

RARE NEW ENGLAND

ANNUAL REPORT

RNE



RARE NEW ENGLAND

2022

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PRESIDENT REPORT LETTER FROM THE PRESIDENT

Rare New England is pleased to present our 2022 annual report, detailing another successful year of serving the rare disease community. Through our third year in the COVID-19 pandemic we continued to fulfill our mission by offering our programs virtually to decrease risk of further illness and complications within the rare disease community. We are proud to have transitioned our programs well in the virtual space and all events were accepted in high regard by all who participated. Rare New England welcomed the addition of its first Executive Director who was hired part time to oversee daily operations. After six years, this was considered a huge accomplishment and an anticipated increase to the capacity of the organization's needs. RNE also updated our logo to help highlight our efforts in growth and diversity, as well as built a more streamlined website to enable viewers to more easily navigate through the many resources we offer.

Rare New England was previously known as Mito New England, which was founded in 2013 by Julie Gortze to allow patients and families to find connections and emotional support among those with similar complicated medical problems. After recognizing the unmet needs of all of those affected by rare disorders, Rare New England (RNE) was established in 2016 by a small group of medical professionals, researchers, patients and caregivers. Our non-profit strongly believes in empowering patients with information relevant to their medical issues and enabling improved quality of life. RNE also grasps the importance of medical providers having access to information about rare diseases and their impact on patients and their families in order to provide the best care possible. 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 caregivers to improve the many aspects of rare disease treatment and support available. 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 to build a solid foundation and to carry out our mission, and we are very appreciative to each and every one who has contributed in time and funding to help us serve our rare disease community.

Julie Gortze, President/CEO/Founder RNE

MISSION

Our 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 and support the professional needs of healthcare providers.

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



ABOUT US

Office and mailing address:

Rare New England, Inc.
120 North Main Street, Suite 303
Attleboro, MA 02703

Connect with us!

Website: www.rarenewengland.org

Email: info@rarenewengland.org

Instagram: [@rarenewengland](https://www.instagram.com/rarenewengland)

Twitter: [@rarenewengland](https://twitter.com/rarenewengland)

Facebook: www.facebook.com/www.rarenewengland.org

YouTube: tinyurl.com/RareNewEngland

BOARD OF DIRECTORS

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Kristin Archibald

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Kathleen Berentsen-Swenson, MPH, MS
Lisa Brailey, MD, DABMGG
Robert Campbell

OUR PROGRAMS

Rare Disease Day Speaker Series

Medical Genetics Career Fairs

Annual Conference

Rare Connections

Rare Disease Data Mapping Project

The World of Rare Disease



Rare Disease Day Speaker Series



Jan 13	Fabry disease
Jan 26	X-linked adrenoleukodystrophy (xALD)
Feb 1	Phenylketonuria (PKU)
Feb 8	Homocystinuria
Feb 9	Huntington disease
Feb 17	Acute intermittent porphyria
Feb 23	Glut-1 defect
Feb 23	Very long chain acyl CoA dehydrogenase (VLCAD) deficiency
Mar 2	Wilson disease
Mar 12	Pompe disease
Mar 14	Glycogen storage disease (GSD) type Ia

During the weeks around Rare Disease Day, 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.

These sessions provide the medical community the chance to see patients with disorders they might not otherwise see. This opportunity also makes it more likely that they will recognize such patients in the future.

Career Fairs in Medical Genetics



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.

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.

Attendees of the Career Fairs will have an opportunity to hear from three different types of geneticists - a clinical (or general) geneticist, a biochemical (or metabolic) geneticist, and a research/laboratory/industry geneticist. Speakers typically describe “a day in the life of a geneticist.” They talk about interesting cases and share their passion for patient care and/or contributing to science and the development of new therapies.

RNE Annual Conference

VIRTUAL CONFERENCE
October 2022
"Learning from Each Other"

Date/Time	Panel Topic/Description	Speakers
October 6th 6-7pm EST	Challenges and Successes in Today's Healthcare System We will address challenges to the consistency in tertiary care centers and advice that can be given to patients to overcome the hospital quarantine and services that are available to assist patients in the hospital and communities	<ul style="list-style-type: none"> Mark Koran, M.D. Christa Pflanzlhubel, M.D. Michael Spencer Munson, M.D. Christine Von Raesfeld
October 13th 12-1pm EST	Grassroots Research Funding We will collaborate with top researchers in rare disease to Engender hope in agency using examples from the rare and ultra-rare community.	<ul style="list-style-type: none"> Karen Frenet, MBA Sarah Kurat Baderon Ruth Hoogen, MBA
October 20th 12-1pm EST	Rare Resources in New England PNIC and intentionally formed relationships with advocates will provide contacts and information about resources that are available in New England. These presentations will generate ideas for the audience for services they can look for, ask for, and receive.	<ul style="list-style-type: none"> Rachael Kuhn, LMSW Gracie Carolea MacDonald, MBA Laura Kelly Chuck Bergman, J.D.
October 27th 12-1pm EST	Mental Health in the Rare Disease Community PNIC board members and mental health advocates will discuss mental health challenges and strategies for rare disease patients.	<ul style="list-style-type: none"> Tina Rebecky, MBA Emily Pears Kimberly Sauer, M.D. David Rizzo, M.D. Carol Barrett O'Loughlin

THANK YOU TO OUR SPONSORS! Please Register Here: [Register Here](#)

SPONSORS: HOMOLOGY, HORIZON, Stealth, GRAIL, ultragenyx

Our annual conference is designed for an audience of patients and caregivers, and create an atmosphere for them to meet and find sources of support as they share similar stories about living with a rare disease and obstacles they encounter.

Open to anyone who would like to obtain information to be utilized for their patient's care, we often attract genetic counselors, social workers, industry, patient organizations, legislators, and more.

Due to the covid pandemic, our 2022 conference was held virtually but highlighted several great topics and speakers through individual talks and panels.

The World of Rare Disease



RNE has invited guests who are known expert contributors in our rare disease community into to be interviewed and share their insight which is then made publicly available. Guests have enjoyed the opportunity to share their expertise and insight, while viewers have been thrilled to learn, interact and grow from our shows. This is truly an inclusively collaborative endeavor for the rare disease community.

RNE Data Mapping Project



Rare New England (RNE) wants to ensure information is available to drive the access to equitable healthcare and other services for people of all races, ethnicities, creeds, gender, and sexuality in the rare disease community.

There is no data on the prevalence of the variety of rare diseases across the region by location or community. Unfortunately, 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. These 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.

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 disease 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.

In late 2022, we completed a pilot survey as a “soft opening” to test for progress and kinks. We developed ideas for the dataset, protection of privacy, and utilization of the data. We settled on a very small dataset that collected zip code, diagnoses, and mutation if known. A survey was built and published in early November.

Rare Connections Support Groups



Rare diseases are individually rare but collectively common, affecting over 30 million Americans. Rare diseases can be difficult to diagnose, and patients may go years with unrelieved symptoms. In fact, due to a lack of available treatments, patients may never receive the relief they need to live a deserved quality of life. These families face challenges every day that the general public does not understand and finding adequate support is a major obstacle for patients and families living with rare diseases.

Recognizing this need, Rare New England launched a program, “Rare Connections”, to provide opportunities for adult patients and for 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. These hour-long sessions are moderated by a trained member of RNE who follows a guideline prepared specifically for this program.

MEETING FORMAT

There are two meetings held per month, one focused on bringing together caregivers and another focused on adult patients. On occasion there might be a guest speaker to share on an appropriate topic in consideration for the group.

2022 Program Accomplishments

Medical Genetics Career Fairs

4

Virtual Events

88

Pre-Med, Primary Care & Medical Students Registered

19

Universities & Medical Schools Reached

Rare Disease Day Speaker Series

11

Universities & Medical Schools Reached

11

Rare Diseases Highlighted

616

Student Participants

Annual Conference

4

Virtual Events

16

Rare Disease Medical Professional, Nonprofit, & Patient Speakers

230

Registrants

Rare Connections Patient & Caregiver Support Groups

12

Patient Meetings

12

Caregiver Meetings

50

Patient & Caregiver Participants

Rare Disease Data Mapping Pilot

215

Surveys Completed

YouTube Educational Channel The World of Rare Disease

40

Subscribers

137

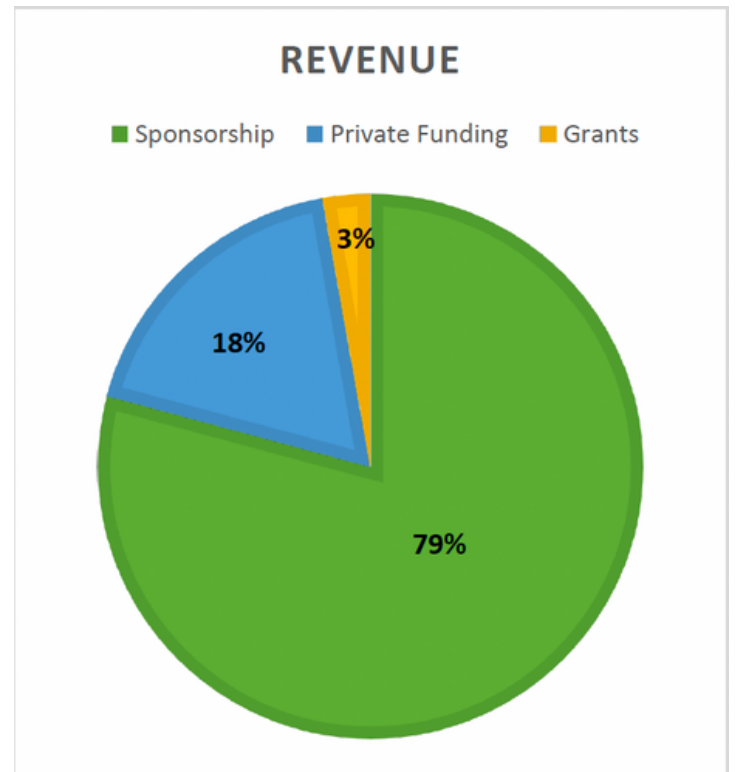
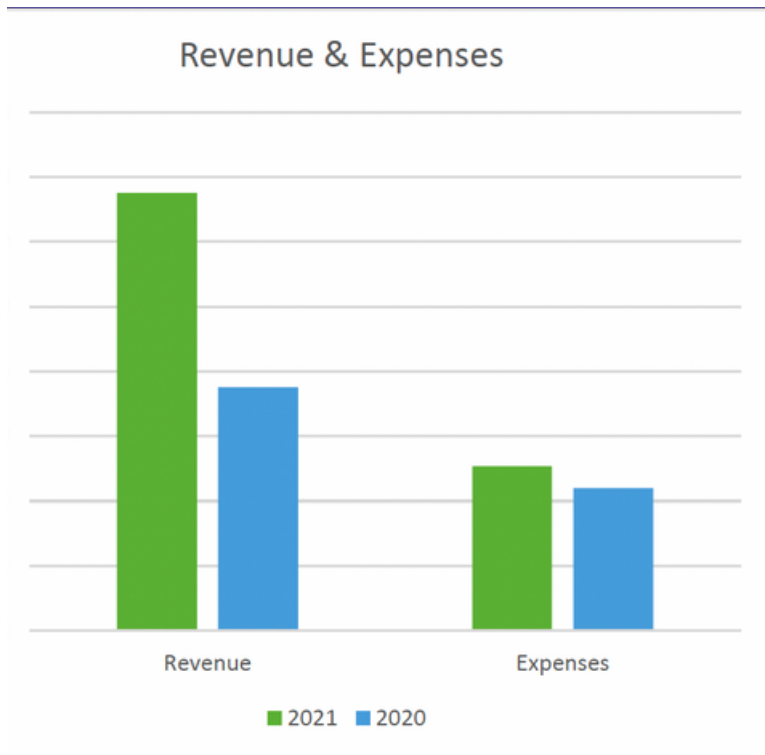
Videos

3,900+

Views

Financials

Rare New England's revenue for 2022 was \$109,303.69. Revenue came from sponsorships (79.38%), grants (2.59%), private donations, and other sources (18.03%). Expenses for 2022 totaled \$54,638.91. 63.32% percent of funds were spent on programs and events, and 36.38% percent of funds were spent on operations. In 2021, total revenue for Rare New England was \$135,057.43 and expenses totaled to \$50,768.81. Revenue increased by \$59,906.43 and expenses increased by \$6,822.81.



2022 Accomplishments

Rare New England has taken action to build capacity that allows the organization to continue to grow our impact and meet our mission. We hired our first Executive Director, part time to oversee daily operations. This increase in capacity has given Rare New England a chance to strengthen our outreach, increase awareness, and manage demand.

Brand recognition and building brand image was implemented as we updated our logo. Rebranding has made a positive impact on Rare New England's relationship with the rare disease community and has helped us increase connections with supporters. Rare New England has been able to increase visibility in both the local community and New England states as well as highlighting our efforts in diversity and inclusion.

In addition, the ability to develop and upgrade to a more streamlined website has made it easier for viewers to navigate throughout to learn more about our efforts, programming, resources, and to find ways of support. We are able to effectively communicate our mission clearly and professionally, as well as assisting the organization with communicating more effectively while reaching a wider audience.



HOME ABOUT BLOG PROGRAMS & EVENTS DONATE CONTACT



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for PROVIDERS & CLINICIANS

SEARCH

RARE NEW ENGLAND:

Serving the Rare Disease Community.



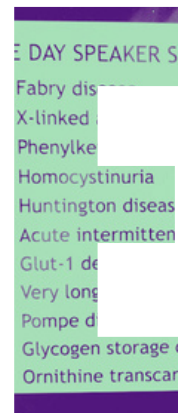
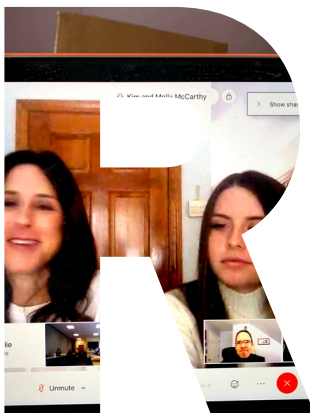
2023 Goals

As Rare New England continues to grow, we will carry out our mission and serve members of our community. We have established the following goals for the upcoming 2023 year.

- Increase capacity via adding additional skilled staff
- Continue RNE programming, increasing reach to patients, caregivers, medical providers, and the public
- Collecting and analyzing demographic information regarding the New England rare disease community
- Utilize opportunities to return to organizing and attending in person events

With the continued support of our incredible volunteers, hardworking board members, and support from additional donors, Rare New England will provide assistance to families afflicted with rare diseases while continuing to raise awareness about these conditions.

As long as there are individuals and families who struggle with rare conditions, RNE will strive to help them and promote their well-being!



To our speakers, donors, and volunteers:
RNE's successful year could not have been possible
without your help!

As well as the organizations, medical facilities, and
businesses who supported our mission,

Thank You



Thank you to the New England Regional
Genetics Network for supporting our
Rare Disease Day Speaker Series &
Medical Genetics Career Fairs

