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# *Rare New England*

Coordinating Resources for Patients and Families  
With Rare and Complex Disorders



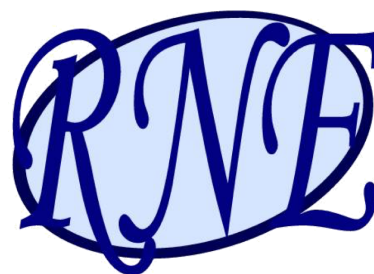
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# 2019 ANNUAL REPORT

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# EXECUTIVE SUMMARY



Rare New England is pleased to present our 2019 Annual Report. 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 through educational opportunities, enabling improved quality of life. RNE provides educational opportunities with group presentations by physicians, bio-ethicists and other professions familiar with the Rare Disease Community. RNE collaborates with many stakeholders in the 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 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.

This report contains Rare New England's accomplishments throughout the year, future goals, financial information, testimonials, and photos

# 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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Visit our website to learn more about who we are and what we do.

[www.rarenewengland.org](http://www.rarenewengland.org)

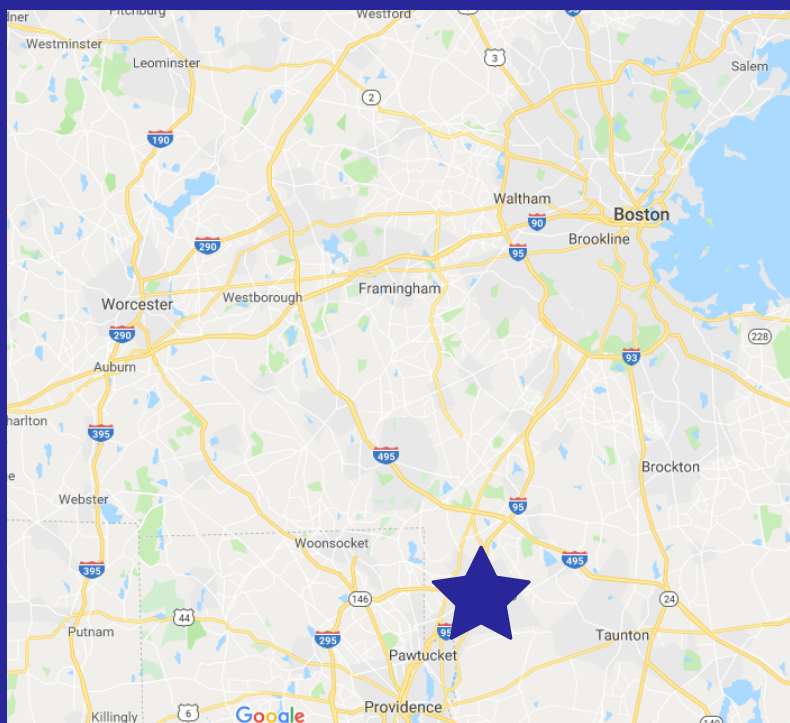
Find us on social media!

Facebook:

[www.facebook.com/www.rarenewengland.org](https://www.facebook.com/www.rarenewengland.org)

Twitter: @RareNewEngland

Instagram: @rarenewengland



# RNE BOARD OF DIRECTORS



*Julie Gortze, RN  
President*



*Mark Korson, MD  
Director*



*Lois Foster, LICSW  
Secretary*



*John C. Campbell, BS  
Director*



*Janet Silva, MSF  
Treasurer*



*Allison Wood  
Director*

# RNE TEAM

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

## **RNE Committee Members**

Debra McEleney

Lisa Deck

Rita Mauss

## **RNE Volunteers**

Heather Ruggiero

Joanna Mechlinski

Melissa Hoyt

## **Medical Advisory Board**

Amel Karaa, MD

Richard Barnum, MD

Pradeep Chopra, MD

Jessica Shriver, MA, MS



# ACCOMPLISHMENTS

2019 was a successful year for Rare New England. We continued to carry out our mission to bring together New England patients, families, and providers touched by rare and complex disorders: offering educational opportunities, creating awareness of available resources, and building foundations for support to improve patient quality of life. RNE was able to help hundreds of patients and families this year.

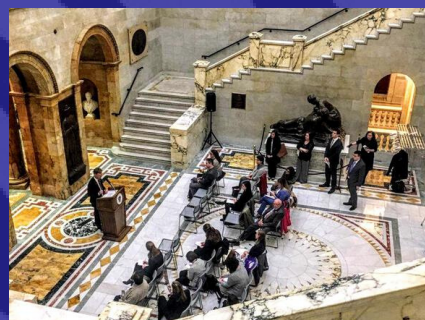
These accomplishments include:

- Hosted our annual Rare Disease Conference in Portland, ME
- Began Career Fairs in Medical Genetics
- Continued the annual Rare Disease Day Speaker Series
- Supported rare disease legislative efforts
- Organized an Advocacy Day for H.1934
- Added episodes to our World of Rare Disease series on Mansfield Cable TV
- Offered support to many patients and families through emails, phone calls, and in-person meetings
- Built and maintained a website full of information and resources

# PROGRAM OVERVIEW

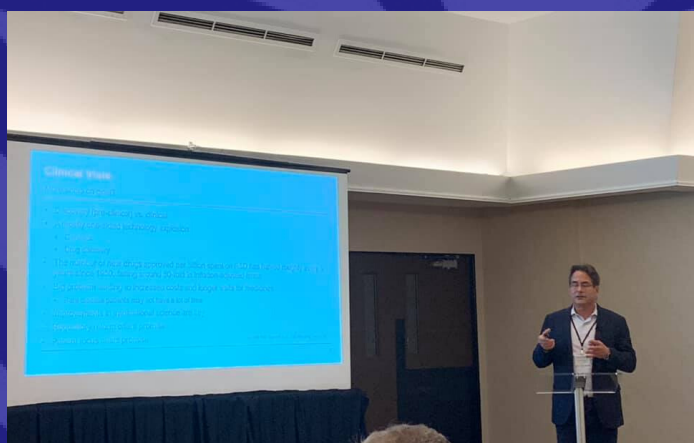
## Legislative Efforts

- Worked with MA State Representatives Hannah Kane and Joseph McKenna to sponsor H.1934 "An Act to Create a Rare Disease Advisory Council" in Massachusetts
  - The bill focuses on the rare disease community and allows members to share their challenges and receive the support they deserve
- Hosted an Advocacy Day to promote the bill and attended a hearing to support the legislation



## "Improving Health Care Experiences in the Rare Disease Community"

RNE hosts an annual conference every year and this year we hosted our event in Maine. We had a variety of speakers from healthcare professionals to advocacy groups and rare disease patients who spoke on many issues facing the rare disease community. Topics included legislative tips, telegenetics, advocacy, clinical trials for rare diseases, direct to consumer genetic testing, and many more!





## "The World of Rare Disease"

RNE has continued working with Mansfield Cable Access to produce a show about rare and complex diseases. The program offers information, education, and highlights resources available to those living and working in the rare disease community. Recent episodes have focused on the caregiver perspective, the role of patients as teachers, the proposed Rare Disease Council bill in Massachusetts, Huntington Disease, and Barth Syndrome.



## Rare Disease Day Speaker Series

Each year, the last day of February is Rare Disease Day. During the "Rare Disease Day season" (January-March), RNE arranges for rare disease patients and family members to speak to medical audiences at major teaching hospitals and medical schools around New England. The presentation topics included: the diagnostic journey, living with the disease, coping strategies, and challenges in the healthcare and educational systems. At each event, the patient presentation was preceded by a brief clinical overview of the disease by Mark Korson, MD or Amel Karaa, MD to ensure that the audience had a medical foundation on the condition.

Such learning opportunities provide the medical community a chance to see patients with disorders they might not otherwise see. They also make it more likely that they will recognize such patients in the future.



# Locations

January 15th - Brandeis University Genetic Counseling Program - Waltham, MA - Acute Intermittent Porphyrria

February 4th - Tufts Medical School - Boston, MA - Fabry Disease

February 12th - Yale - New Haven Hospital - New Haven, CT - Pompe Disease

February 19th - University of New England - Biddeford, ME - "A Walk Through the Metabolism Clinic"

February 22nd - Rhode Island Hospital - Providence, RI - Acute Intermittent Porphyrria

February 25th - Dartmouth-Hitchcock Medical Center - Lebanon, NH - Very Long Chain Acyl CoA Dehydrogenase Deficiency

February 27th - Boston University Genetic Counseling Program - Boston, MA - Barth Syndrome

February 27th - University of Vermont Medical Center - Burlington, VT - Barth Syndrome

April 24th - Bay Path University Genetic Counseling Program - Longmeadow, MA - TANGO II Metabolic Encephalopathy



RARE DISEASE DAY SPEAKER SERIES, 2019	
Jan 15	Brandeis University GC Program (MA)
Feb 4	Tufts Medical School (MA)
Feb 12	Yale-New Haven Med Ctr (CT)
Feb 19	UNE College of Osteopathic Medicine (ME)
Feb 22	Rhode Island Hospital (RI)
Feb 25	Dartmouth-Hitchcock Med Ctr (NH)
Feb 27	University of VT Med Ctr (VT)
Feb 27	Boston University GC Program (MA)
Mar 4	Bay Path University GC Program (MA)



## Career Fairs in Medical Genetics

RNE hosted two Career Fairs in the Boston area at Massachusetts General Hospital and Boston Medical Center. Genetics impacts every aspect of medicine, however there is a workforce shortage of geneticists in the US. RNE decided to address this situation by developing these talks about genetics for medical students as a way to promote genetic medicine as a possible career choice.

Participants heard from a Clinical Geneticist, a Biochemical Geneticist, and a Research/Laboratory Geneticist about their professions and a Q & A session followed. We also informed the students about opportunities available in the genetics field and gave them the time to ask questions.



# GOALS FOR 2020

As Rare New England continues to grow, we plan to continue to carry out our mission and help even more people. We have established goals for the upcoming 2020 year.

- Increasing the number of Rare Disease Day Speaker Series sites
- Increasing the attendees of our Medical Genetics Career Fairs
- Cataloging and promoting "The World of Rare Disease"
- Collaborating with other organizations

With the continued support of our incredible volunteers, hardworking board members, and new aid from additional donors; Rare New England hopes to provide more help for families afflicted with rare diseases as well as continuing to raise awareness for research on these diseases.

If there are individuals and families who struggle with a rare disease, RNE will help them and promote their well-being.

## TESTIMONIALS

2019 Conference: "Opportunities, such as this one, provide my family with current, relevant information about my child's rare medical condition, current treatment approaches and resources, as well as learning about the current medical climate for rare disease patients, which often times is unpredictable. This collection of valuable information offered at this conference is not available in any other forum"

- Rare Disease Caregiver

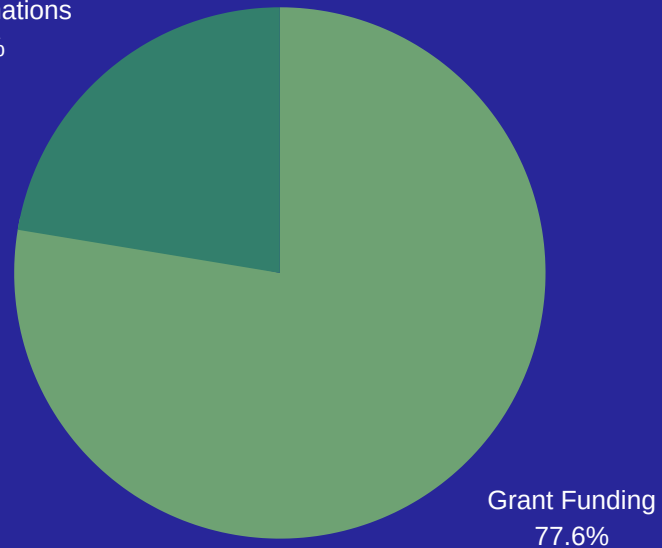
2019 Career Fairs: "In school, we are not taught about the different career paths in genetics and how to go about them. I feel that today, hearing geneticists speak and hearing their passion, I feel like I'm taking that passion with me and moving forward"

- Minseo Jeong

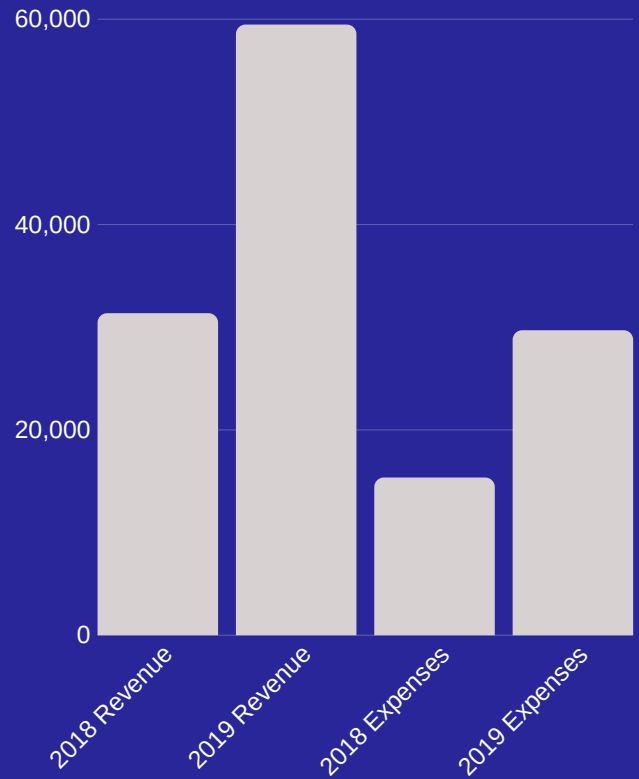
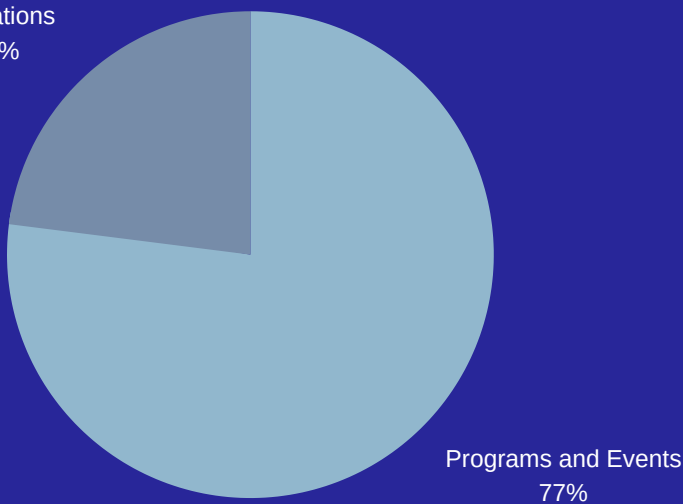
# FINANCIALS

Rare New England's revenue for 2019 was \$59,425. Revenue came from grants, private donations, and other sources. 77.6% percent of revenue came from grant funding, 22.4% percent came from private donations and other sources. Expenses for 2019 totaled \$29,654. 77% percent of funds were spent on programs and events, and 23% percent of funds were spent on operations. In 2018, total revenue for Rare New England was \$31,314 and expenses totaled to \$15,310. Revenue increased by \$28,111 and expenses increased by \$14,344

Private Donations  
22.4%



Operations  
23%



# THANK YOU

The successful 2019 year, could not have been possible without everyone who has contributed to our success in assisting patients and families, whether through financial contributions, shared insights, feedback and suggestions, time spent on our projects, or for providing us support for our work in the rare disease community.

RNE appreciates the collaborations with other organizations, medical facilities, and businesses who have all had a part in our success as a patient organization. Each one has shown remarkable understanding and passion for the rare disease cause and RNE has learned a great deal more by working with them.

Rare New England would also like to sincerely thank our donors!



Acton Pharmacy



# CALL FOR ACTION

## **Help Create Awareness!**

Rare diseases impact 350 million people worldwide and 15 million in the New England area are affected by rare disease.

## **Advocate For The Rare Disease Community!**

Many rare disease patients will wait years to receive a correct diagnosis, receiving multiple incorrect diagnoses and visiting many different specialists in the meantime. Many rare disease patients suffer with reduced quality 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 more.

## **Talk To Your Legislators!**

To have a lasting impact on rare diseases and the people that it affects, we need to act.





# CONCLUSION

As a nonprofit, we are proud to report our growth and success during 2019. Rare New England will continue to grow and develop over the years in the hopes of combating the increasing need for assistance with rare conditions. Despite the long road ahead of us, there was still progress and many milestones were met. Rare New England was able to reach these milestones because of the support that we received, and we are eager to grow and develop as our support increases. We welcome the new year and look forward to continuing to carry out our mission of bringing together New England patients, families and providers touched by rare and complex disorders.

*Rally for Rare,*

*The Rare New England Team*



# Rare New England

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With Rare and Complex Disorders

