



Lisa Phelps Sarfaty, MPH **Vice President, Community Engagement**

Lisa currently serves as the Vice President of Community Engagement at the National Organization for Rare Disorders (NORD®). Lisa is responsible for strengthening NORD's ties to the community and fostering engagement with individuals living with rare disease and their families, advocates, and patient organizations. She oversees and aligns the organization's community outreach and engagement programs here in the U.S. and abroad – working closely with global partners on advocacy, education, and capacity building. She also leads strategic planning for the organization, aligning NORD's short and long-term goals – enabling the organization to pursue innovative and promising ideas that reduce or eliminate the myriad of challenges patients face daily.

Lisa joined NORD in 2011 and has since helped to oversee, advance, and launch the organization's marketing, community relations, advocacy, and membership plans. Her achievements include the creation of the Rare Action Network – comprised of 15,000 grassroots advocates working at the local, state, and federal level to raise awareness, influence policymakers and help pass legislation; helping to found Rare Diseases International (RDI), a global alliance of patient organizations representing the 300 million people living with rare diseases worldwide; growing NORD's reach and web presence from 300k visitors per month to more than 1.2 million; and the development and launch of NORD's Rare Disease Centers of Excellence program.

Lisa received her MPH from the Milken Institute School of Public Health at George Washington University and her BA in political science and law and policy from Bernard Baruch College, a public research university. Her training is a combination of public health, health policy and law.

1779 MASSACHUSETTS AVENUE NW, SUITE 500
WASHINGTON, DC 20036
T 202-588-5700 ■ F 202-588-5701

55 KENOSIA AVENUE
DANBURY, CT 06810
T 203-744-0100 ■ F 203-263-9938

1900 CROWN COLONY DRIVE, SUITE 310
QUINCY, MA 02169
T 617-249-7300 ■ F 617-249-7301

rarediseases.org ■ orphan@rarediseases.org

NORD® and icon are registered trademarks of the National Organization for Rare Disorders. NORD is a registered 501(c)(3) charity organization.