



News Release
FOR IMMEDIATE RELEASE

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UMDF FORMS COLLABORATIVE PARTNERSHIP WITH INDUSTRY

(Pittsburgh, PA) The United Mitochondrial Disease Foundation (UMDF) has announced the formation of an Industry Advisory Council (IAC). The formation of the IAC allows the UMDF to collaborate with key members of the pharmaceutical industry to address priorities within the three key pillars of the Mitochondrial Disease Roadmap. Those priorities, announced at the UMDF International Symposium in 2016, have been identified as diagnosis, Therapeutic Development and Patient Care. “The valuable insight and advice from members of industry will help guide us in developing faster non-invasive diagnostics and potential therapies for mitochondrial patients as well as develop a model for enhanced patient care,” said Charles A. Mohan, Jr., CEO and Executive Director of the UMDF. “We look forward to a productive and mutually beneficial working relationship.”

Joining the UMDF Industry Advisory Council are:

John DiCecco
IAC Co-Chair
UMDF Board of Trustees

Gene Kelly
Senior Director
Commercial & Scientific Liaison
Stealth Biotherapeutics

Marko Rosa
Product Manager
Tishcon Corporation

Mann Shoffner
Pharmaceutical Relationships
Courtagen Corporation

Matthew Klein, MD, MS, FACS
Chief Medical Officer
BioElectron Technology Corporation

IAC Committee Members

Edmund H. Doherty, Pharm D
Associate Vice President, Product Strategy
Reata Pharmaceuticals, Inc.

Andrew Sanford
Operations Manager
Solace Nutrition

Andrew T.J. Hope, Ph.D.
Senior Director
Business Development & Strategic Alliances
GeneDx

Jodi Wolf, Ph.D.
Director Patient Advocacy & Medical Science Liaison
Santhera Pharmaceuticals

Mohan says the patient community will also play a key role in the IAC. “The formation of this council has the sole mission of sharing the expertise that is needed to bring about faster diagnosis, better treatments, and, ultimately a cure”, he added. “Patient participation, especially in the Mitochondrial Disease Community Registry (MDCR) is paramount to helping our community reach that goal.”

ABOUT MITOCHONDRIAL DISEASE

Every 30 minutes, a child is born who will develop a mitochondrial disease by age 10, although the actual number of children born with the disease is thought to be much higher. More and more adults are being diagnosed with a mitochondrial disease. Recent research indicates that one in 200 people harbors a genetic mutation that can lead to mitochondrial disease in them or their offspring. Most patients suffer symptoms for years before they are accurately diagnosed with a mitochondrial disease. Mitochondrial diseases result from the failure of the mitochondria, which are located in the cells of our bodies. Mitochondria are responsible for creating more than 90% of the energy needed to sustain life and support growth. When mitochondria fail, less energy is produced causing cell injury or cell death. On a larger scale, organ systems begin to fail. The disease is often debilitating. In some cases, it may result in death. Adult onset is becoming more and more common. There is no cure for mitochondrial disease.

ABOUT THE UMDF

Founded in 1996, the United Mitochondrial Disease Foundation (UMDF) works to promote research and education for the diagnosis, treatment and cure of mitochondrial diseases and to provide support for affected individuals and families. Since its inception, the UMDF has funded more than \$11 million in research, making it the leading non-governmental contributor of grants focused solely on mitochondrial disease. The UMDF, based in Pittsburgh, PA, is a national organization, represented around the world by thousands of members. For more information about mitochondrial disease or the UMDF, visit www.umdf.org