Thank you for attending today’s event. We encourage you to continue spreading the word about rare diseases. To learn more visit: rarediseaseday.org

Thank You!

Light refreshments will be served on both campuses following the event courtesy of the Rutgers Drug Information Association Student Chapters and the Rutgers University - Health Informatics/BioPharma Departments.

For additional information about today’s sponsors visit:
shr.p.rutgers.edu/dept/biopharma
pharmacy.rutgers.edu
shr.p.rutgers.edu/current_students/shrp_oss_home.html

Please also consider attending:
“Navigating the Diagnosis and Care of a Child with a Rare Disorder”

Rare Disease Day 2014: Join Together for Better Care
Pediatric Grand Rounds - Rutgers New Jersey Medical School
February 28, 2014 - 9:00-11:00am
New Jersey Medical School
Medical Science Building, Room B-610
185 South Orange Avenue

February 25th, 2014
5:00pm - 6:30pm
Newark & Piscataway Campuses
(simultaneously connected on-line)

Please visit our event website @

Sponsored by:
The School of Health Related Professions
Rutgers Drug Information Association
MS—Clinical Trials Program & Office of Student Affairs
Clinical Trials & School of Pharmacy Student Chapters
RARE DISEASE DAY

February 25, 2014

Each year during February, Rare Disease Day is observed with the goal of drawing attention to an important public health issue.

According to the National Institutes of Health (NIH), there are nearly 7,000 rare diseases affecting between 25 and 30 million Americans.

Many—but not all—of these diseases are genetic. Some are apparent at birth. Some do not appear until much later in life. It is believed that approximately two-thirds of those living with rare diseases are children. Everyone knows someone with a rare disease.

Many rare diseases still have no approved treatment. And many are not even being studied by medical researchers at this time. Often, people with rare diseases are treated “off-label” (with treatments that are not approved by FDA for their specific disease). Increasingly, patients experience reimbursement problems for off-label treatments.

Brian L. Strom, MD, MPH, RBHS Chancellor

Brian L. Strom, inaugural chancellor of Rutgers Biomedical and Health Sciences, leads the efforts to strengthen medical and other health professions education and practice in New Jersey, provide increased academic opportunities for students, deliver excellent health care, and allow Rutgers to excel in health sciences research, education, and service.

Julie Raskin, Dir. Congenital Hyperinsulinism International

Julie Raskin is the executive director of Congenital Hyperinsulinism International (CHI), an organization dedicated to improving the lives of patients with the rare condition, Congenital Hyperinsulinis (CHI). Prior to that, Julie was vice president of the Board of Directors of CHI from 2005-2010. From 1999-2005 she served as part of a working group of parents of children with HI advocating for HI patients. Julie became involved in rare disease patient community working through her personal experiences raising a child with a rare condition.

Murad Husain, VP Regulatory Affairs

As Vice president of Regulatory affairs, Mr. Murad Husain leads the regulatory efforts to support PTC’s lead product candidate, ataluren, and other clinical programs. Mr. Husain has more than 25 years of pharmaceutical industry experience, with 20 years in regulatory affairs. He has led numerous worldwide regulatory teams for drug and biologics development and registrations. He achieved approvals of original NDAs, BLA and new indications for drugs and biologics in pulmonary, oncology, CNS, rheumatology and anti-infective therapeutic areas.

Jayne Gershkowitz, Vice President, Patient & Professional Advocacy and Public Policy, Amicus Therapeutics

Jayne Gershkowitz, is a long-time patient advocacy professional with expertise in the rare disease community, who has been extending her perspective to the broader biotech arena. She is a member of the Steering Committee of the Healthcare Institute of New Jersey, the Government Relations Committee of BIO, a co-founder of the Patient Advocacy Committee of BioNJ, which she chairs, and participates on the Policy Working Group of the NORD Corporate Council (National Organization for Rare Disorders).

Please see our event website for more information on our speakers.