NEUROMUSCULAR DISEASE FOUNDATION

JOIN THE GLOBAL EFFORT TO CURE NEUROMUSCULAR DISEASES

Annual Report & Impact Statement

Review of the 2019 Calendar Year

2020

Dear supporters,

In 2018 we set lofty goals for the next two years of our organization. In 2019, not only did we meet – but we exceeded – our financial goals. With your help, in a short 16 months, we matched our almost-unheard-of $2.5M challenge grant. These funds will allow us to sponsor all of the studies for FDA approvals that are required to take the next steps toward gene therapy.

For an orphan disease, we are fortunate to be working directly with the world's best experts from Yale University to Nationwide Children's Hospital, Hadassah, and many others, including international government agencies. For example, the NIH is in the process of enrolling patients in its final phase of clinical trials for ManNAc, a potential treatment to slow the progression of GNEM. In short, NDF's funding and leadership have fostered data-sharing and collaborations in unprecedented ways that are expediting progress.

NDF's Advocacy, Education and Awareness Programs have also made tremendous global impact. Without these programs, it would be impossible to promote proper and timely diagnosis, or build our database of patients, all of which are critical to support the science necessary to end the scourge of this disease. Through our symposia in Philadelphia and Tel Aviv, and other gatherings in places such as Mumbai, New York, and Ivory Coast, NDF was able to coordinate the expertise of internationally renowned scientists, industry professionals, patients and family members alike, in a common mission to educate and advocate for our patient community. Simultaneously, the events benefited our scientific efforts with the collection of blood, saliva and tissue samples for our whole genomic sequencing initiatives, as well as our growing biobank. By growing our database of patients around the world, we build our attractiveness to biotech companies that could take on GNEM as their next project.

None of this remarkable progress would be possible without the support of you, our donors. On behalf of our board of directors, scientific advisors, staff, and our patients and their family members, I wish to thank each and every one of you for your generous donations and for honoring the pledges that you made in 2018 and 2019. I look forward to keeping you updated on our continued progress throughout 2020.

Sincerely,

Lalé J. Welsh
CEO, Neuromuscular Disease Foundation

About GNE Myopathy

Our mission is to enhance the quality of the lives of people living with GNE Myopathy (also known as HIBM)[1] through advocacy, education, outreach, and funding for critical research focused on treatments and a cure.

GNE Myopathy—or HIBM—is a distal myopathy: a rare genetic disease starting at the feet, causing muscles to slowly weaken. GNE Myopathy is not life-threatening, but it may lead to physical debilitation within two decades of diagnosis. Symptoms usually begin to develop in early adulthood, between late teens to early 30's. GNE Myopathy exists in all races and nationalities, worldwide; however, ongoing natural history studies[2] show elevated carrier rates in certain populations of Eastern European and Asian heritage; including but not limited to Jewish, Persian, Uzbeki, Arab, East Indian, Indonesian and Japanese.

> “NDF is my security that someone is doing something good for the GNEM community.
>
> It makes me feel that there is a large, connected community trying to find a cure for me. I can sleep better knowing that NDF is fighting for my health.
>
> - **Maya**
> GNEM Patient and NDF Certified
> Patient Advocate, Israel

NDF has documented GNE Myopathy patients & scientists around the world

> The Neuromuscular Disease Foundation was created at a time when there was very little research available — I would not have the faith that I have today without their pioneering efforts.
>
> \- **Michelle**
> GNEM Patient, 2019 Gala Chair
> 2019 Philanthropy Award Recipient

35 COUNTRIES & TERRITORIES

Bangladesh
Brazil
Bulgaria
Canada
China
Côte d’Ivoire
Egypt
England
France

Germany
Guyana
India
Iran
Ireland
Israel
Italy
Japan
Malaysia

Nepal
The Netherlands
Northern Ireland
Pakistan
Palestinian Territories
Philippines
Portugal
Russia
Saudi Arabia

Scotland
South Korea
Suriname
Taiwan
Turkey
United Arab Emirates
United States
Zambia

NDF Awards

Scientific Advancement Award issued to:

Leadiant Biosciences & National Institutes of Health

NDF Board Co-Chair Ralph Loren and NDF Board and Scientific Advisory Committee member Dr. Tahseen Mozzafar present NDF's 2019 Scientific Advancement Award to Dr. Nuria Carrillo and Michael Minarich on behalf of NIH and Leadiant Biosciences.

Philanthropy Award issued to:

Michelle & Bob Etebar

2018 NDF Philanthropy Award winner, David Dahl, presents 2019 Philanthropy Award to Michelle & Bob Etebar.

Allstar Awards issued to:

Amy Curran, Maya Davidovich-Cohen, Kelly Ma, Mona Patel, and Tara Voogel

NDF Allstar Awards are presented to Certified Patient Advocates Maya Davidovich-Cohen (Israel), Kelly Ma (China & Taiwan), Tara Voogel (U.S.), Amy Curran (U.S. not pictured) and Mona Patel (U.K. not pictured) by NDF Board Co-Chair Tricia Mullins and C.O.O. Nancy Lurie.

2019 Achievements

Clinical Research

Funded Hadassah Medical Center with a 2-year grant for creation of animal models. Their successful zebra fish model—as a direct result of this funding— is the first reliable animal model developed that can be used in clinical testing and can ascertain the efficacy of the approach. Dr. Mitrani-Rosenbaum's lab is also developing a mouse model due in 2020.

Funding of Lek Lab at Yale University biomarker and CRISPR studies. The results obtained from the Lek Lab will allow us to determine the feasibility of using this approach in clinical trials.

Funded Dr. Kelly Crowe at Mount St. Joseph/ Nationwide Children's Hospital's project using sialylation-sensitive lectins to identify biomarkers of the disease which can then be used to assess the therapeutic potential of therapies such as gene therapy. This important study may also help get valid outcome measures for future clinical trials.

Completed 1st phase of Whole Genomic Sequencing in 40 samples tested at PerkinElmer and Yale, with some additional assistance from the NIH. This helps identify any modifiers and allows the medical community to better understand the reasons that patients show such diversity in the progressions of the disease.

Provided gift funds to NIH for critical human resources support for their GNEM studies. This supports late stage clinical trials for ManNAc to develop outcome measures to be used for FDA approval for ManNAc, as well as for any future treatments currently in development.

> “In all my years of working in the HIBM community, I have never before seen the kind of enthusiastic collaboration and scientific momentum that NDF has been able to inspire these past few years.
>
> - **Carmen Bertoni, PhD**
> Gene Therapy Scientist and
> Associate Professor, Dept. of Neurology, UCLA

We are grateful to our vast and impressive consortium of scientific minds with their expertise in GNEM for collaborating with NDF in various ways, not the least of which is the sharing of samples and data which will exponentially expedite our collective goals.

Dr. Stella Mitrani-Rosenbaum, Hadassah Medical Center; Yale University; Nationwide Children's Hospital; The NIH (NHGRI); Leadiant Biosciences; Dr. Ichizo Nishino, National Center of Neurology and Psychiatry, Japan; Dr. Perry Shieh, UCLA; and Dr. Tahseen Mozaffar, UCI who tirelessly assisted with sample collection; and to the members of our Scientific Advisory Committee and Scientific Proposal Review Team, who always go above and beyond in their attention to detail and commitment to good science and for volunteering to further our cause.

2019 Scientific Advisory Committee members: Dr. Zohar Argov, Dr. Carmen Bertoni, Dr. Wayne Grody, Dr. John Hakimi, Dr. Madhuri Hegde, Dr. Angela Lek, Dr. Monkol Lek, Dr. Tahseen Mozaffar, Dr. Laura Rufibach and Dr. Kathy Shenassa.

NDF Certified Patient Advocates

Abdullah Al-Shamrani	Saudi Arabia
Amy Curran*	USA
Maya Davidovich-Cohen	Israel
Imad Kazim	USA
Suleyman Kus	Turkey
Kelly Ma	Taiwan & China
Saskia Melches	Germany
Rose Okama	Italy & Côte d'Ivoire
Michela Onali	Italy
Valeria Pace	Italy
Mona Patel	UK
Guy Ratson	Israel
Ashutosh Verma	India
Tara Voogel*	USA

* Patient Advocacy Program Managers

Online Webinars

GNE Biobank Progress

with special guest,
Dr. Monkol Lek

NIH Update on Phase 2 of ManNAc

with special guest,
Dr. Nuria Carrillo

Coping with Disappointment & Grief

with special guest,
Dr. Gretchen Kubacky

Unaffected father of a GNEM patient volunteers to give samples at an NDF Symposium

Advocacy - NDF Events

Hosted & produced symposia in Philadelphia and Tel Aviv

Co-sponsored patient events in Israel, India, Côte d'Ivoire, Palo Alto, and New York

Sponsored multiple NDF Ambassadors awareness and friend-raising events

Created NDF All Star Awards contest

Facilitated monthly patient HUDDLES

Hosted quarterly Certified Patient Advocacy (CPA) meetings

Dr. Monkol Lek (Yale University) presents to attendees at an NDF Symposium

NDF scientific team and staff visit the team at Hadassah Medical Center

Industry Conferences & Key Memberships

NDF as a Whole:

Media coverage in multiple cultural publications and websites

Member, Global Genes Rare Foundation Alliance

Member, Classy Collaborative

Member, Jewish Genetic Disease Consortium

Our CEO, Lalé Welsh:

Featured speaker at Patients Associations for Distal Myopathies Conference (Tokyo, Japan)

Featured speaker at WWGNE Conference (Mumbai, India)

Featured speaker at Global Genes Patient Summit (Irvine, CA)

Featured Speaker at Gene Therapy for Rare Disorders Conference (Boston, MA)

Our CEO & Scientific Advisory Committee:

Pitched Biotech Corporations, JP Morgan Conference (San Francisco, CA)

Published educational article on GNE Myopathy; Rare Neurological Disease Report

Our Chief Operating Officer, Nancy Lurie :

Attended and sponsored genetic screening event in Los Angeles

Collaborative efforts with GeneTestNow.com

Attended the EveryLife Foundation Community Congress, Washington DC.

Attended the Rare Disease Legislative Advocates Rare Voice Awards

NDF is grateful to have been awarded grants by:

Ultragenyx
for Advocacy

A private California-based foundation
for Clinical Research

Iranian American Jewish Federation - New York
for Clinical Research

Whittier Trust
for Clinical Research

Rotary Club of Beverly Hills
for Education

Confidence Foundation
for General Funds

Looking Above and Beyond, Inc.
for General Funds

Teach a Man to Fish Foundation
for General Funds

Guidestar
Platinum Seal of Transparency

2019 by the Numbers

NDF collaborates with scientists and patients from Japan and India

26%
growth in NDF patient registry

50 states
Now registered as a charitable organization across the US

522
attendees at our sold-out Gala

220
Symposia/Patient Day attendees

210
Ambassadors' Events attendees

38
scientific minds engaged with GNEM & NDF

18
core advisors

11
board members

3
employees

Financial Impact

$ 3,187,000
donated & pledged[3]

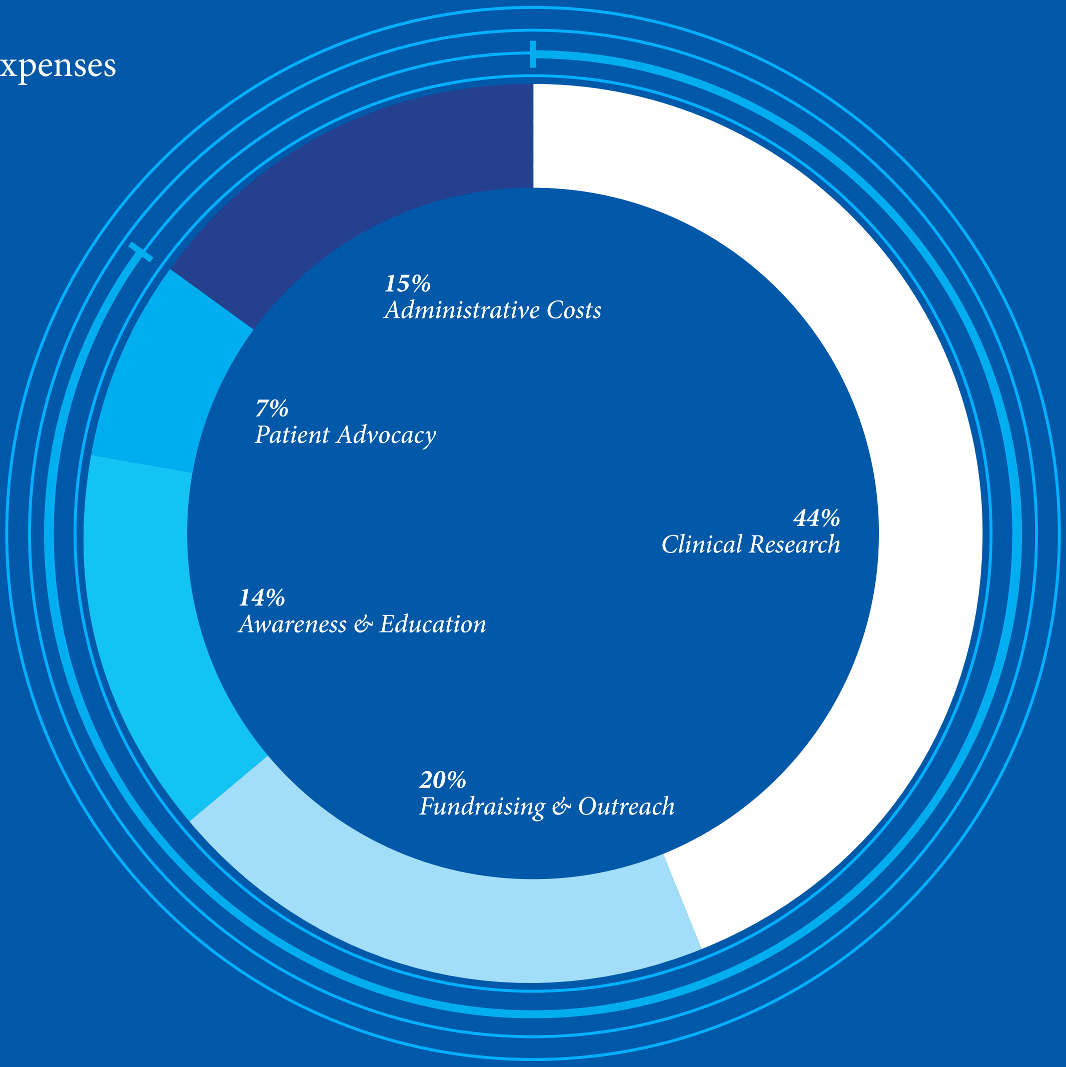
511
donors

$ 22,000
raised on social media

Income Sources

NDF is the world's largest GNEM-only patient advocacy organization. Our programs fund scientific research and provide comprehensive resources, support and advocacy to affected individuals and their families/caregivers. We provide outreach and education to scientists and physicians who collaborate, share data to facilitate proper diagnosis, and encourage timely genetic testing to prevent the passing down of the disorder to future generations.

Expenses



85%

*85 cents[4] of every dollar goes towards funding scientific research and core programs providing critical support to families living with GNE Myopathy.**

*vs. US based non profit organization average of 63%[5]

Giving

Thank you to all of our generous donors

$1,000,000 and up

Anonymous 501(c)(3) Private Foundation

Visionaries - $100,000 and up

Michelle & Bob Etebar
Iranian American Jewish Federation NY*
Anna & Bijan Rodd
Ramesh & Emanuel Yashari*

Benefactors - $50,000 to $99,999

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Witherbee Foundation
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Nioufar & Avi Yroshalmiane

> “Living with an ultra rare, progressively debilitating neuromuscular disease with no approved treatment or cure often feels scary, lonely and dark. The NDF is the one bright light that shines upon me, my family and the patient community at large, offering reassurance that we are not being forgotten and hope that our futures hold the promise of strength.
>
> **- Jennifer**
> GNEM patient and NDF founding family member

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* Pledged and honoring as agreed.

1 Officially called GNE Myopathy, commonly known as HIBM (Hereditary Inclusion Body Myopathy). Also known as: Nonaka Myopathy, DMRV (Distal Myopathy with Rimmed Vacuoles), QSM (Quadriceps Sparing Myopathy), HIBM2 (Hereditary Inclusion Body Myopathy Type 2), IBM2 (Inclusion Body Myopathy Type 2).

2 For more details see clinicaltrials.gov ID: NCT01784679 and NCT01417533.

3 Including 2019 income and pledges.

4 Based on publicly shared IRS compliant financial statements. Please visit guidestar.org or curehibm.org for more financial details.

5 According to Grey Matter Research & Consulting, Phoenix, AZ as reported in *The NonProfit Times*.

NEUROMUSCULAR
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cureHIBM.org

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