

Rare New England

Coordinating Resources for Patients and Families
With Rare and Complex Disorders



ANNUAL REPORT – 2016

Rare New England herein referred to as (RNE) was established in April 2016 by founder Julie Gortze RN, and a group of medical providers, after recognizing the unmet needs of those affected by rare/complex/chronic disorders. It is the mission of (RNE) to offer support to patients and families diagnosed with rare and complex disorders in our local community and throughout New England.. RNE also helps patients / families find support from each other and promote awareness about the daily challenges facing patients with rare/complex disorders.

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.

Board of Directors:

Julie Gortze RN – President

Lois Foster LICSW – Secretary

Mark Korson MD - Director

Amel Karaa MD – Director

Jeantine Lunshoff PhD – Director

John Campbell BS – Director

Jessica Shriver MA Theology, MS Biomedical Ethics - Director

According to the 2013 census, there were 14,618,806 people living in the New England area, 1 out of every 10 people affected by rare disease. Approximately 50% are children, 30% of whom will not live to see their 5th birthday. (Global Genes)

Many rare disease patients will wait years to find their correct diagnosis, receiving multiple incorrect diagnoses and visiting many different specialists in the meantime. Many rare disease patients suffer with reduced qualities of life due to large medical expenses, difficulty finding treatment and medical care, lack of education and awareness about their disease, feelings of isolation and worry, loss of jobs and careers, long term disability and even more.

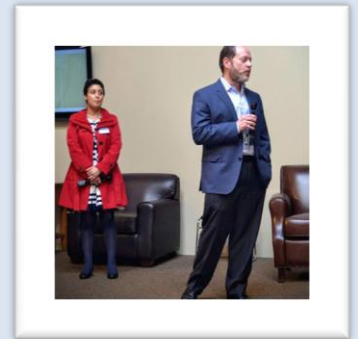
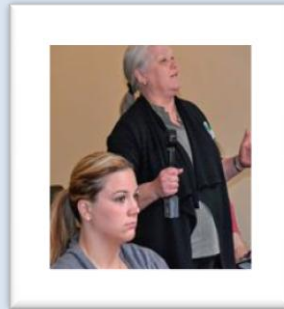
RNE strives to reduce the burdens that can come with rare/complex disease by helping patients/ families learn about utilizing community resources, educating patients, and medical providers on rare and complex disorders and by promoting awareness of the unique needs of the rare disease community.

RNE provides educational opportunities with group presentations by physicians, attorneys, bio-ethicists and other professions familiar with the Rare Community. RNE also provides for patients and families to learn about resources available to them by hosting speakers who represent entities such as Make-A-Wish, Icing Smiles and other wish granting organizations. RNE collaborates with many stakeholders in the many areas of rare disorders including, physicians across the United States and Canada, hospitals, state agencies, schools, advocacy groups, pharmaceuticals, patients, families and caretakers about the many aspects of rare disease treatment and support that must be improved. RNE also provides phone, e-mail, and in person support, both one-on-one and in a group setting.

During our first year, RNE hosted educational programs: "Challenges in Care for Rare Disease patients", "Exercise for the Rare and Complex Disease Patient" & "Staying Safe in a Medically Complex World-Improving Communication between Patients, Families, and Medical Teams". RNE was able to host these events utilizing an in kind donation of venue from Cardi's of South Attleboro, MA. All events were held in the Community Conference room at this location.

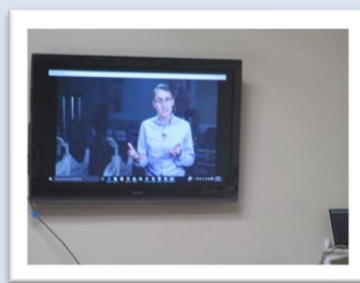
“Challenges in Care for Complex Disease Patients”

At our inaugural event in April, Mark Korson MD and Amel Karaa MD, both RNE Members of the Board, spoke about challenges in health care faced by patients with complex medical illnesses.



“Exercise and Physical Therapy with a Rare Disorders”

In July, RNE hosted an event featuring Dr. Michael Healy spoke about exercising with connective tissue disorders.

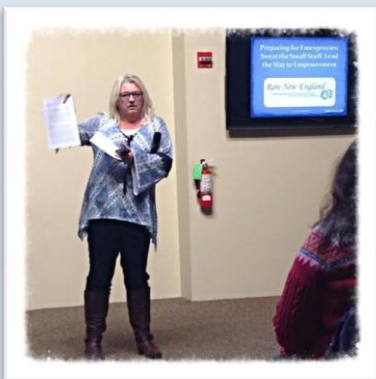
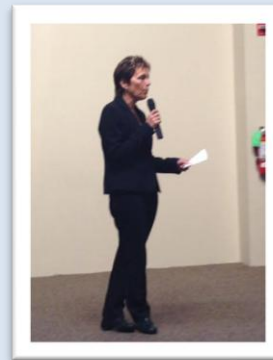
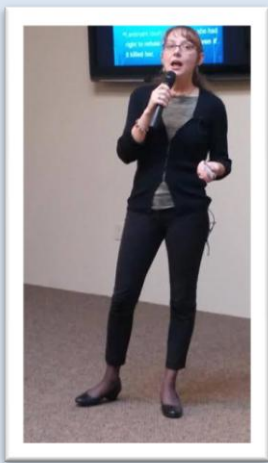
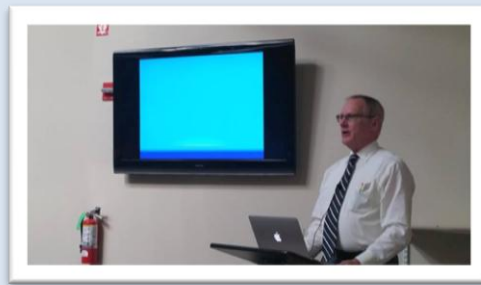


“Staying Safe in a Medically Complex World- Improving Communication between Patients, Families, and Medical Teams”

According to the NIH, almost 30 million American adults and children live with a rare disease. Yet, our country's healthcare system is not well-designed to support the complex, long-term care needs that rare disease patients require. Patients and caretakers dealing with rare diseases face many challenges in managing medical care, with one of the most often reported concerns centering on the difficulties of communicating effectively with care providers.

Patients and families must rely on care teams to order and organize needed medical care, but conflicts and communication problems with providers can jeopardize many aspects of a patient's well-being. Communication problems involving rare diseases can delay treatments and lead to incorrect diagnoses, as well as result in accusations of "doctor shopping", fabricating medical problems, medical child abuse and drug seeking, and may lead to being dropped from care by doctors, being denied care in Emergency Rooms or in the hospital, denial of needed medications, refusal of other doctors to consult with a patient's expert specialists, and more.

RNE held a 2-day conference in November 2016 to share insight.



**RNE received product support and/or
program sponsorship from the following**

Donors in 2016:

Whole Foods

Shaws

Costco

Confectionary Creations

Dunkin Donuts

Acton Pharmacy

Shire Pharmaceuticals

KJC Law Firm

In 2016, total revenue for Rare New England was \$12,920 and expenses totaled to \$11,346.

