

**DYSTONIA MEDICAL RESEARCH FOUNDATION**

**FINANCIAL STATEMENTS**

**for the years ending December 31, 2020 and 2019**

# DYSTONIA MEDICAL RESEARCH FOUNDATION

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## INDEPENDENT AUDITORS' REPORT

The Board of Directors  
Dystonia Medical Research Foundation

### **Opinion**

We have audited the accompanying financial statements of the Dystonia Medical Research Foundation (a California not-for-profit corporation) (the "Foundation"), which comprise the statement of financial position as of December 31, 2020 and 2019, and the related statements of activities, functional expenses, and cash flows for the years then ended, and the related notes to the financial statements.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of the Foundation as of December 31, 2020 and 2019, and the changes in its net assets and its cash flows for the years then ended in accordance with accounting principles generally accepted in the United States of America.

### **Basis for Opinion**

We conducted our audit in accordance with auditing standards generally accepted in the United States of America. Our responsibilities under those standards are further described in the Auditor's Responsibilities for the Audit of the Financial Statements section of our report. We are required to be independent of the Foundation and to meet our other ethical responsibilities in accordance with the relevant ethical requirements relating to our audit. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

### **Responsibilities of Management for the Financial Statements**

Management is responsible for the preparation and fair presentation of the financial statements in accordance with accounting principles generally accepted in the United States of America, and 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.

In preparing the financial statements, management is required to evaluate whether there are conditions or events, considered in the aggregate, that raise substantial doubt about the Foundation's ability to continue as a going concern within one year after the date that the financial statements are available to be issued.

### **Auditor's Responsibilities for the Audit of the Financial Statements**

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not absolute assurance and therefore is not a guarantee that an audit conducted in accordance with generally accepted auditing standards will always detect a material misstatement when it exists. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control. Misstatements, including omissions, are considered material if there is a substantial likelihood that, individually or in the aggregate, they would influence the judgment made by a reasonable user based on the financial statements.

In performing an audit in accordance with generally accepted auditing standards, we:

- Exercise professional judgment and maintain professional skepticism throughout the audit.
- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, and design and perform audit procedures responsive to those risks. Such procedures include examining, on a test basis, evidence regarding the amounts and disclosures in the financial statements.
- Obtain an understanding of internal control relevant to the audit 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 Foundation's internal control. Accordingly, no such opinion is expressed.
- Evaluate the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluate the overall presentation of the financial statements.
- Conclude whether, in our judgment, there are conditions or events, considered in the aggregate, that raise substantial doubt about the Foundation's ability to continue as a going concern for a reasonable period of time.

We are required to communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit, significant audit findings, and certain internal control related matters that we identified during the audit.

*Barnes, Givens & Barnes, Ltd.*

Mount Prospect, Illinois  
February 20, 2021

**DYSTONIA MEDICAL RESEARCH FOUNDATION**

Statements of Financial Position

December 31, 2020 and 2019

	<u>2020</u>	<u>2019</u>
<b><u>ASSETS</u></b>		
Assets		
Cash and cash equivalents including segregated Dystonia Coalition cash of \$323,019 in 2020 and \$293,952 in 2019	\$ 701,885	\$ 638,027
Investments	5,252,235	4,544,096
Unconditional promises to give	33,481	124,680
Other current assets	72,614	29,184
Equipment and leasehold improvements, less \$29,605 in 2020 and \$26,918 in 2019, of accumulated depreciation	11,551	15,809
Total Assets	<u>\$ 6,071,766</u>	<u>\$ 5,351,796</u>
<b><u>LIABILITIES AND NET ASSETS</u></b>		
Liabilities		
Grants and fellowships payable	\$ 816,189	\$ 623,916
Accounts payable and accrued expenses	66,576	101,190
Deferred rent payable	108,925	111,538
Deferred revenue	91,500	73,700
Dystonia Coalition agency liability funds	323,019	293,952
Total Liabilities	<u>1,406,209</u>	<u>1,204,296</u>
Net Assets		
Without donor restrictions:		
Undesignated	1,384,156	1,058,132
Board designated for science	1,500,000	1,500,000
Total net assets without donor restrictions	<u>2,884,156</u>	<u>2,558,132</u>
With donor restrictions:		
Purpose restricted	1,781,401	1,589,368
Total net assets with donor restrictions	<u>1,781,401</u>	<u>1,589,368</u>
Total Net Assets	<u>4,665,557</u>	<u>4,147,500</u>
Total Liabilities and Net Assets	<u>\$ 6,071,766</u>	<u>\$ 5,351,796</u>

See Accompanying Notes to Financial Statements and  
Independent Auditors' Report

**DYSTONIA MEDICAL RESEARCH FOUNDATION**

Statements of Activities

For the Years Ended December 31, 2020 and 2019

	2020			2019		
	Without Donor Restrictions	With Donor Restrictions	Total	Without Donor Restrictions	With Donor Restrictions	Total
Revenue, Gains and Support						
Donations and grants	\$ 1,409,297	\$ 544,490	\$ 1,953,787	\$ 1,612,398	\$ 418,931	\$ 2,031,329
PPP SBA grant	142,797	-	142,797	-	-	-
Bequests	22,052	-	22,052	147,846	-	147,846
Special events, net of direct benefits to donors of \$686 and \$62,493, respectively	337,484	-	337,484	461,635	-	461,635
Investment income	323,629	424	324,053	484,271	2,197	486,468
Other income	3,779	-	3,779	3,849	-	3,849
Net assets released from restrictions	352,881	(352,881)	-	551,938	(551,938)	-
<b>Total Revenue, Gains and Support</b>	<b>2,591,919</b>	<b>192,033</b>	<b>2,783,952</b>	<b>3,261,937</b>	<b>(130,810)</b>	<b>3,131,127</b>
Expenses						
Program services-						
Science	1,199,379	-	1,199,379	1,454,572	-	1,454,572
Awareness and education	384,641	-	384,641	421,979	-	421,979
Membership and support	143,633	-	143,633	148,226	-	148,226
Advocacy	83,764	-	83,764	134,809	-	134,809
Total program services	1,811,417	-	1,811,417	2,159,586	-	2,159,586
Supporting services-						
Administrative	189,920	-	189,920	194,339	-	194,339
Fundraising	264,558	-	264,558	304,428	-	304,428
<b>Total Expenses</b>	<b>2,265,895</b>	<b>-</b>	<b>2,265,895</b>	<b>2,658,353</b>	<b>-</b>	<b>2,658,353</b>
Change in Net Assets	326,024	192,033	518,057	603,584	(130,810)	472,774
Net Assets, Beginning of Year	2,558,132	1,589,368	4,147,500	1,954,548	1,720,178	3,674,726
Net Assets, End of Year	\$ 2,884,156	\$ 1,781,401	\$ 4,665,557	\$ 2,558,132	\$ 1,589,368	\$ 4,147,500

See Accompanying Notes to Financial Statements and  
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**DYSTONIA MEDICAL RESEARCH FOUNDATION**

Statement of Functional Expenses  
For the Year Ended December 31, 2020

	Program Services				Total Program Services	Supporting Services		Total
	Science	Awareness and Education	Membership and Support	Advocacy		Adminis- trative	Fund Raising	
Compensation	\$ 186,713	\$ 200,395	\$ 106,772	\$ 23,325	\$ 517,205	\$ 120,543	\$ 166,899	\$ 804,647
Medical research	743,770	-	-	-	743,770	-	-	743,770
Consultants/Professional fees	162,119	10,370	436	50,601	223,526	24,472	2,373	250,371
Occupancy	21,726	21,325	14,774	2,522	60,347	14,329	17,968	92,644
Postage/Delivery	5,048	45,611	4,500	419	55,578	3,329	11,612	70,519
Printing/Media	562	45,642	113	403	46,720	119	23,126	69,965
Meetings, workshops and symposia	30,371	3,347	1,550	3,078	38,346	1,133	1,810	41,289
Supplies	3,557	24,215	3,182	328	31,282	2,419	5,680	39,381
Computer	14,813	7,522	3,382	283	26,000	2,331	10,983	39,314
Travel	20,737	4,803	1,707	2,087	29,334	1,298	4,039	34,671
Miscellaneous	1,454	657	462	97	2,670	14,816	11,868	29,354
Communications	4,824	6,123	3,807	350	15,104	2,892	4,622	22,618
Website	577	10,515	148	14	11,254	112	179	11,545
Insurance - property/liability	2,006	2,657	1,807	166	6,636	1,373	2,193	10,202
Depreciation	1,102	1,459	993	91	3,645	754	1,206	5,605
<b>Total</b>	<b>\$ 1,199,379</b>	<b>\$ 384,641</b>	<b>\$ 143,633</b>	<b>\$ 83,764</b>	<b>\$ 1,811,417</b>	<b>\$ 189,920</b>	<b>\$ 264,558</b>	<b>\$ 2,265,895</b>

See Accompanying Notes to Financial Statements and  
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**DYSTONIA MEDICAL RESEARCH FOUNDATION**

Statement of Functional Expenses  
For the Year Ended December 31, 2019

	Program Services				Total Program Services	Supporting Services		Total
	Science	Awareness and Education	Membership and Support	Advocacy		Adminis- trative	Fund Raising	
Medical research	\$ 957,273	\$ -	\$ -	\$ -	\$ 957,273	\$ -	\$ -	\$ 957,273
Compensation	184,957	202,916	106,636	23,480	517,989	119,366	177,595	814,950
Consultants/Professional fees	157,323	10,644	408	52,813	221,188	26,523	2,513	250,224
Meetings, workshops and symposia	50,327	20,743	5,211	42,077	118,358	3,773	6,966	129,097
Occupancy	21,777	19,922	14,288	2,528	58,515	13,639	17,547	89,701
Travel	29,870	8,582	3,291	10,892	52,635	1,762	23,823	78,220
Postage/Delivery	8,847	43,491	4,943	556	57,837	3,200	12,772	73,809
Printing/Media	361	38,626	496	1,294	40,777	93	24,876	65,746
Supplies	5,397	41,789	2,933	265	50,384	2,089	4,208	56,681
Computer	20,390	7,515	2,747	211	30,863	1,662	10,531	43,056
Miscellaneous	5,455	1,246	1,048	129	7,878	17,793	15,600	41,271
Communications	6,465	5,147	3,005	276	14,893	2,176	3,941	21,010
Website	339	16,904	124	3	17,370	21	38	17,429
Insurance - property/liability	3,291	2,531	1,759	162	7,743	1,274	2,283	11,300
Depreciation	2,500	1,923	1,337	123	5,883	968	1,735	8,586
<b>Total Expenses by Function</b>	<b>\$ 1,454,572</b>	<b>\$ 421,979</b>	<b>\$ 148,226</b>	<b>\$ 134,809</b>	<b>\$ 2,159,586</b>	<b>\$ 194,339</b>	<b>\$ 304,428</b>	<b>\$ 2,658,353</b>

See Accompanying Notes to Financial Statements and  
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**DYSTONIA MEDICAL RESEARCH FOUNDATION**

Statements of Cash Flows

For the Years Ended December 31, 2020 and 2019

	<u>2020</u>	<u>2019</u>
Cash Flows from Operating Activities:		
Change in net assets	\$ 518,057	\$ 472,774
Adjustments to reconcile change in net assets to net cash provided by (used in) operating activities-		
Unrealized loss (gain) on investments	(231,972)	(403,169)
Depreciation	5,605	8,586
(Increase) decrease in assets-		
Unconditional promises to give	91,199	(34,394)
Other current assets	(43,430)	(8,658)
Increase (decrease) in liabilities-		
Grants and fellowships payable	192,273	64,969
Accounts payable and accrued expenses	(34,614)	(14,501)
Deferred rent payable	(2,613)	(2,981)
Deferred revenue	17,800	73,700
Dystonia Coalition agency liability funds	29,067	95,374
Net Cash Provided by (Used in) Operating Activities	<u>541,372</u>	<u>251,700</u>
Cash Flows from Investing Activities:		
Sale of investments	621,751	396,366
Purchase of investments	(1,097,918)	(740,769)
Purchase of equipment	(1,347)	(12,848)
Net Cash Provided by (Used in) Investing Activities	<u>(477,514)</u>	<u>(357,251)</u>
Net Increase (Decrease) in Cash and Cash Equivalents	63,858	(105,551)
Cash and Cash Equivalents - Beginning of Year	<u>638,027</u>	<u>743,578</u>
Cash and Cash Equivalents - End of Year	<u>\$ 701,885</u>	<u>\$ 638,027</u>
	* * * *	* *
<u>Supplemental Disclosure of Cash Flow Information</u>		
Cash paid during the year for:		
Income tax	<u>\$ -</u>	<u>\$ -</u>
Interest	<u>\$ -</u>	<u>\$ -</u>

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## **DYSTONIA MEDICAL RESEARCH FOUNDATION**

Notes to the Financial Statements

December 31, 2020 and 2019

### **Note A – Organization and Nature of Activities**

The Dystonia Medical Research Foundation (the “Foundation”) has three main missions: (1) to advance scientific research by supporting the training of physicians through the clinical fellowship program and awarding grants to and developing contracts with basic researchers, clinical investigators and medical/scientific institutions committed to finding the cause and cure for dystonia; (2) to build awareness and further dystonia education by sponsoring workshops and symposia for medical professionals and patients and by producing and distributing educational materials; and (3) to support patients and their families through ongoing support programs and sponsored symposia. Approximately 75% in 2020 and 70% in 2019 of the Foundation’s support came from donations and grants. The balance is from investment income, special events, and other revenue. In 2020, 31% of the Foundation’s support came from four donors who individually contributed greater than \$100,000 during the year. In 2019, 37% of the Foundation’s support came from five donors who individually contributed greater than \$100,000 during the year.

### **Note B – Summary of Significant Accounting Policies**

#### Basis of Accounting

The financial statements of the Foundation have been prepared on the accrual basis of accounting and, accordingly, reflect all significant receivables, payables, and other liabilities.

#### Use of Estimates

The preparation of financial statements in conformity with accounting principles generally accepted in the United States of America requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities and disclosure of contingent assets and liabilities (if any) at the date of the financial statements and the reported amounts of revenues, gains and expenses during the reporting period. Actual results may differ from those estimates.

#### Cash and Cash Equivalents

Cash equivalents are considered to be highly liquid depository accounts with a maturity of less than one year. Deposits held in all non-interest bearing transactional bank accounts and interest-bearing accounts with each banking institution are aggregated by entity and are fully insured up to \$250,000 per bank.

## DYSTONIA MEDICAL RESEARCH FOUNDATION

Notes to the Financial Statements

December 31, 2020 and 2019

### **Note B – Summary of Significant Accounting Policies (continued)**

#### Fair Value of Financial Instruments

FASB ASC Topic 820, *Fair Value Measurements and Disclosures*, defines fair value as a market-based measurement, not an entity-specific measurement. The objective of a fair value measurement is to estimate the price at which an orderly transaction to sell an asset or to transfer a liability would take place between market participants at the measurement date under current market conditions (that is, an exit price at the measurement date from the perspective of a market participant that holds the assets or owes the liability). A fair value measurement assumes that the transaction to sell an asset or to transfer a liability occurs either in the principal market (or in its absence, the most advantageous market) for the asset or liability.

For some assets and liabilities, observable market transactions or market information may be available. For other assets and liabilities, observable market transactions and market information may not be available. When a price for an identical asset or liability is not observable, the Foundation measures fair value using other valuation techniques which maximize the use of relevant observable inputs and minimize the use of unobservable inputs. Because fair value is a market-based measurement, it is measured using the assumptions that market participants would use when pricing the asset or liability, including assumptions about risk. As a result, the Foundation's intent to hold an asset or settle or otherwise fulfill a liability is not relevant when measuring fair value.

#### Unconditional Promises to Give

Contributions are recognized when the donor makes a promise to give to the Foundation that is, in substance, unconditional. Contributions that are restricted by the donor are reported as increases in net assets without donor restrictions if the restrictions expire in the reporting period in which the revenue is recognized. All other donor-restricted contributions are reported as increases in net assets with donor restrictions, depending on the nature of the restrictions. When a restriction expires, net assets with donor restrictions are reclassified to net assets without donor restrictions and reported in the statement of activities as net assets released from restrictions. Unconditional promises to give due in more than one year are recognized at fair value, using present value techniques and the current risk-free investment interest rate.

The Foundation uses the allowance method to determine uncollectible unconditional promises receivable. The allowance is based on prior years' experience and management's analysis of specific promises made, and there was no reserve necessary at December 31, 2020 and 2019.

#### Equipment and Leasehold Improvements

Expenditures for equipment and leasehold improvements in excess of \$1,000 are capitalized at cost if the life of the asset is one year or greater.

## DYSTONIA MEDICAL RESEARCH FOUNDATION

Notes to the Financial Statements

December 31, 2020 and 2019

### **Note B – Summary of Significant Accounting Policies (continued)**

#### Equipment and Leasehold Improvements (continued)

Depreciation is computed using the straight-line method over the estimated useful lives of the related assets. When assets are sold or otherwise disposed of, the cost and related accumulated depreciation are removed from the accounts, and any resulting gain or loss is included in the statement of activities.

#### Deferred Revenue

Sponsorship income is recognized when the related meeting or conference occurs.

#### Net Assets

Net assets, revenues, gains, and losses are classified based on the existence or absence of donor or grantor-imposed restrictions. Accordingly, net assets and changes therein are classified and reported as follows:

*Net Assets Without Donor Restrictions* – Net assets available for use in general operations and not subject to donor (or certain grantor) restrictions. The governing board has designated, from net assets without donor restrictions, net assets for science.

*Net Assets With Donor Restrictions* – Net assets subject to donor (or certain grantor) imposed restrictions. Some donor-imposed restrictions are temporary in nature, such as those that will be met by the passage of time or other events specified by the donor. Other donor-imposed restrictions are perpetual in nature, where the donor stipulates that resources be maintained in perpetuity. Donor-imposed restrictions are released when a restriction expires, that is, when the stipulated time has elapsed, when the stipulated purpose for which the resource was restricted has been fulfilled, or both.

#### Donated Services

No amounts have been reflected in the statements for donated services inasmuch as no objective basis is available to measure the value of such services; however, a substantial number of volunteers have donated significant amounts of their time in the Foundation's program and support services.

## **DYSTONIA MEDICAL RESEARCH FOUNDATION**

Notes to the Financial Statements

December 31, 2020 and 2019

### **Note B – Summary of Significant Accounting Policies (continued)**

#### **Functional Allocation of Expenses**

The costs of providing the various programs and other activities have been summarized on a functional basis in the statement of activities and the statement of functional expenses. Expenses which are easily and directly associated with a particular program or supporting service are charged directly to that functional area. Certain other expenses have been allocated to the program and supporting services benefited based on time devoted by the Foundation staff or the square footage allocated to the functional area.

#### **Note C - Income Taxes**

The Foundation is a not-for-profit organization exempt from paying corporate federal income tax under Section 501 (c)(3) of the Internal Revenue Code. It has been classified as an organization that is not a private foundation under the Internal Revenue Code and charitable contributions by donors are tax deductible.

The Foundation files Form 990, Return of Organization Exempt from Income Tax with the Federal government. Management has determined that the Foundation has no income tax liability as of December 31, 2020. The Foundation has evaluated its tax positions and determined it has no uncertain tax positions at December 31, 2020. The Foundation's 2018-2020 tax years are open for examination by the IRS. Should the Foundation's tax-exempt status be challenged in the future, all years since inception could be subject to review by the IRS.

#### **Note D – Related Party Transactions**

Donations include \$645,418 and \$720,947 from Directors of the Foundation and organizations they control for the years ended December 31, 2020 and 2019, respectively. Net special event revenue includes \$143,230 and \$300,429 raised by groups or individuals who fund raise on behalf of the Foundation for the years ended December 31, 2020 and 2019, respectively. In addition, the Foundation received \$37,730 in 2020 and \$59,613 in 2019 from Dystonia Medical Research Foundation Canada.

#### **Note E – Board Designated Funds**

In 2016, the Board of Directors of the Foundation designated \$1,500,000 of a bequest to be used for future science projects to be recommended by the Foundation's Science Committee. As such, these funds are presented as Board Designated on the statement of financial position.

## DYSTONIA MEDICAL RESEARCH FOUNDATION

### Notes to the Financial Statements

December 31, 2020 and 2019

#### **Note F – Net Assets with Donor Restrictions**

The following summaries sets forth the activity in net assets with donor restrictions for the years ended December 31, 2020 and 2019, which are available for the following purposes:

	<u>2019</u>	<u>Increase</u>	<u>Decrease</u>	<u>2020</u>
Scientific Research	\$ 547,422	\$ 25,000	\$ 1,970	\$ 570,452
Clinical Fellowships	207,165	55,000	68,901	193,264
Cure Dystonia Initiative –				
Acceleration Fund	290,640	424	-	291,064
Dystonia Coalition Project II	215,455	-	-	215,455
Advocacy Efforts and DAN Initiative	50,000	-	50,000	-
Myoclonus Research	182,653	150,000	179,000	153,653
Myoclonus Program	-	240,156	-	240,156
CD Research	16,819	250	-	17,069
Global Dystonia Registry	5,499	-	5,499	-
Dorothy Feiss Research Fund	29,507	60,075	15,000	74,582
David Rudolph Research Fund	30,633	6,509	30,633	6,509
Education Programs and Dystonia				
Dialogue	7,200	-	-	7,200
Other	6,375	7,500	1,878	11,997
	<u>\$ 1,589,368</u>	<u>\$ 544,914</u>	<u>\$ 352,881</u>	<u>\$ 1,781,401</u>

	<u>2018</u>	<u>Increase</u>	<u>Decrease</u>	<u>2019</u>
Scientific Research	\$ 529,040	\$ 54,507	\$ 6,618	\$ 576,929
Clinical Fellowships	138,965	135,000	66,800	207,165
Cure Dystonia Initiative –				
Acceleration Fund	288,443	2,197	-	290,640
Dystonia Coalition Project II	215,455	-	-	215,455
Advocacy Efforts and DAN Initiative	50,000	50,000	50,000	50,000
Myoclonus Research	252,193	150,000	219,540	182,653
CD Research	81,819	-	65,000	16,819
Cure Dystonia Now – Brain Networks				
Study	60,000	-	60,000	-
Global Dystonia Registry	18,999	-	13,500	5,499
David Rudolph Research Fund	56,209	24,424	50,000	30,633
Education Programs and Dystonia				
Dialogue	19,197	-	11,997	7,200
Other	9,858	5,000	8,483	6,375
	<u>\$ 1,720,178</u>	<u>\$ 421,128</u>	<u>\$ 551,938</u>	<u>\$ 1,589,368</u>

## DYSTONIA MEDICAL RESEARCH FOUNDATION

Notes to the Financial Statements

December 31, 2020 and 2019

### **Note F – Net Assets with Donor Restrictions (continued)**

Net assets with donor restrictions consist of:

	2020	2019
Cash, cash equivalents and short-term investments	\$ 2,160,304	\$ 1,819,368
Grants and fellowships payable	(378,903)	(230,000)
Total	<u>\$ 1,781,401</u>	<u>\$ 1,589,368</u>

### **Note G – Fair Value of Investments**

The framework for measuring fair value provides a fair value hierarchy that prioritizes the inputs to valuation techniques used to measure fair value. Fair value is the price that would be received to sell an asset or paid to transfer a liability regardless of whether an observable liquid market price exists (exit price). The hierarchy gives the highest priority to unadjusted quoted prices in active markets for identical assets or liabilities (Level 1 measurements) and the lowest priority to unobservable inputs (Level 3 measurements).

The three levels of the fair value hierarchy under FASB ASC 820 are described as follows:

- Level 1 Inputs to the valuation methodology are unadjusted quoted prices for identical assets or liabilities in active markets that the Foundation has the ability to access on the measurement date.
- Level 2 Inputs to the valuation methodology include quoted prices for similar assets or liabilities in active markets; quoted prices for identical or similar assets or liabilities in markets that are not active; inputs other than quoted prices which are observable for the asset or liability; and inputs that are derived principally from or corroborated by observable market data by correlation or other means.

If the asset or liability has a specified (contractual) term, the Level 2 input must be observable for substantially the full term of the asset or liability.

- Level 3 Inputs to the valuation methodology are unobservable and significant to the fair value measurement.

Each asset's or liability's fair value measurement level within the fair value hierarchy is based on the lowest level of any input which is significant to the fair value measurement. Valuation techniques utilized maximize the use of observable inputs and minimize the use of unobservable inputs.

## DYSTONIA MEDICAL RESEARCH FOUNDATION

Notes to the Financial Statements

December 31, 2020 and 2019

### Note G – Fair Value of Investments (continued)

Following is a description of the valuation methodologies for assets measured at fair value. There have been no changes in the methodologies used at December 31, 2020.

Mutual Funds – Valued at the daily closing price as reported by the fund. Mutual funds held by the Foundation are open-ended mutual funds which are registered with the SEC. These funds are required to publish their daily net asset value (NAV) and to transact at that price. The mutual funds held by the Foundation are deemed to be actively traded.

The methods described above could produce fair value calculations which may not be indicative of net realizable value or reflective of future fair values. Furthermore, while the Foundation's management believes that the valuation methods used are appropriate and consistent with those utilized by other market participants, the implementation of different methodologies or assumptions to determine the fair value of the Foundation's investment portfolio might result in different fair value measurements at report date.

The Foundation invests in various types of investment securities. Investment securities are exposed to various risks such as interest rate, market and credit risks. Due to the level of risk associated with certain investment securities, it is at least reasonably possible that changes in the value of the portfolio will occur in the near term (1 year) and such changes could materially affect the Foundation's investments and the amounts reported in the accompanying statement of financial position.

The following tables set forth, by level within the fair value hierarchy, the Foundation's assets at fair value as of December 31, 2020 and 2019.

At December 31, 2020, the Foundation's portfolio investments were classified as follows, based on fair values:

<u>Assets</u>	<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>	<u>Total</u>
Money Market Funds	\$ 1,202,351	\$ -	\$ -	\$ 1,202,351
Certificates of Deposit	-	5,500	-	5,500
US Equity Mutual Funds	1,720,986	-	-	1,720,986
US Fixed Inc. Mutual Funds	1,866,804	-	-	1,866,804
Int'l Equity Mutual Funds	290,248	-	-	290,248
Int'l Fixed Inc. Mutual Funds	166,346	-	-	166,346
Total	<u>\$ 5,246,735</u>	<u>\$ 5,500</u>	<u>\$ -</u>	<u>\$ 5,252,235</u>



**DYSTONIA MEDICAL RESEARCH FOUNDATION**

Notes to the Financial Statements

December 31, 2020 and 2019

**Note G – Fair Value of Investments (continued)**

At December 31, 2019, the Foundation’s portfolio investments were classified as follows, based on fair values:

<u>Assets</u>	<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>	<u>Total</u>
Money Market Funds	\$ 837,011	\$ -	\$ -	\$ 837,011
Certificates of Deposit	-	5,500	-	5,500
US Equity Mutual Funds	1,438,457	-	-	1,438,457
US Fixed Inc. Mutual Funds	1,831,429	-	-	1,831,429
Int’l Equity Mutual Funds	225,420	-	-	225,420
Int’l Fixed Inc. Mutual Funds	206,279	-	-	206,279
<b>Total</b>	<b>\$ 4,538,596</b>	<b>\$ 5,500</b>	<b>\$ -</b>	<b>\$ 4,544,096</b>

The Foundation holds the following investments which are stated at fair market value:

	<u>2020</u>		<u>2019</u>	
	<u>Cost</u>	<u>Fair Value</u>	<u>Cost</u>	<u>Fair Value</u>
Money Market Funds	\$ 1,202,351	\$ 1,202,351	\$ 837,011	\$ 837,011
Certificates of Deposit	5,500	5,500	5,500	5,500
US Equity Mutual Funds	1,486,459	1,720,986	1,311,157	1,438,457
US Fixed Inc. Mutual Funds	1,751,204	1,866,804	1,807,927	1,831,429
Int’l Equity Mutual Funds	245,707	290,248	222,919	225,420
Int’l Fixed Inc. Mutual Funds	161,651	166,346	212,595	206,279
	<b>\$ 4,852,872</b>	<b>\$ 5,252,235</b>	<b>\$ 4,397,109</b>	<b>\$ 4,544,096</b>

For the years ended December 31, net investment return includes the following:

	<u>2020</u>	<u>2019</u>
Interest and Dividends	\$ 114,134	\$ 123,212
Net Realized and Unrealized Gain (Loss)	231,972	384,811
Advisory Fees	(22,053)	(21,555)
	<b>\$ 324,053</b>	<b>\$ 486,468</b>

## DYSTONIA MEDICAL RESEARCH FOUNDATION

Notes to the Financial Statements

December 31, 2020 and 2019

### Note H – Unconditional Promises to Give

Unconditional promises to give consists of the following:

	<u>2020</u>	<u>2019</u>
Amounts due in:		
Greater than one year	\$ -	\$ 5,000
Less than one year	<u>33,481</u>	<u>119,680</u>
Total	<u>\$ 33,481</u>	<u>\$ 124,680</u>

### Note I – Operating Leases

In July 2016, the Foundation amended the terms of its non- cancellable operating lease for office space and extended the lease to August 31, 2028. Under terms of the amended lease, the Foundation receives abatement of the base rent and operating expense charges for 13 months including the periods July 2016 – May 2017, September 2017 and September 2018. As a result, the Foundation estimated the monthly rent expense on a monthly basis for the term of the lease and has accrued the pro rata portion of rent expense since the inception of the lease. The Foundation also leases a copier and postage meter under operating leases which expire in 2022. Future minimum lease payments including anticipated operating expense charges for the operating leases are as follows:

2021	\$ 105,611
2022	107,054
2023	102,997
2024	105,751
2025	109,021
Thereafter	<u>318,087</u>
Total	<u>\$ 848,521</u>

The Foundation has a sublease agreement for a portion of their office space for a term ending June 30, 2021. The sublease is expected to be extended for one year. The sublease agreement requires the sub lessee to pay the Foundation monthly rent of \$750.

Rent expense was \$89,727, net of sublease income of \$8,850 and \$85,178, net of sublease income of \$8,550 for the years ended December 31, 2020 and 2019, respectively.

## DYSTONIA MEDICAL RESEARCH FOUNDATION

Notes to the Financial Statements

December 31, 2020 and 2019

### **Note I – Operating Leases (continued)**

The Foundation has a \$5,000 irrevocable standby letter of credit that provides financial assurance that it will fulfill its obligation with respect to its obligations under terms of the office lease. The letter of credit expires August 31, 2028 unless the Foundation is notified by the lending institution.

### **Note J – 401(k) Plan**

The Foundation has a 401(k) plan which covers substantially all full-time employees. The Foundation matches eligible employees' first 3 percentage points of voluntary contributions plus one half of the next 2 percentage points of voluntary contributions. The Foundation's matching contributions for the years ending December 31, 2020 and 2019 were \$24,991 and \$26,621, respectively. There were no employer discretionary contributions in 2020 and 2019.

### **Note K—Liquidity and Availability of Financial Assets**

The following reflects the Foundation's financial assets as of the statement of financial position date, reduced by amounts not available for general use because of contractual or donor-imposed restrictions within one year of the statement of financial position date. Amounts available include donor restricted amounts that are available for general expenditure in the following year. Amounts not available include amounts set aside for science that could be drawn upon if the Board of Directors approves that action.

	<u>2020</u>	<u>2019</u>
Financial assets, at year-end:		
Cash and cash equivalents	\$ 701,885	\$ 638,027
Investments	5,252,235	4,544,096
Unconditional promises to give	33,481	124,680
Less contractual or donor-imposed restrictions:		
Cash restricted for Dystonia Coalition	(323,019)	(293,952)
Donor restrictions for specific purposes	(1,781,401)	(1,589,368)
Board designated fund for science	<u>(1,500,000)</u>	<u>(1,500,000)</u>
Financial assets available to meet cash needs for general expenditure within one year	<u>\$ 2,383,181</u>	<u>\$ 1,923,483</u>

## **DYSTONIA MEDICAL RESEARCH FOUNDATION**

Notes to the Financial Statements

December 31, 2020 and 2019

### **Note L – Paycheck Protection Program Loan**

On April 30, 2020, the Foundation was granted a loan from Hinsdale Bank & Trust Company, N.A. in the aggregate amount of \$142,797, pursuant to the Paycheck Protection Program (the “PPP”) under Division A, Title I of the CARES Act, which was enacted March 27, 2020. Funds from the Loan were used for payroll costs, costs used to continue group health care benefits, rent, and utilities. The Foundation used the entire Loan amount for qualifying expenses. Under the terms of the PPP, certain amounts of the Loan may be forgiven if they are used for qualifying expenses as described in the CARES Act. On November 6, 2020, the Foundation was granted full forgiveness for this loan and have recorded \$142,797 as a PPP SBA Grant on the Statement of Activities.

### **Note M - Dystonia Coalition and Dystonia Community Projects**

As a pro bono service to the community, the Foundation serves as the administrative center for the Dystonia Coalition (the “Coalition”), a network of clinical research centers working to advance the understanding of primary focal dystonias that is supported through a five-year grant from the National Institutes of Health’s (NIH) Office of Rare Disease Research and the National Institutes of Neurological Disorders & Stroke (grant number 1U54NS065701).

In this role, the Foundation works with the grant’s Principal Investigator, Dr. Hyder A. Jinnah of Emory University, and all Coalition Main Clinical Project Leaders to support the activities of the Coalition, including but not limited to: meeting planning; managing payments to clinical sites participating in the Coalition’s Main Clinical Projects as well as to Coalition consultants and recipients of the Coalition’s Career Development and Pilot Projects Awards; managing the private funds given in support of the Coalition’s activities or programs; participating in monthly administrative planning meetings; participating in the Coalition’s Executive Committee; and performing other duties as requested by the Principal Investigator and/or Coalition Main Clinical Project Leaders or the Coalition Executive Committee. Total Coalition payments administered were \$185,353 in 2020 and \$126,142 in 2019.

The Foundation also provides use of its conference call and webinar services for use by the Coalition as needed and has provided financial support for miscellaneous expenses such as graphic design, photography and other costs not covered by the grant but deemed appropriate and needed. The Foundation provides these services at no cost to the Coalition to maximize the use of the NIH grant funds to advance dystonia research. The Foundation’s unreimbursed costs (including compensation, occupancy and other out of pocket costs) of providing the administrative center services for the Coalition were \$17,352 in 2020 and \$22,616 in 2019.

## **DYSTONIA MEDICAL RESEARCH FOUNDATION**

Notes to the Financial Statements

December 31, 2020 and 2019

### **Note M - Dystonia Coalition and Dystonia Community Projects (continued)**

The Foundation also serves as the administrative center for various Dystonia Community Projects. Total receipts for Dystonia Community Projects were \$24,420 in 2020 and \$17,250 in 2019. Total disbursements for Dystonia Community Projects were \$20,250 and \$18,000 in 2020 and 2019. As of December 31, 2020, \$4,170 was received in support of Dystonia Community Projects for future expenditures.

Included in the Foundation's liabilities on the statement of financial position at December 31, 2020 and 2019 was an agency liability of \$323,019 and \$293,952, respectively, for Coalition funds held. The Foundation holds these funds in segregated cash accounts. Agency liabilities for Dystonia Community Projects at December 31, 2020 and 2019 were \$3,000 and \$2,250, respectively.

### **Note N – Concentration of Credit Risk**

Financial instruments that potentially subject the Foundation to concentration of credit risk consist principally of cash and short-term investments. Accounts at each financial institution are insured by the Federal Deposit Insurance Corporation ("FDIC") up to \$250,000. At December 31, 2020, the Foundation had \$1,912,581 on deposit in excess of the FDIC insured limit. In 2021, to mitigate this credit risk, the Foundation has deposited funds into a program that allows participants to increase the maximum amount of FDIC insurance coverage by purchasing CDs from multiple separate community bank chartered in Illinois and Wisconsin.

### **Note O – Subsequent Events**

The Foundation's operations may be affected by the recent and ongoing outbreak of the coronavirus disease (COVID-19), which was declared a pandemic by the World Health Foundation in March 2020. The ultimate disruption which may be caused by the outbreak is uncertain; however, it may result in disruption to the Foundation's donors and revenue streams (including attendance of future events), and a decline in value of the Foundation's marketable securities.

The Foundation postponed the 2020 Samuel Belzberg 6<sup>th</sup> International Dystonia Symposium to 2023 and is in the process of negotiating settlements with the scheduled meeting vendors.

The Foundation was granted an additional PPP forgivable loan of \$144,660, which was funded on January 28, 2021.

Other than the matters noted above, the Foundation has determined that no material events or transactions occurred subsequent to December 31, 2020 and through the date of the independent auditor's report, the date the financial statements were available for issuance, that would require adjustments to and/or additional disclosure to the financial statements.