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MEDIA ADVISORY

Dr. Rand Paul Announces Witnesses for Hearing on Expediting Treatments for Patients with Rare Diseases

WASHINGTON, D.C. – Today, U.S. Senator Rand Paul (R-KY), chairman of the Children and Families Subcommittee for the Senate Health, Education, Labor and Pensions (HELP) Committee, announced witnesses for his upcoming hearing entitled, "Rare Diseases: Expediting Treatments for Patients," which will take place on Wednesday, October 3, at 2:30 p.m. eastern.

Dr. Paul's subcommittee will hear from patient advocates, clinicians, and industry professionals as it examines what Congress can do to improve a slow-moving regulatory process that leaves the needs of many patients with rare genetic diseases unmet, as well as how to help ensure these patients have timely access to treatment options to alleviate their conditions.

WHEN: Wednesday, October 3rd, 2018
WHAT: Subcommittee on Children and Families hearing entitled, "Rare Diseases: Expediting Treatments for Patients"
WHEN: 2:30 p.m. eastern
WHERE: SD-430, Dirksen Senate Office Building

WITNESSES

Mark Dant *(Louisville, KY)*
Board chair of EveryLife Foundation for Rare Diseases
Volunteer Executive Director, The Ryan Foundation
Mark founded The Ryan Foundation, named for his son who was diagnosed with Mucopolysaccharidosis 1 (MPS I) at age 3 with a life expectancy of 10 years old, and Mark has spent over 25 years working on behalf of the rare disease community. His son, Ryan, graduated from the University of Louisville in 2017.

Marc Patterson, MD, FRACP, FANA, FAAN
Professor of Neurology, Pediatrics, and Medical Genetics, Mayo Clinic
Dr. Patterson is the chair of the Division of Child and Adolescent Neurology at the Mayo Clinic, where he focuses on rare diseases in children.

Michael Strupp, MD, FRCP, FANA, FEAN
Professor at the University of Munich, Germany, in the Department of Neurology and German Center for Vertigo and Balance Disorders
Dr. Strupp's work in drug development has centered around finding known compounds that have a demonstrated safety profile and testing their efficacy for rare and incurable diseases.

Lincoln Tsang, LLB, PhD, BPharm
Partner at Arnold & Porter Kaye Scholer LLP – Former Head of Biologicals/Biotechnology for the United Kingdom's Medicines and Healthcare products Regulatory Agency
At Arnold and Porter, Dr. Tsang continues to advise large and small companies working to develop novel technologies to treat pediatric and orphan diseases, and he brings a unique perspective of both the U.S. and EU regulatory systems.

Mallory Factor
Founder, Chairman, and CEO of IntraBio
IntraBio, founded in 2015, translates research in the fields of lysosomal biology, autophagy, and neurology into orphan drugs and treatments to improve the lives of patients.