

**THE NEUROMUSCULAR DISEASE FOUNDATION**  
FINANCIAL STATEMENTS  
YEAR ENDED DECEMBER 31, 2019

**THE NEUROMUSCULAR DISEASE FOUNDATION**

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**DECEMBER 31, 2019**

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**INDEPENDENT AUDITOR'S REPORT**

November 24, 2020

Board of Directors  
The Neuromuscular Disease Foundation

We have audited the accompanying financial statements of The Neuromuscular Disease Foundation (a nonprofit organization), which comprise the statement of assets, liabilities, and net assets – modified cash basis as of December 31, 2019, and the related statements of support, revenue, and expenses – modified cash basis and functional expenses – modified cash basis for the year then ended, and the related notes to the financial statements,

**Management's Responsibility for the Financial Statements**

Management is responsible for the preparation and fair presentation of these financial statements in accordance with the modified cash basis of accounting as described in Note 2; this includes determining that the cash basis of accounting is an acceptable basis for the preparation of the financial statements in the circumstances. Management is also responsible for the design, implementation, and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

**Auditor's Responsibility**

Our responsibility is to express an opinion on these financial statements based on our audit. We conducted our audit in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. Accordingly, we express no such opinion. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

### **Opinion**

In our opinion, the financial statements referred to above present fairly, in all material respects, the assets, liabilities, and net assets of The Neuromuscular Disease Foundation as of December 31, 2019, and its support, revenue, and expenses for the year then ended in accordance with the modified cash basis of accounting as described in Note 2.

### **Basis of Accounting**

We draw attention to Note 2 of the financial statements, which describes the basis of accounting. The financial statements are prepared on the modified cash basis of accounting, which is a basis of accounting other than accounting principles generally accepted in the United States of America. Our opinion is not modified with respect to this matter.

*Beeson, Hoffman & Siddall, Inc.*

November 24, 2020

**THE NEUROMUSCULAR DISEASE FOUNDATION**  
STATEMENT OF ASSETS, LIABILITIES AND NET ASSETS - MODIFIED CASH BASIS  
DECEMBER 31, 2019

**ASSETS**

Cash	\$ 290,031
Investments, at Fair Value	<u>2,847,854</u>
<b>TOTAL ASSETS</b>	<b><u>\$ 3,137,885</u></b>

**LIABILITIES AND NET ASSETS**

**LIABILITIES**

Credit Cards and Payroll Liabilities	\$ 5,332
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**NET ASSETS**

Without Donor Restrictions	935,450
With Donor Restrictions	<u>2,197,103</u>
<i>Total Net Assets</i>	<u>3,132,553</u>

<b>TOTAL LIABILITIES AND NET ASSETS</b>	<b><u>\$ 3,137,885</u></b>
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- See Accompanying Notes -

**THE NEUROMUSCULAR DISEASE FOUNDATION**  
**STATEMENT OF SUPPORT, REVENUE AND EXPENSES - MODIFIED CASH BASIS**  
**YEAR ENDED DECEMBER 31, 2019**

	Without Donor Restrictions	With Donor Restrictions	Total
<b>SUPPORT AND REVENUE</b>			
Contributions - Annual Giving	\$ 162,106	\$ -	\$ 162,106
Gala	953,082	-	953,082
Grants	-	1,683,000	1,683,000
Interest and Dividend Income (reinvested)	23,459	-	23,459
Unrealized Gains	29,535	-	29,535
Net Assets Released from Restrictions	555,897	(555,897)	-
Total support and revenue	<u>1,724,079</u>	<u>1,127,103</u>	<u>2,851,182</u>
<b>EXPENSES</b>			
Program Services			
Awareness and Education	224,114	-	224,114
Clinical Research	629,368	-	629,368
Patient Advocacy	117,824	-	117,824
Outreach	4,234	-	4,234
Total Program Services	<u>975,540</u>	<u>-</u>	<u>975,540</u>
General and Administrative	139,032	-	139,032
Fundraising	301,085	-	301,085
Total Expenses	<u>1,415,657</u>	<u>-</u>	<u>1,415,657</u>
<b>CHANGE IN NET ASSETS</b>	308,422	1,127,103	1,435,525
Net Assets, Beginning of Year	<u>627,028</u>	<u>1,070,000</u>	<u>1,697,028</u>
<b>NET ASSETS, END OF YEAR</b>	<u>\$ 935,450</u>	<u>\$ 2,197,103</u>	<u>\$ 3,132,553</u>

- See Accompanying Notes -

**THE NEUROMUSCULAR DISEASE FOUNDATION**  
**STATEMENT OF FUNCTIONAL EXPENSES - MODIFIED CASH BASIS**  
**YEAR ENDED DECEMBER 31, 2019**

	Program Services						TOTAL
	Awareness and Education	Clinical Research	Patient Advocacy	Outreach	Total Program Services	General and Administrative	
	\$	\$	\$	\$	\$	\$	\$
Administrative	-	-	-	-	-	4,433	-
Bank and Merchant Fees	-	-	-	-	-	4,605	16,060
Board Meetings	-	-	-	-	-	3,521	-
Conference and Meetings	175	16,213	840	-	17,228	-	187
Entertainment	6	6	6	-	18	-	15,500
Events	43,548	-	1,353	150	45,051	-	-
Fundraising	5,424	-	-	157	5,581	-	1,285
Gifts	448	471	3,034	-	3,953	553	663
Grants / Contracts	-	431,499	-	95	431,594	32,235	28,150
Insurance	-	-	-	-	-	4,877	-
Marketing	-	-	302	1,848	2,150	20	2,560
Meals	9,948	13,158	9,290	-	32,396	312	5,597
Office Space	-	82	-	-	82	5,351	-
Office Supplies	773	-	94	341	1,208	653	-
Other Gala Expenses	-	-	-	-	-	-	34,168
Outreach and Education	49,584	-	-	-	49,584	-	-
Parking and Mileage	60	1,534	40	-	1,634	183	245
Party Decorations	-	-	-	-	-	-	6,026
Patient Day	-	273	273	-	546	-	-
Payroll and Other Taxes	2,706	2,706	2,706	-	8,118	180	2,706
Postage and Delivery	2,797	698	957	193	4,645	406	851
Printing and Copying	929	290	270	-	1,489	-	2,089
Professional Development	-	-	-	-	-	1,125	-
Professional Services	13,261	36,400	2,533	-	52,194	336	-
Salaries	60,000	60,000	60,000	-	180,000	70,000	70,000
Subscriptions and Membership	1,611	825	1,008	-	3,444	4,052	1,757
Symposium	10,471	3,844	14,646	-	28,961	-	-
Telephone and Internet	1,935	32	480	1,300	3,747	2,995	-
Travel	20,438	61,337	19,167	150	101,092	3,195	8,128
Venue	-	-	825	-	825	-	105,113
	<u>\$ 224,114</u>	<u>\$ 629,368</u>	<u>\$ 117,824</u>	<u>\$ 4,234</u>	<u>\$ 975,540</u>	<u>\$ 139,032</u>	<u>\$ 301,085</u>
							<u>\$ 1,415,657</u>

- See Accompanying Notes -

**THE NEUROMUSCULAR DISEASE FOUNDATION**  
**NOTES TO FINANCIAL STATEMENTS**  
**DECEMBER 31, 2019**

**1. Description of Organization**

**Organization**

The Neuromuscular Disease Foundation is the world's leading foundation in funding research that supports the search for a cure for GNE Myopathy (also known as HIBM). The mission of the Organization is to enhance the quality of the lives of people living with GNE Myopathy through advocacy, education, outreach and funding critical research focused on treatments and a cure.

**2. Significant Accounting Policies**

**Basis of Accounting**

The financial statements of the Organization have been prepared on the modified cash basis of accounting, which is a basis of accounting other than accounting principles generally accepted in the United States of America. Modifications to the cash basis of accounting include accruing for credit card liabilities and payroll taxes. Revenue is recorded when received rather than when earned and expenses are recorded when paid rather than when the obligation is incurred.

**Basis of Presentation**

The Organization reports information regarding its assets, liabilities and net assets and support, revenue and expenses according to two classes of net assets that are based upon the existence or absence of restrictions on use that are placed by its donors:

- net assets without donor restrictions
- net assets with donor restrictions.

Net assets with donor restrictions are resources that are subject to donor-imposed restrictions. Some restrictions are temporary in nature, such as those that are restricted by a donor for use for a particular purpose or in a particular future period. Other restrictions may be perpetual in nature; such as those that are restricted by a donor that the resources be maintained in perpetuity.

The Organization's unspent contributions are reported in net assets with donor contributions if the donor limited their use. When a donor's restriction is satisfied, either by using the resources in the manner specified by the donor or by the passage of time, the expiration of the restriction is reported in the financial statements by reclassifying the net assets from net assets with donor restrictions to net assets without donor restrictions.

**Donated Services**

No amounts have been reflected in the financial statements for donated services. The Organization generally pays for services requiring specific expertise.



**THE NEUROMUSCULAR DISEASE FOUNDATION**  
**NOTES TO FINANCIAL STATEMENTS**  
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**2. Significant Accounting Policies (continued)**

**Estimates**

Management uses estimates and assumptions in preparing financial statements. Those estimates and assumptions affect the reported amounts of assets and liabilities, the disclosure of contingent assets and liabilities, and the reported revenues and expenses. On an ongoing basis, management evaluates the estimates and assumptions based on new information. Management believes that the estimates and assumptions are reasonable in the circumstances; however, actual results could differ from those estimates.

**Functional Allocation of Expenses**

The costs of providing various programs and other activities have been summarized on a functional basis in the Statement of Support, Revenue and Expenses – Modified Cash Basis. The Statement of Functional Expenses – Modified Cash Basis presents the natural classification of expenses by function. Accordingly, certain costs have been allocated among the programs and supporting services benefited. The expenses that are allocated include symposium costs, program expenses, travel, and personnel costs, which are allocated on the basis of estimates of time and effort.

**Income Tax Status**

The Organization is exempt from income tax under the provisions of Section 501(c)(3) of the Internal Revenue Code and comparable state law. However, income from certain activities not directly related to the Organization's tax-exempt purpose is subject to taxation as unrelated business income. In addition, the Organization qualifies for the charitable contribution deduction under Section 170(b)(1)(A) and has been classified as an organization other than a private foundation under Section 509(a)(2). The Organization does not have any uncertain tax positions that are material to the financial statements.

**Investments**

The Organization invests cash in excess of its immediate needs in money market funds, which are reported as short-term investments in the Statement of Assets, Liabilities and Net Assets.

Investment income and gains restricted by donors are reported as increases in net assets without donor restrictions if the restrictions are met (either a stipulated time period ends, or a purpose restriction is accomplished) in the reporting period in which the income and gains are recognized.

**Revenue with and without Donor Restrictions**

Contributions received are recorded as increases in net assets without donor restrictions and net assets with donor restrictions, depending on the existence and/or nature of any donor restrictions. When a restriction expires, net assets with donor restrictions are reclassified to net assets without donor restrictions and reported in the Statement of Support, Revenue and Expenses – Modified Cash Basis, as net assets released from restrictions.

**THE NEUROMUSCULAR DISEASE FOUNDATION**  
**NOTES TO FINANCIAL STATEMENTS**  
**DECEMBER 31, 2019**

**2. Significant Accounting Policies (continued)**

**Concentration of Contribution Revenue**

For the year ended December 31, 2019, approximately 54% of the Organization's contribution revenue came from one donor.

**3. Fair Value Measurements**

The Organization's investments consist of government-backed money market funds and are valued at fair value, as measured by quoted prices in active markets for identical securities (Level 1 in the hierarchy of fair value measurements).

**4. Financial Instruments**

The Organization's excess cash may occasionally exceed the FDIC deposit insurance limit, and management has placed these funds in a high-quality institution in order to minimize the risk.

**5. Net Assets with Donor Restrictions**

Net assets of \$2,197,103 are restricted for the purpose of gene therapy advance studies.

**6. Operating Lease**

The Organization is subject to an operating lease for its primary office in Los Angeles, California. The lease term is for the calendar year 2020, with monthly rent of approximately \$500.

**7. Related Party Transactions**

Transactions with related parties include approximately \$27,000 in contributions received from board members, and approximately \$12,000 in expenses paid to board members.

**THE NEUROMUSCULAR DISEASE FOUNDATION**  
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**8. Liquidity**

The Organization regularly monitors liquidity required to meet its operating needs and other contractual commitments. The Organization's main source of liquidity at its disposal is cash.

For purposes of analyzing resources available to meet general expenditures over a 12-month period, the Organization considers all expenditures related to its ongoing activities of operating a nonprofit to be general expenditures. In addition to financial assets available to meet general expenditures over the next 12 months, the Organization operates within an annual budget and anticipates collecting sufficient contributions to cover general expenditures. Financial assets available to meet general expenditures over the next 12 months comprise the following:

Cash and investments	\$ 3,137,885
Donor-imposed restrictions	<u>(2,197,103)</u>
Financial assets available to meet cash needs for general expenditures within one year	<u>\$ 940,782</u>

**9. Subsequent Events**

Subsequent events were evaluated through November 24, 2020, which is the date the financial statements were available to be issued.

In late 2019, an outbreak of a novel strain of coronavirus (COVID-19) originated in China and has since spread across the world. On March 11, 2020, the World Health Organization characterized COVID-19 as a pandemic. In addition, the state of California, where the Organization is located, has declared a state of emergency. The effects of the outbreak and related actions by governments around the world to mitigate its spread have impacted the Organization's operations and donors.

In May 2020, the Organization received loan proceeds of \$26,250 under the Paycheck Protection Program ("PPP"). Under the terms of the PPP, certain amounts may be forgiven if they are used for qualifying expenses, such as payroll, health care benefits and utilities. The Organization has used the entire amount for qualifying expenses.

Management cannot reasonably estimate the length or severity of this pandemic, nor the full impact on the financial statements for the year ended December 31, 2020.