

**Media Contact:**

Ellynn Decter Szoke  
973-761-4403  
eszoke@sculptahealth.com

FOR IMMEDIATE RELEASE

## **New Jersey Rare Disease Alliance Commemorates Global Rare Disease Day 2018** *Program to Focus on Legislative and Clinical Development Progress*

**Millburn, NJ (February 26, 2018)** —The New Jersey Rare Disease Alliance will hold its annual Rare Disease Day commemoration on Monday, March 5, at the New Jersey State Museum, 205 W. State Street, Riverview Court (1<sup>st</sup> floor), Trenton, from 8:30a.m.-12:30p.m. Entitled “A Better World for People Living with Rare Diseases: State, National, and Global Action”, this year’s event will feature Congressman Leonard Lance, Co-Chair of the Rare Disease Caucus of the United States Congress, as the keynote speaker.

Co-sponsored by the National Organization for Rare Diseases (NORD), the HealthCare Institute of New Jersey (HINJ) and BioNJ, the event will begin with networking and a continental breakfast followed by two panels, “Effective Advocacy – Real World Advice” and “A Collaborative Approach to Rare Disease Treatment Development”. Panelists will feature representatives from the rare disease community including patients, patient advocates, biomedical healthcare professionals, and industry leaders. Attendees will also hear from members of the New Jersey legislature. Following lunch, all in attendance are invited to walk to the State House and engage with legislators and staff about issues of concern to the rare disease community.

“This is an important event for the rare disease community to connect, learn, and share and we invite everyone to attend,” commented Ellynn Szoke, co-founder of the New Jersey Rare Disease Alliance. “This year’s panels have participants from across the rare disease continuum and offer a wonderful opportunity to understand the challenges and successes in both clinical development and the legislative process. It is important for patients and advocates to understand how their voices can be integrated into both. We look forward to continuing to work together to strengthen the impact of the rare disease community in New Jersey. Together we are stronger than any of us are alone.”

To register for Rare Disease Day 2018 in Trenton, please use this link: [bit.ly/NJRDA2018](http://bit.ly/NJRDA2018)

### **About The New Jersey Rare Disease Alliance**

The New Jersey Rare Disease Alliance is dedicated to improving the lives of the 800,000 rare disease patients in NJ. The group’s mission is to bring recognition to the issues rare disease patients face and to work together towards better treatment options and improved access to care. Patients, supporters, advocates, legislators, biopharmaceutical and life science industry executives, healthcare professionals, academia, and individuals committed to making a difference in patients’ lives are all encouraged to participate.

### **About NORD**

The National Organization for Rare Disorders (NORD), a 501(c)(3) organization, is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

For more information on NORD visit [rarediseases.org](http://rarediseases.org)

### **About HINJ**

Founded in 1997, the HealthCare Institute of New Jersey (HINJ) serves as the voice for the state's life sciences industry. HINJ seeks to expand patient access to the most innovative biopharmaceuticals and medical technologies and promote awareness of the industry's impact on New Jersey's quality of life and economic well-being.

For more information, visit [www.hinj.org](http://www.hinj.org)

### **About BioNJ**

BioNJ is a trade association of nearly 400 Member companies representing research-based life sciences organizations and stakeholders dedicated to propelling a vibrant ecosystem where Science is Supported, Companies are Created, Drugs are Developed and Patients are Paramount. Because Patients Can't Wait®, BioNJ supports its Members in the discovery, development and commercialization of therapies and cures that save and improve lives and lessen the burden of illness and disease to society by driving capital formation, fostering entrepreneurship, advocating for public policies that advance medical innovation, providing access to talent and education and offering a cost-saving array of critical commercial resources. For more information about BioNJ, please visit [www.BioNJ.org](http://www.BioNJ.org).