

Rare New England

Coordinating Resources for Patients and Families
With Rare and Complex Disorders



2020 Annual Report

508-699-4035

www.rarenewengland.org

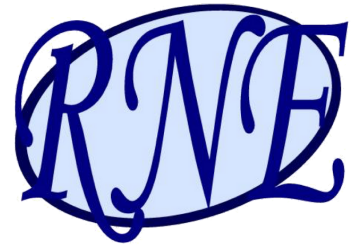
info@rarenewengland.org

Executive Summary

Rare New England is pleased to present our 2020 Annual Report. Like everyone, the COVID-19 pandemic forced RNE to adapt in 2020. We took our programs virtual and continued to serve the rare disease community without missing a beat. We added new members to our Board of Directors and are looking toward building capacity through staff and volunteers. This report contains Rare New England's accomplishments throughout the year, future goals, financial information, testimonials, and photos.

Rare New England was previously known as Mito New England, which was founded in 2013 to allow patients and families to find connections and emotional support among those with similar complicated medical problems. Rare New England (RNE) was established in 2016 by a group of medical professionals after recognizing the unmet needs of those affected by rare disorders. Our non-profit strongly believes in empowering patients with information relevant to their medical issues and enabling improved quality of life. RNE provides educational opportunities with group presentations by physicians, bioethicists and other professions involved in the treatment of rare diseases. RNE collaborates with stakeholders about the many aspects of rare disease treatment and support that need improvement. RNE provides phone, e-mail, and in-person support, both one-on-one and in a group setting. Rare New England relies on the effort and support of its Board of Directors, volunteers, and donors.

Our Mission



RNE'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.

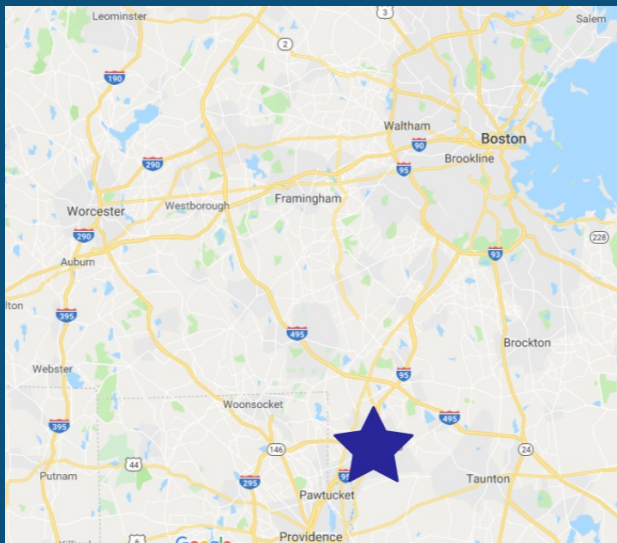
RNE offers patient and family support, highlights our region's medical and community resources, connects patients to appropriate national support and advocacy groups, and creates educational opportunities for New England patients and providers to advance care and quality of life for rare disorder patients and their families.

RNE strives to increase awareness that patients with rare and complex disorders live, work, attend school, and participate in communities across New England. Individually, we may be "rare," but together we are a vibrant, strong community with much to offer!

RNE provides education about issues affecting rare and complex patients and their families to the medical community, the education system, regional legislators, workplaces, and others. We address topics such as complex care coordination, ADA and IEP accommodations, medical insurance problems, and more.

About Us

Rare New England strives to meet the needs of the rare disease community in the New England area, including Maine, New Hampshire, Vermont, Massachusetts, Rhode Island and Connecticut.



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Rare New England, Inc
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Visit our website to learn more about
who we are and what we do!
www.rarenewengland.org

Connect with us on Social Media!



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RNE Board of Directors



Julie Gortze, RN
Director



Mark Korson, MD
Director



Lois Foster, LICSW
Secretary



Sophia Zilber
Director



Janet Silva
Treasurer



Lisa Deck
Director



Kristin Archibald
Director



**Faye Weiner-Jackson,
Esq.**
Director



Kevin W Freiert, MBA
Director

Acknowledgements



RNE is grateful for the insight, support, and efforts of the following RNE Committee Members and Volunteers; our accomplishments shine through their selfless efforts for the rare disease cause.

RNE Committee Members

Tasia Rechisky
Michael Middlebrook
Kathleen Swenson

RNE Volunteer Team

Emma Li
Melissa Hoyt
Rachael Friend

Medical Advisory Board

Lisa Louise Brailey, MD DABMGG
Richard Barnum, MD



Program Overview

Legislative Efforts

In 2020 we received the thrilling news that Senate Bill 2984 passed in the state of Massachusetts! The second amendment to the healthcare bill with created a Rare Disease Advisory Council to advise the Governor, the Legislature, and DPH on rare diseases. The council allows for representation and advocacy of those affected by rare diseases by the state. Rare New England worked tirelessly with MA State Representatives Hannah Kane and Joseph McKenna to pass this legislation and we are excited to see it come to fruition.



"Improving Health Care Experience in the Rare Disease Community"

2020 Annual Conference

The conference speakers included healthcare professionals, patients, and advocates from around the New England area. In addition to various speakers, there was a break-out session which allowed attendees to meet and network with the Fatty Oxidation Disorders (FOD) Family Support Group. We're excited to announce that our 2021 conference will continue to be hosted virtually.



Every year Rare New England hosts an annual conference surrounding topics and issues related to the rare disease community. Unfortunately, COVID-19 prevented us from meeting in person this year; however, thanks to the efforts of our team, the conference successfully transitioned to a virtual interactive platform for the year 2020!



Participating in Research: What you Need to Know (A Rare Disease Perspective)

David A. Weinstein, M.D., M.M.Sc.
VP, Clinical Development, Passage Bio
Adjunct Professor, University of Connecticut Health Center

Your Visit to a Genetics Center *How You Can Prepare*

Edward M. Kloza, MS, CGC
New England Regional Genetics Network

Rare New England
October 24, 2020



2020 Conference topics and Speakers

- Genetic Testing: Practical Consideration and Ethical Issues - Michele Spencer-Manzon, MD
- Caregiver Burden and Quality of Life of Caregivers in the Rare Disease Community - Julie Bolduc Deflippo, MSW, LCSW
- Participating in Research: What you Need to Know (A Rare Disease Perspective) - David A. Weinstein, M.D., M.M.Sc.
- Legal Advocacy - Annette M. Hines
- Legislative Advocacy - Lisa Deck
- Your Visit to a Genetics Center: How You Can Prepare - Edward M. Kloza, MS, CGC
- Genetics Education Materials for School Success (GEMSS): School Can Be a Great Experience for Everyone! - Karen Volle
- Advocacy at Any Age - Taylor Kane



The World of Rare Disease

Rare New England has continued to produce its monthly show, The World of Rare Disease (TWORD). The show offers information, education and resources to all stakeholders living and working in the rare disease community. While the show was previously conducted in person, it has seamlessly transitioned to an online interview modality because of COVID-19. Hosted by RNE Board Member and patient advocate, Lisa Deck, the show brings in a variety of experts to discuss a wide range of subjects relating to rare disease and complex healthcare issues. 2020 episodes have focused on patient registries, genetic counseling, The Rare Fair, Our Odyssey, and patient stories.



Rare Disease Day Speaker Series

During the month of Rare Disease Day, RNE arranges for rare disease patients and family members to speak to medical audiences at major teaching hospitals and schools 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's presentation is preceded by a brief clinical overview of the disease by a Mark Korson, MD to ensure that the audience has a medical foundation about the condition.



Locations & Topics:

- Brandeis University Genetic Counseling - Very Long Chain Acyl CoA Dehydrogenase Deficiency
- Yale-New Haven Medical Center - X-linked Adenoleukodystrophy
- MGH Institute of Health Professions Genetic Counseling Program - Fabry Disease
- Tufts University School of Medicine - Moyamoya Disease
- Dartmouth-Hitchcock Medical Center - Urea Cycle Disorder
- University of Vermont Medical Center - Acute Intermittent Porphyria
- Boston University School of Medicine Genetic Counseling Program - Barth Syndrome
- Bay Path University Genetic Counseling Program -
- University of New England College of Osteopathic Medicine - Glucose Transporter Type 1 Deficiency

2020 Accomplishments

Despite challenges, 2020 was a successful year for Rare New England as we continued to carry out our mission to bring together New England patients, families, and providers touched by rare disorders: offering educational opportunities, creating resources, and building foundations for support to improve patient care. One of our major challenges proved to be the transitioning much of our work to a virtual platform, which we did successfully.

These accomplishments include:

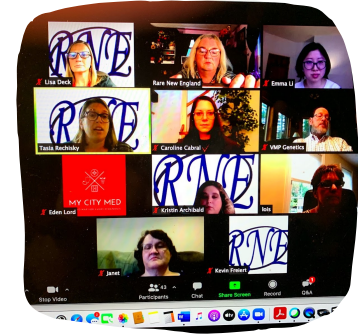
- Contributing to the passing of the Rare Disease Bill in Massachusetts
- Expanding our staff by hiring Caroline Cabral as Operational Assistant
- Transitioning our Rare Disease Day Soeaker Series to a virtual format and adding additional speaking venues
- Successfully holding our programs such as the 2020 Conference, Career Fair in Medical Genetics, The World of Rare Disease, and all of our staff learned to work virtually
- Creating a Diversity Committee as we continue to work towards healthcare equity
- Building and maintaining a website full of information and resources
- Working with many industry organizations and other non-profits collaboratively



Testimonials



"Your conference was the best of virtual conferences that I have attended. There were no connection issues, and the virtual rooms were enjoyable. I have no additional suggestions. It was great" - David Weinstein, M.D., M.M.Sc. VP of Clinical Development



"I was very impressed by Tasia's courage to share her very personal experience of living with metabolic disease. Despite the challenges this illness brings to every day life, Tasia seems to be doing very well and living a full life. I am very encouraged by that. I am certain that seeing her and others like her gives other individuals with metabolic disease the hope and encouragement they need." - Esther Orr, Brandeis University Genetic Counseling student on Rare Disease Day Speaker Series



"My time at RNE has been as fulfilling as it has been educational. I'm improving on my communication skills, while also gaining the irreplaceable experience of hearing the impact of rare diseases on patients and their families. I'm thankful for the opportunity to be surrounded by people with such passion for advocacy." - Clare Morris, RNE Intern

"We look forward to this continued partnership with TWORD and Rare New England. Seeing Tasia on the show reminded me of how connected we all are in the rare disease community and what a "small world" it really is." - Phil Toran (TWORD guest)

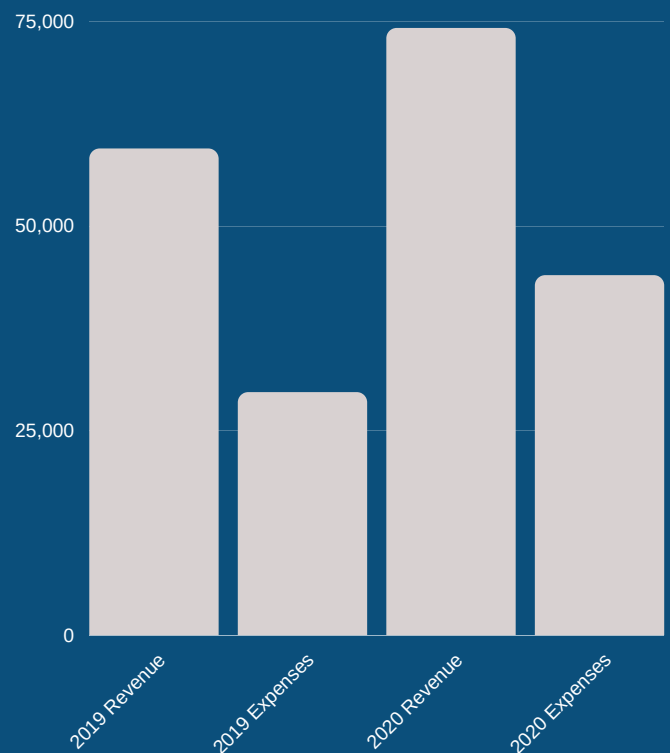
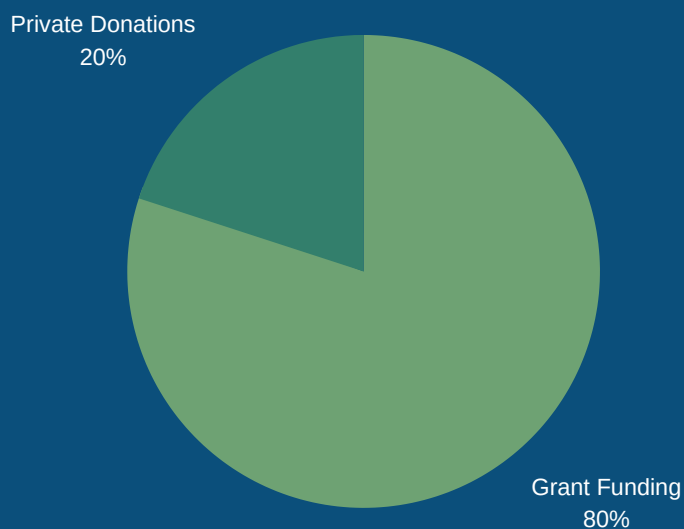
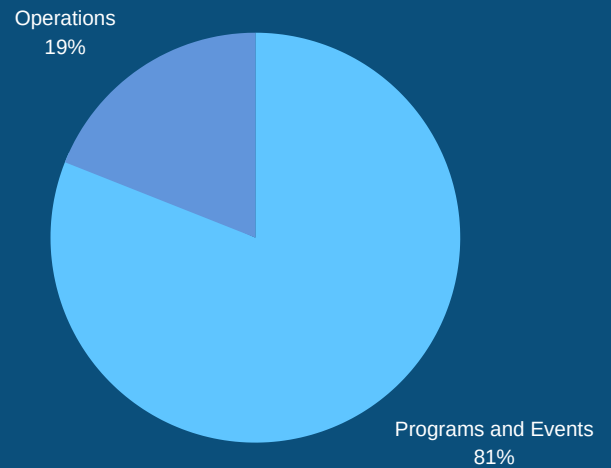
Goals for 2021

- We will engage with our partners to best assist patients and families affected by rare diseases.
- We will expand our internal structure, clients, and our membership to reflect a more diverse representation of the rare disease community, and provide a safe and inclusive environment.
- We will utilize and enhance virtual programming and any 2021 initiatives to bring the most benefit to the rare disease community through ensuring options for educational events, support opportunities, and more.
- We will improve the efficacy and efficiency of our programming by securing proper funding to grow our staff team, upgrading equipment to improve task performance, and engaging specialized services such as informational technology, graphic designing, and grant writing.
- We will confirm a three-year strategic plan detailing routes for growth of RNE structure.



Financials

Rare New England's revenue for 2020 was \$74,151. Revenue came from grants, private donations, and other sources. 80% percent of revenue came from grant funding, 20% percent came from private donations and other sources. Expenses for 2020 totaled \$43,946.



Thank You

Despite the challenges of 2020, Rare New England still had a successful year which could not have been possible without everyone who has supported us.



RNE appreciates the collaborations with other organizations, medical facilities, and businesses who have all had a part in our success as a patient organization. We sincerely appreciate the continued support, whether through financial contributions, shared insights, feedback and suggestions, time spent on our projects, or assisting in our mission for the rare disease community.

Rare New England would also like to sincerely thank everyone for their contributions!



Call to Action

1. Unite

Rare New England brings together patients, families and providers within one community. According to the National Institutes of Health, there are more than 7,000 rare diseases. The rare and complex community consists of 300 million patients worldwide. While 72% of rare diseases are genetic and 70% of rare diseases are identified in childhood, the commonality of experiences bonds us and together. We are stronger as a group than individually.

2. Educate & Advocate

Rare New England's aim is to educate and advocate for the rare and complex community. On average, it takes eight years for an individual to receive a proper diagnosis. By sharing information with the community, we bring overall awareness to rare and complex conditions and also credibility to those who are skeptical about whether the conditions are legitimate. With this information, we are able to advocate for the rare and complex community both locally and within the state & federal legislature.

3. Support

Support within and from the rare and complex community leads to diagnosis, treatments and cures for rare diseases.. You can help us by joining us as a Board member or volunteer, through collaboration efforts, supporting us via sponsorship or making a contribution.

Conclusion

Rare New England's efforts in awareness and support for rare disease stakeholders has continued to grow exponentially. We have continued our main programming, abiding by our mission to educate, provide information, highlight resources, and create support opportunities for all in the rare disease space. We have expanded our programming reach through increased stakeholder membership and medical institution additions. We have broadened our board to offer different perspectives and strengthen a foundation that supports our mission; we have added staff to assist with our workload, all growth meant to increase capacity and opportunities to increase the potential for improving lives in the rare disease community.

Rare New England has recognized the issue of racial and ethnic injustices that lead to healthcare disparities in the rare disease community and has created a committee to address this issue and make efforts toward acceptance and inclusion for all.

Rare New England acknowledges the importance of collaboration and has made great strides in building relationships with organizations, legislators, medical staff, industry and more, in order to continue a dialog around issues of rare diseases and their effects on patients and families. We will continue utilizing this strategy as we move forward and grow stronger relationships that will benefit patients and families living with rare diseases.

Awareness is key. It's time for the world to understand the impact of rare diseases and we all must use our voices to spread the word. We are very thankful to all of those who are working to better the lives of those affected by rare diseases and wish us all strength and better opportunities as we move forward.

