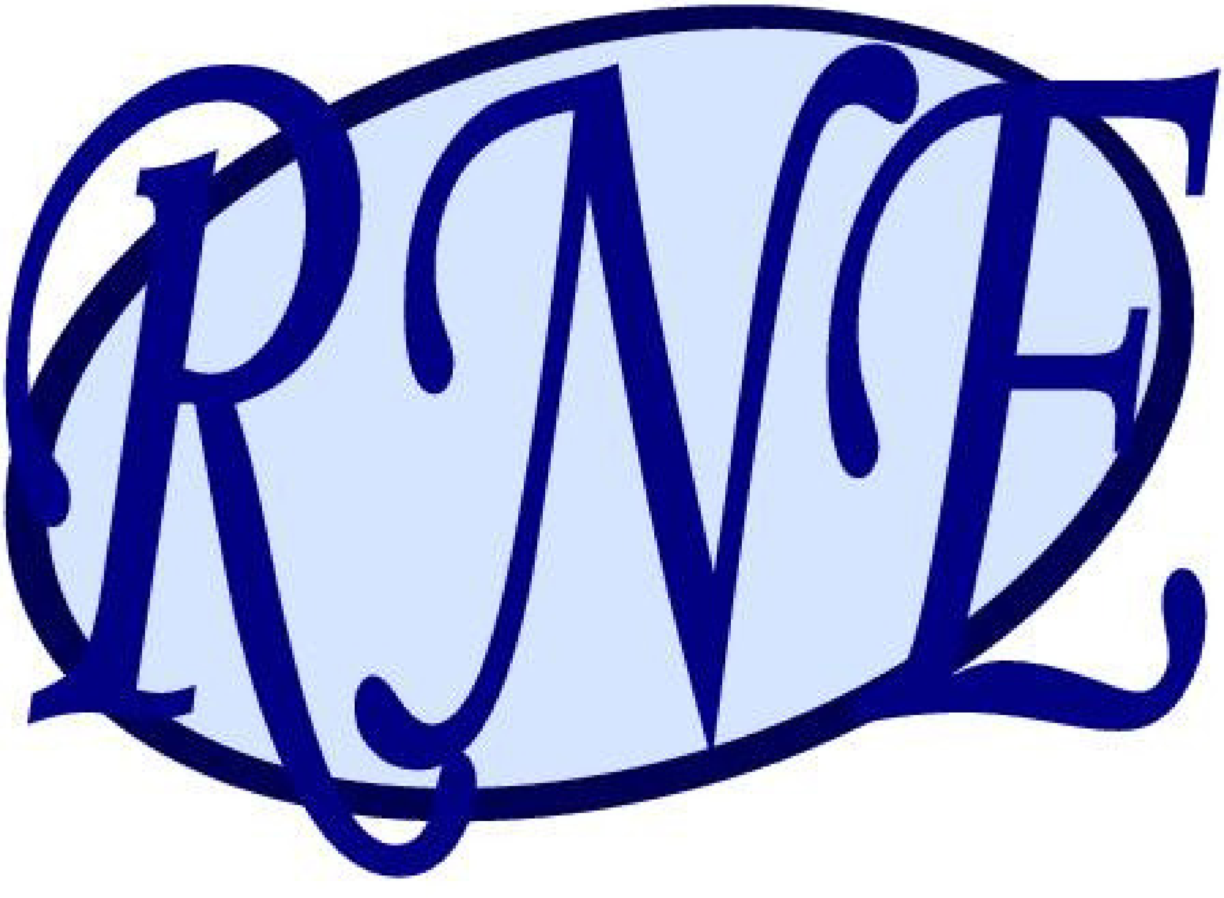
RARE NEW ENGLAND INC.

ANNUAL REPORT 2018



WWW.RARENEWENGLAND.ORG

EXECUTIVE SUMMARY

Rare New England is pleased to present our 2018 Annual Report. Rare New England was previously known as Mito New England, which was founded in 2013 to allow patients and families find connections and emotional support among those with similar complicated medical problems. Rare New England herein referred to as (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 advocates for patients and families and seeks to offer educational opportunities to patients, families and healthcare professionals regarding how to achieve and maintain quality of life for patients and families dealing with rare disease.

RNE's goal is to empower patients and families around their own individual care needs. 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.

Rare New England

Coordinating Resources for Patients and Families
With Rare and Complex Disorders

RNE

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 aims to bridge the gap between patients and families, clinics and clinicians, and the many resources available to them by existing government programs, advocacy organizations, patient groups, and state agencies, in the New England area.

ABOUT US

Rare New England, INC is based out of Attleboro, Massachusetts and strives to meet the needs of the whole New England area living and working with rare diseases including Maine, New Hampshire, Vermont, Massachusetts, Rhode Island and Connecticut.

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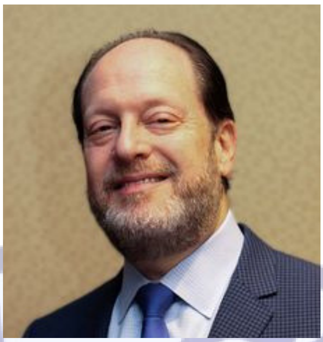
Visit our website to learn more about who we are and what we do.
www.rarenewengland.org

Find us on social media!
Facebook:
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

Amel Karaa, MD
Director

ACKNOWLEDGEMENTS

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

Medical Advisory Board
Jessica Shriver
Richard Barnum, MD
Pradeep Chopra, MD

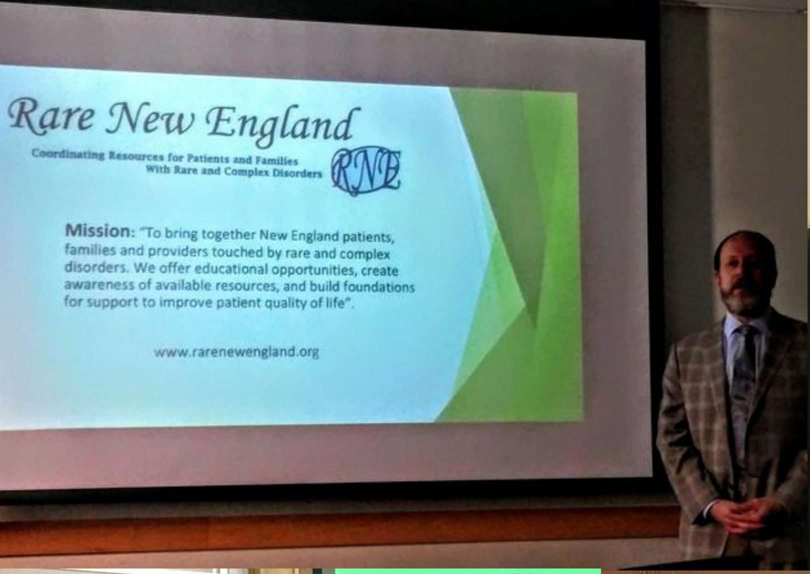
RNE Team Volunteers
Heather Ruggiero
Joanna Mechlinski
Melissa Hoyt

ACCOMPLISHMENTS

2018 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:

- Hosting our annual Rare Disease Conference in Massachusetts
- Starting the Rare Disease Speaker Series across schools and hospitals in New England
- Supporting rare disease legislative efforts in multiple states
- Hosting a comedy show fundraiser, featuring a silent auction
- Re-introducing Wine for a Cause
- Started our World of Rare Disease series on Mansfield Cable TV
- Presenting at various events and conferences, including the Rare Disease Day Seminar at Northeastern University
- Offering support to many patients and families through emails, phone calls, and in-person meetings
- Building and maintaining a website full of information and resources



Rare New England

Coordinating Resources for Patients and Families With Rare and Complex Disorders

RNE

Mission: "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".

www.rarenewengland.org

My Life with EPP

Jennifer Beck

PROGRAM OVERVIEW

Legislative Efforts

RNE supports bills and efforts to aid the rare disease community in having a voice in the government. This past year we have worked with MA State Representatives Paul Heroux, Hannah Kane, and Joseph McKenna to sponsor "An Act to Create a Rare Disease Advisory Council" in Massachusetts. This bill would put a focus on the rare disease community and allow members of our community to share their challenges and receive the support they deserve.

"Improving Health Care Experiences in the Rare Disease Community"

RNE puts on an annual conference every year and this year we hosted our event in Massachusetts. 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, clinical trials for rare diseases, medical nutrition therapy, and many more!

"The World of Rare Disease"

RNE has begun working with Mansfield Cable Access to produce a show series about rare and complex diseases. The program offers information, education, and highlights resources available to those living and working in the rare disease community. Previous episodes have focused on what is Rare New England, mental health concerns in rare disease patients, how pharmaceuticals impact the rare disease community, and sharing about Team IMPACT, a resource for kids with a chronic condition.

Rare Disease Day Speaker Series

During the week of Rare Disease Day, RNE arranged for rare disease patients and family members to speak to medical audiences at major teaching hospitals and 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 to ensure that the audience had a medical foundation on the condition.

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

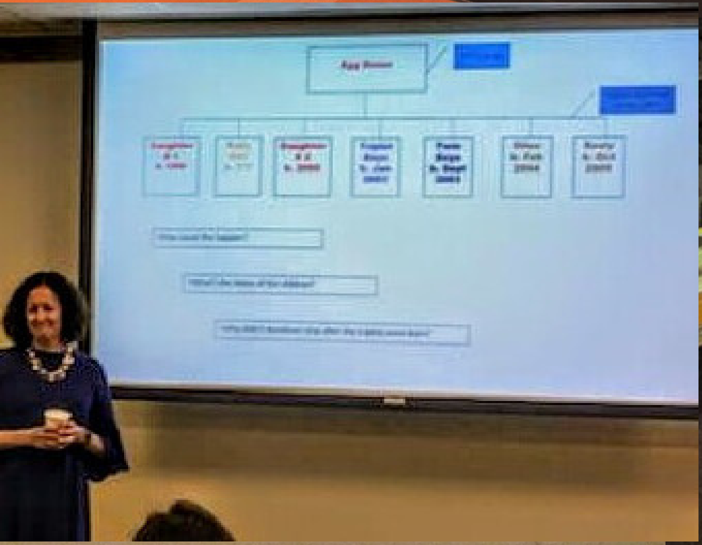
We hosted these talks at Dartmouth-Hitchcock Medical Center, Yale-New Haven Medical Center, University of Vermont Medical Center, Brandeis University Genetic Counseling Program, Boston University Genetic Counseling Program, and Newton-Wellesley Hospital.

Why should you care?

Global Scale…
- Influence legislators
- Impact major change
- Powerful results

Personal Scale…
- Empower advocates
- Available to everyone
- Platform for to tell your story
- Hands on learning
- Building connections

White House Cardiovascular Summit



GOALS FOR 2019

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 2019 year. These goals include expanding the Rare Disease Day Speaker Series, hosting an informational conference in a New England State, and starting Medical Genetics Career Fairs to expand interest in becoming a Geneticist.

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.

Rare New England desires to continue to grow and improve how it provides resources for those within the area. If any individuals and their families continue to struggle against rare diseases, we will continue to help them get through their struggles. If this problem persists, we hope that Rare New England will not only persist along with it, but continue to grow.

TESTIMONIALS

"I thoroughly enjoyed the presentation by Dr. Korson and the porphyria patient. She told a compelling story about her diagnostic odyssey and living after the diagnosis. This was a worthy prelude to Rare Disease Day." - Lisa Louise Brailey, MD, Technical Director, Clinical Geneticist

"You may see yourself as 'small,' but your gifts and reach are HUGE!" - Mary Castro Summers, Patient and Family Resource Specialist, Franciscan Children's Hospital

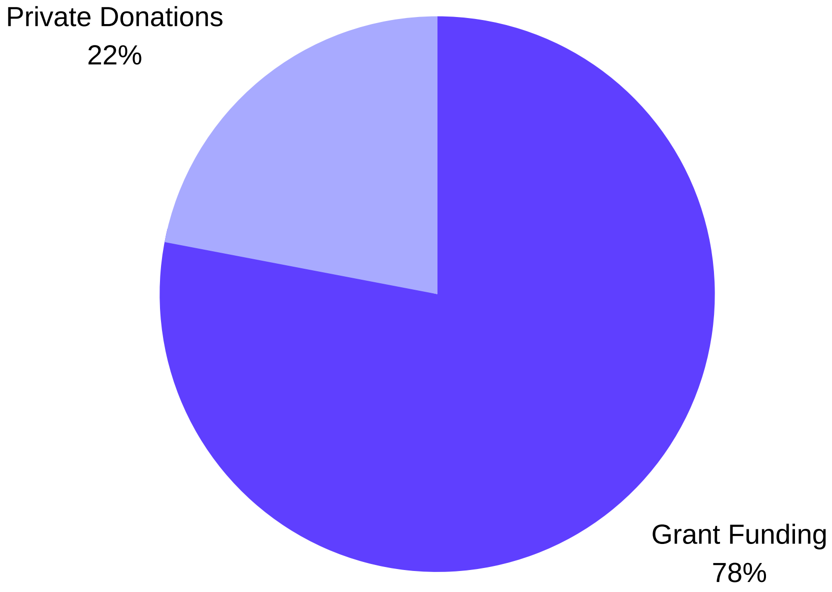
"Another great informative program! Another great conference!" - Anonymous

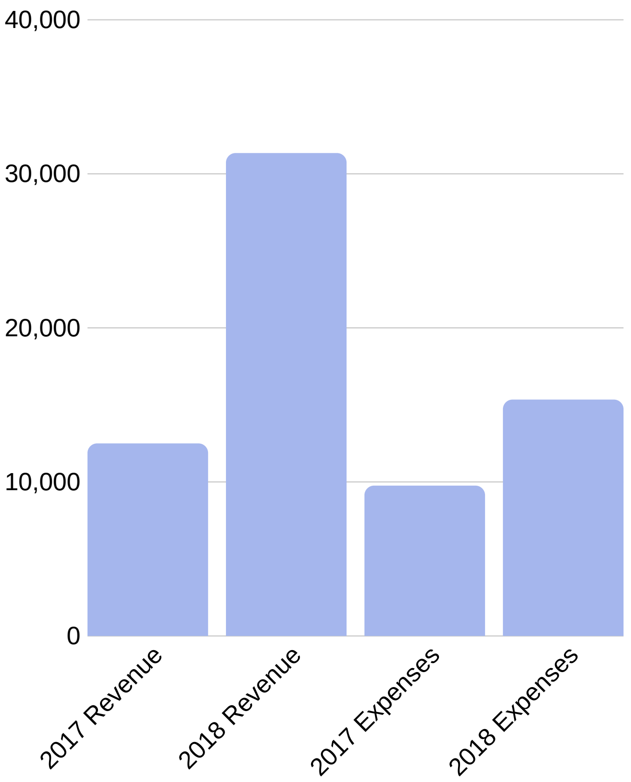
"Hearing from people who are directly affected by genetic disease, of the day-in and day-out situations they face, the hurdles they’ve overcome or how they’ve gone about managing symptoms gives us an important perspective that makes us more effective healthcare professionals. We are truly grateful to Rare New England for such an opportunity." - Kathleen Berentsen Swenson, MS, MPH, CGC, Director, Master's Program in Genetic Counseling Boston University School of Medicine

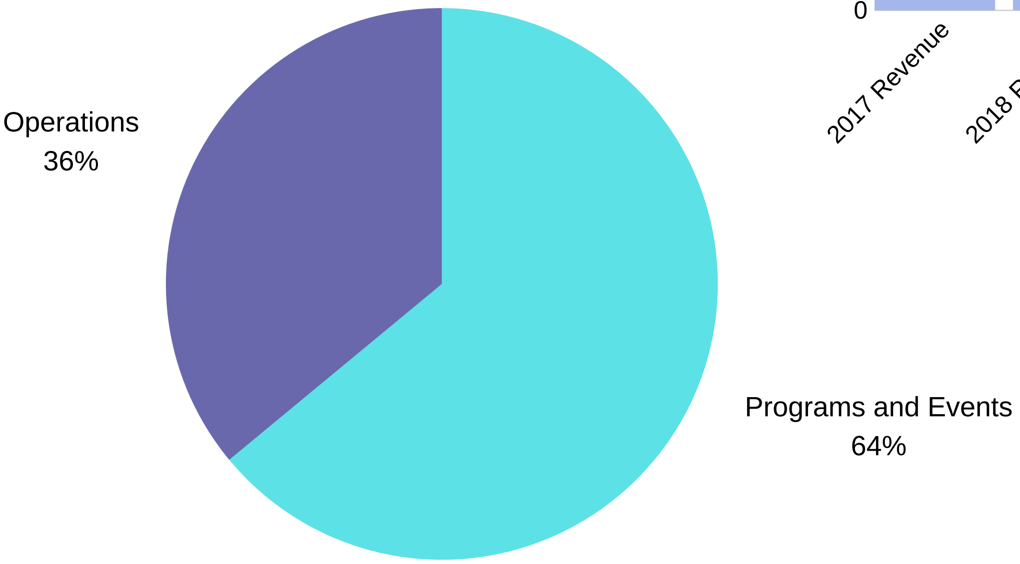
"Thank you again for inviting us to join your conference as a resource for your patients and their families! We have already received flight requests from a few of the people I met over the weekend. We truly appreciated the opportunity to be part of your panel." - Amy Camerlin, Hospital and Physician Outreach, Angel Flight NE

FINANCIALS

Rare New England's revenue for 2018 was $31,314. Revenue came from grants, private donations, and other sources. 78 percent of revenue came from grant funding, 22 percent came from private donations and other sources. Expenses for 2018 totaled $15,310. 64 percent of funds were spent on programs and events, and 36 percent of funds were spent on operations. In 2017, total revenue for Rare New England was $12,464 and expenses totaled to $9,724. Revenue increased by $18,850 and expenses increased by $5,586.







THANK YOUS

The successful 2018 year, could not have been possible without the support and dedication of the Board of Directors as well as the Rare New England Committee Members and Volunteers. Rare New England would like to thank everyone who has contributed to our success in assisting patients and families one-by-one, 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 new 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 - Cambrooke Therapeutics, Sanofi Genzyme, Recordati Rare Diseases, Stealth Biotherapeutics, Acton Pharmacy, Walmart, Backpack Health, Shire, Invitae and City Spirits, as well as all our individual donors who have made our services possible.

CAMBROOKE THERAPEUTICS

Stealth BIOTHERAPEUTICS

DINNO HEALTH Acton Pharmacy

CITY SPIRITS LIQUORS

RECORDATI RARE DISEASES GROUP Focused on the Few™

Shire

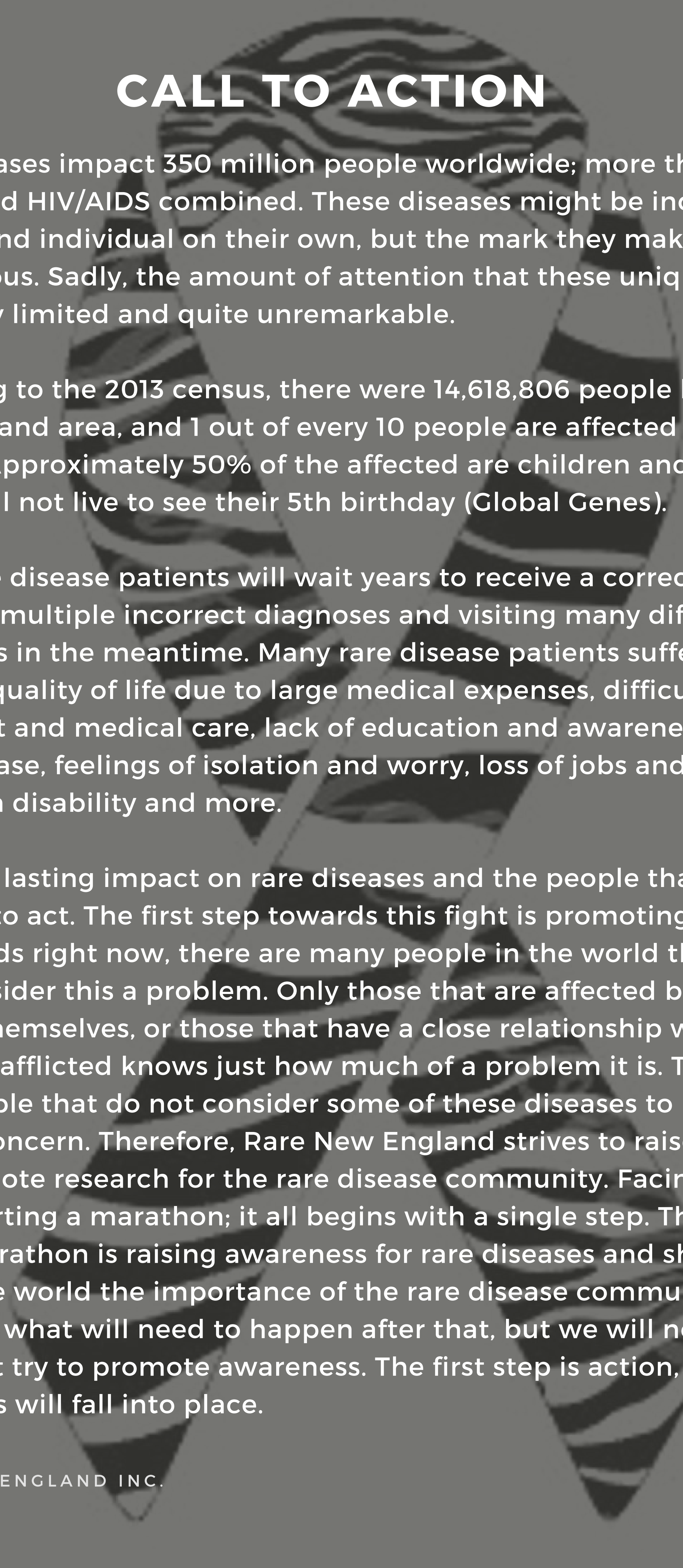
BACKPACK HEALTH

Walmart

INVITAE

SANOFI GENZYME

CALL TO ACTION



Rare diseases impact 350 million people worldwide; more than both cancer and HIV/AIDS combined. These diseases might be incredibly specific and individual on their own, but the mark they make on society is enormous. Sadly, the amount of attention that these unique diseases get is very limited and quite unremarkable.

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

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.

To have a lasting impact on rare diseases and the people that it affects, we need to act. The first step towards this fight is promoting awareness. As it stands right now, there are many people in the world that do not even consider this a problem. Only those that are affected by rare disease themselves, or those that have a close relationship with someone afflicted knows just how much of a problem it is. There are even people that do not consider some of these diseases to be real, let alone a concern. Therefore, Rare New England strives to raise awareness and promote research for the rare disease community. Facing a problem is like starting a marathon; it all begins with a single step. The first step in our marathon is raising awareness for rare diseases and showing the rest of the world the importance of the rare disease community. We do not know what will need to happen after that, but we will never know if we do not try to promote awareness. The first step is action, after that the pieces will fall into place.

CONCLUSION

As a nonprofit, we are proud to report our growth and success during 2018. 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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