. This award means so much to us because it reflects some of our core values as a family, and it feels wonderful to have our positive efforts ratified by our UMDF extended family. It is amazing to be recognized for how we live, encourage, achieve, and persist through our everyday lives while shouldering our own struggles with this disease.

Our first UMDF symposium we attended as a family was in Newport Beach, California. We reconnected with so many old friends while also gaining new ones, many of which we talk with still on a daily basis. We had such great experiences during this time, among them seeing The Magic Bracelet for the first time - a film written by our beloved friend and Mito sister Rina Goldberg, getting our family genomes sequenced to better understand the complexities of our diseases, and also meeting high-profile celebrities such as Jack Black and Diablo Cody, who are huge advocates and supporters of the UMDF in so many ways.

Natalie remembers meeting Jack Black, saying, “It was so great to meet him because it really made me feel somehow validated; that someone outside of our community, a celebrity with a big stage, was fighting for us too. I felt that we were somehow validated in
our advocacy; that it is the right thing to do, to keep advocating and fighting.”

Stephen remembers being awestruck by Jack Black, and he also distinctly remembers how, at fifteen years old, he stood a noticeable head taller than the Hollywood star.

From that point in 2012, we knew that the UMDF was going to continue playing an important role in our lives.

“LEAP” stands for “living, encouraging, achieving, and persisting,” and if you’re living with mitochondrial disease it’s only natural to want to feel stationary, discouraged, and defeated. Yet, the very essence of this award is to highlight how we as Mito Warriors, even though we may be defined in some ways by this disease, are not destined to be held back by it.

Although we could spend hours retracing our steps down paths well-trodden, we’d like to highlight what we feel have been defining moments in our walk with mito.

NATALIE:
One of the things I absolutely LOVE that the UMDF does that I feel really gave me the confidence to be a stronger advocate is the Day on the Hill experience we have had in Washington DC over the years. Before that first experience, I was okay talking to people about our lives, but that first experience really taught me that it is okay to advocate for what you need from those who could help to provide it. Even if what you are advocating for is not a pressing issue for you personally at the time, it is important to fight for others who are having trouble because of this issue; and maybe it will even help you in the future!

My brother, Stephen, took charge that first Day on the Hill we attended. I learned from him how to use the resources the UMDF provides, make it personal, and then bring it back to what they can do for you. I feel that the UMDF, along with help from my brother have given me the chance to be a great advocate, but I know I can grow more in that respect, and I look forward to doing that and making the biggest impact I can! I know the UMDF can help me grow even more by providing more guidance and experiences to help me grow my skills, and I am so looking forward to the next Day on the Hill! I got some practice talking with legislators on my own last time we were in DC, and I’ll definitely be building on those skills now that my brother lives in a new State and has his own politicians to wrangle!

STEPHEN:
As a family, we have made every effort possible to make sure that a representative from the Holmes squad is present at the UMDF symposium each year. Of course, it’s always best when the three of us can travel together, but this is not always possible. In 2016, I got the chance to travel on my own for the first time at the age of nineteen as I made my way across the country to the Emerald City of Seattle (an experience that I will write a memoir over sometime in the future.)

A slight, but necessary digression for the sake of context - I grew up playing soccer. I loved playing, and as I got older, I got better, and as I got better the game became all the more fun to me. My friends and I would play soccer in P.E. and would talk about whose team was the best and whether Ronaldo was better than Messi and vice versa. Then came the day for school soccer tryouts, to be on the official team. If I could make the team, it would be the first time I had ever played for my school rather than a separate league. Soccer is a physically taxing sport on your stamina, it’s essentially cross country with a ball. As a child, I had no problem keeping up, but that day of soccer tryouts will forever stick in my memory - I was noticeably exhausted after only a few drills and I struggled to keep up the whole day. I left those tryouts without gaining a spot on the team, upset by my performance. As the years went on, I noticed my stamina continuing to decline in the few spaces I was still required to physically exert myself (thankfully we transitioned to weight training in P.E. so I didn’t have to feel embarrassed when I could only run a few laps around the track.)

I kept this all to myself, quietly sulking and being angry with my body for not being able to do what I wanted it to do. After all, there were those who had it worse, and I suppose at the time I felt that my inability to play my favorite sport with a team paled in comparison to what my younger sister had already had to endure through her illness, so I stayed silent.

Fast forward back to 2016, I’ve arrived at the symposium and I’m hugging all of my friends and introducing them to my new mito friend Josh (who is serving as a groomsman in my wedding later this year!) On the first day of the Teen/Young Adult sessions, we began with a session called “Body Positivity.” I wasn’t sure what to expect, but I was all here for it.

The exercise the body positivity coach had us perform was to write two letters, one from our brain to our body, then one from our body to our brain. I wrote the letters without much issue, my brain complaining about my lost ability and subsequent loss of love for the game I adored, and my body apologizing for what it could no longer do, but bringing my mind’s attention to all I had accomplished apart from soccer. Two letters, no problem.
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Model depicted.
Then came the challenging part of the exercise, the body positivity coach asked if anyone would like to share aloud the letters they had written. Nobody jumped at the opportunity, so I raised my hand, used to taking the lead in situations like this and hoping it would help others to break out of their shell.

I began reading the letter from my brain to my body, and it was filled with anger and resentment. I was angry that I had lost something so important to me and as I read this letter aloud, my eyes widened at the vitriol I had imposed upon myself. Then I began reading the response letter, from my body to my brain - ‘Do you think I don’t feel the same way you do? Don’t you think I miss running across the field, dribbling past defenders, and putting that ball in the back of the net? Some days were filled with hat tricks, and some were frustratingly scoreless, but whether we scored or not, won or lost, I enjoyed every moment of it just as much as you. And then it was gone. Seemingly without warning and without explanation, I couldn’t keep up anymore, I…’ at this point my throat clenched shut and my vision went wet and blurry. All of that pain and anger I had bottled up for eight years, the self-hate, was about to come surging forth in front of everyone in the first Teen/YA session of the symposium. What had I gotten myself into?

I continued reading, struggling at times to get the words out. ‘I’m sorry. I’m sorry that I can’t do what we both want to do anymore. I’m sorry that something we loved so much was taken from us. I hate this disease as much as you do, it’s taken so much from us. But please, realize this - the disease might have taken much from me [the body], but it hasn’t taken everything from you.’

My head dipped and tears stained the letter. Josh, also crying had his hand on my back as he shared in my pain. “Could you look at everyone?” asked the coach, and as I turned my face to the rest of the room I saw that I had touched a nerve, a very raw nerve for all of us. Without even intending to, I had called out the elephant in the room and named it. Yes, mito wasn’t making my life easier, but neither was I. Many others began sharing their pain at the lives they once had before their disease progressed, and we hugged and cried, and we encouraged each other to forgive ourselves, and recognize the strength that we still have.”

MELODY:

[This award] - it’s just who we are and what we do. UMDF is part of us. We are sensitive to the unique needs of others and are willing to learn how we can help them live their best life. For me I feel like I have found my ‘people.’ UMDF is the only place I’ve ever been where I feel no one judges me and speakers do not take offense if I fall asleep during presentations.

One step further than finding my people is helping others find their people. It’s amazing how it feels when you find others you don’t have to describe every little thing to, but they still understand you. I hope to encourage others by helping them experience this by connecting them with others who have the same similarities. I’ve connected two families who live on opposite coasts whose daughters share the same genetic defect. Along with many, many others. I’ve helped many families share medical supplies they no longer need. I’ve helped them to learn how to work through insurance issues and how to document and keep numerous medical records as well as how to communicate with medical professionals effectively.

Much of this I have learned to do through people and presentations at UMDF symposiums. Most of all I’ve helped connect and encourage two people that are very important to me - my kids. I’ve helped them find their people. I attended a break-out session at the symposium in Chicago that REALLY HELPED guide me to raising ‘normal’ kids even though they have a huge medical component in their life.

For me, I love to help others. I often put others first and am always thinking how I could help them live their best life; from making room for their wheelchair in a conference room, running a support group, participating in the Energy for Life Walk, and pushing the record button for a symposium talk so someone can listen to it later from home. Our relationship with UMDF has been give and take. I feel I’ve gained so much from UMDF; it is just natural for me to want to give back. The only limitations are the limitations you place on yourself.
The United Mitochondrial Disease Foundation gratefully acknowledges the following organizations for their support of Mitochondrial Medicine 2020.

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