**For immediate release**

**Contact:**

Name

City, State

Phone number

Email address

**Local *insert descriptor like teen* travels to Washington, D.C. for Rare Disease Day**

(Feb. 26, 2018) ***City, State*** — *Insert descriptor like A local teen and her family* will be traveling to Washington, D.C. in the coming weeks with the National MPS Society to speak with state legislators about a cause that hits close to home — rare diseases. *Insert name* is one of 30 million people in the U.S. suffering from a rare disease, and *she* is going to Washington to make *her* voice heard.

*Insert personal family story here.*

As part of Rare Disease Day on Feb. 28, *insert name* is traveling with the National MPS Society, a nonprofit organization that supports families affected by MPS and ML, as part of a group of speakers and advocates that are heading to our nation’s capital to meet with elected officials about health care legislation, policies and initiatives that affect those with diseases like *insert name’s*.

Local families often have trouble getting access to life-saving medical treatment or other services because insurance companies, medical, elected and other officials may not be familiar with MPS and ML. *Insert name* will also be speaking in support of the OPEN Act (Orphan Product Extensions Now Accelerating Cures and Treatments Act), which helps pharmaceutical companies repurpose already approved drugs for the treatment of rare diseases.

Mucopolysaccharidoses (MPS) and mucolipidosis (ML) are genetic lysosomal storage diseases (LSD) caused by a missing or insufficient enzyme that prevents cells from recycling waste, causing materials to be stored in the cells. This leads to widespread damage throughout the body, affecting joints and organ systems. Of the 11 syndrome types, only four have treatments and none has a cure.

To learn more about MPS and ML, please visit [www.mpssociety.org](http://www.mpssociety.org).

**About the National MPS Society**

The National MPS Society exists to find cures for MPS and ML. We provide hope and support for affected individuals and their families through research, advocacy and awareness of these devastating disorders. MPS and ML are genetic lysosomal storage diseases (LSD) caused by the body’s inability to produce specific enzymes. The malfunctioning cells are unable to recycle waste materials, causing progressive damage throughout the body, including the heart, bones, joints, respiratory system and central nervous system. For information on MPS and ML, please visit [www.mpssociety.org](http://www.mpssociety.org).