RNE

RARE NEW ENGLAND

SERVING THE RARE DISEASE COMMUNITY

Rare New England's Mission is to bring together New England patients, families and providers touched by rare and complex disorders. We offer educational opportunities, create awareness of available resources, and build foundations for support to improve patient quality of life.

We organize programs of which include our Annual Conference, providing educational experiences for medical professionals, and offering virtual support groups for patients and caregivers living with any rare disorders

An estimated 30 million people in the US are affected by a rare disease. There are no cures and only 5% of approximately 7000 rare diseases have an FDA approved treatment. 80% of rare diseases are genetic.

The Orphan Drug Act defines a rare disease as a disease or condition that impacts less than 200,000 people in the U.S. 1 in 10 people are estimated to have a rare disease and affect more people than cancer and AIDS combined.

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Rare New England
120 North Main St, Ste 303
Attleboro, MA 02703
Info@RareNewEngland.org
www.RareNewEngland.org

More information and testimonial videos can be found on our website.

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PROGRAMMING

RNE Honors Rare Disease Day Speaker Series - RNE arranges for patients and/or family members to speak to medical audiences at major teaching hospitals, medical schools, and genetic counseling programs around New England. The presentation topics include any combination of the following possibilities: the diagnostic journey, living with the disease, coping strategies, challenges in the healthcare and/or educational systems, and others.

At each event, the patient presentation is preceded by a brief clinical overview of the disease by a geneticist to ensure that the audience has a medical foundation about the condition

RNE Annual Conferences – Hear from leaders, patients, caregivers, and physicians in the field of rare disease, who share valuable insights, experiences, and resources with those in the rare disease community.

Career Fairs in Medical Genetics - Genetics is a very promising and expanding area of medicine but one with a serious workforce shortage. This shortage is compromising the promising benefits that can come from all the research and clinical effort underway in this country and around the world.

These Career Fairs aim to attract and inspire young professionals - medical students, pediatric and medical interns/residents, and undergraduate/graduate genetics students - to consider a career in Genetics.

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PROGRAMMING CONT.

Rare Connections: Patient & Caregiver Support Groups - Rare Connections provides opportunities for adult patients and caregivers to come together and share their experiences with others facing similar challenges. In this atmosphere, attendees learn from each other and feel supported by people who understand, thus leaving each meeting with feelings of hope.

The World of Rare Disease

A talk show featuring those in or touched by the rare disease community. The World of Rare Disease brings attention to the rare disease community and provides an opportunity for those in that community to share their experiences.

Data Mapping Project - Rare diseases can be invisible to society when considered separately. The awareness is often fragmented. The six states in New England do not address the needs of the rare community in a coordinated fashion. Any efforts are also fragmented. New England is very diverse with respect to social determinants of health (SDoH) which further fragments the understanding of rare diseases.

RNE convened a team from academia, industry, and the non-profit space to guide an effort to consolidate a source of the demographic data across rare diseases across the region. These data are desperately needed by patients, caregivers, and organizations that are seeking funding, policy changes, or almost any other objective they see fit. The rationale for this project is to fill this need by collecting data across all rare diseases, across the region. These data will give the rare community added credibility and leverage to inform and educate legislators, industry leaders, healthcare systems, payers, and other stakeholders in the healthcare community. It will also allow Rare New England to consider and develop policy literacy programs tailored to communities in the future.

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