

**DYSTONIA MEDICAL RESEARCH FOUNDATION**

**FINANCIAL STATEMENTS**

**for the years ending December 31, 2022 and 2021**

# **DYSTONIA MEDICAL RESEARCH FOUNDATION**

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## INDEPENDENT AUDITOR'S 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, 2022 and 2021, 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, 2022 and 2021, 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 11, 2023

**DYSTONIA MEDICAL RESEARCH FOUNDATION**

## Statements of Financial Position

December 31, 2022 and 2021

	<b><u>2022</u></b>	<b><u>2021</u></b>
<b><u>ASSETS</u></b>		
Current Assets		
Cash and cash equivalents including segregated Dystonia Coalition cash of \$378,854 in 2022 and \$318,053 in 2021	\$ 657,300	\$ 1,017,081
Unconditional promises to give	73,439	35,997
Other current assets	57,191	73,469
Financing lease right-of-use asset, current	4,721	-
Operating lease right-of-use asset, current	41,719	-
Total Current Assets	834,370	1,126,547
Noncurrent Assets		
Investments	5,195,634	5,760,796
Equipment and leasehold improvements, less \$32,817 in 2022 and \$33,792 in 2021, of accumulated depreciation	9,322	11,576
Financing lease right-of-use, noncurrent	8,575	-
Operating lease right-of-use asset, noncurrent	208,137	-
Total Noncurrent Assets	5,421,668	5,772,372
Total Assets	<u>\$ 6,256,038</u>	<u>\$ 6,898,919</u>

See Accompanying Notes to Financial Statements

**DYSTONIA MEDICAL RESEARCH FOUNDATION**

## Statements of Financial Position

December 31, 2022 and 2021

	<u>2022</u>	<u>2021</u>
<b><u>LIABILITIES AND NET ASSETS</u></b>		
Current Liabilities		
Grants and fellowships payable	\$ 527,975	\$ 817,754
Accounts payable and accrued expenses	74,578	61,480
Deferred rent payable	-	104,762
Deferred revenue	168,573	210,500
Dystonia Coalition agency liability funds	378,855	318,053
Financing lease liability, current	4,721	-
Operating lease liability, current	47,095	-
Total Current Liabilities	1,201,797	1,512,549
Noncurrent Liabilities		
Financing lease liability, noncurrent	8,575	-
Operating lease liability, noncurrent	249,513	-
Total Noncurrent Liabilities	258,088	-
Total Liabilities	1,459,885	1,512,549
Net Assets		
Without donor restrictions:		
Undesignated	1,142,291	1,650,601
Board designated for science	1,500,000	1,500,000
Total net assets without donor restrictions	2,642,291	3,150,601
With donor restrictions:		
Purpose restricted	2,153,862	2,235,769
Total net assets with donor restrictions	2,153,862	2,235,769
Total Net Assets	4,796,153	5,386,370
Total Liabilities and Net Assets	\$ 6,256,038	\$ 6,898,919

See Accompanying Notes to Financial Statements

# **DYSTONIA MEDICAL RESEARCH FOUNDATION**

## Statements of Activities

For the Years Ended December 31, 2022 and 2021

	<b>2022</b>			<b>2021</b>		
	Without Donor Restrictions	With Donor Restrictions	Total	Without Donor Restrictions	With Donor Restrictions	Total
Revenue, Gains and Support						
Donations and grants	\$ 1,585,532	\$ 302,468	\$ 1,888,000	\$ 1,010,237	\$ 661,711	\$ 1,671,948
Cure Dystonia Now funds received	-	-	-	400,000	-	400,000
PPP SBA grant	-	-	-	144,660	-	144,660
Bequests	111,583	-	111,583	123,366	-	123,366
Special events, net of direct benefits to donors of \$65,821 and \$1,904, respectively	428,416	-	428,416	444,085	-	444,085
Investment income	(609,969)	-	(609,969)	357,825	29	357,854
Other income	44,707	-	44,707	48,112	-	48,112
Net assets released from restrictions	384,375	(384,375)	-	207,372	(207,372)	-
<b>Total Revenue, Gains and Support</b>	<b>1,944,644</b>	<b>(81,907)</b>	<b>1,862,737</b>	<b>2,735,657</b>	<b>454,368</b>	<b>3,190,025</b>
Expenses						
Program services-						
Science	1,346,775	-	1,346,775	1,378,133	-	1,378,133
Awareness and education	457,154	-	457,154	389,889	-	389,889
Membership and support	146,924	-	146,924	139,582	-	139,582
Advocacy	76,067	-	76,067	73,441	-	73,441
Total program services	2,026,920	-	2,026,920	1,981,045	-	1,981,045
Supporting services-						
Administrative	235,304	-	235,304	251,284	-	251,284
Fundraising	244,606	-	244,606	236,883	-	236,883
<b>Total Expenses</b>	<b>2,506,830</b>	<b>-</b>	<b>2,506,830</b>	<b>2,469,212</b>	<b>-</b>	<b>2,469,212</b>
Change in Net Assets	(562,186)	(81,907)	(644,093)	266,445	454,368	720,813
Net Assets, Beginning of Year	3,204,477	2,235,769	5,440,246	2,884,156	1,781,401	4,665,557
Net Assets, End of Year	\$ 2,642,291	\$ 2,153,862	\$ 4,796,153	\$ 3,150,601	\$ 2,235,769	\$ 5,386,370

See Accompanying Notes to Financial Statements

# **DYSTONIA MEDICAL RESEARCH FOUNDATION**

## Statement of Functional Expenses For the Year Ended December 31, 2022

	Program Services					Supporting Services		
	Science	Awareness and Education	Membership and Support	Advocacy	Total Program Services	Adminis- trative	Fund Raising	Total
Medical research	\$ 863,373	\$ -	\$ -	\$ -	\$ 863,373	\$ -	\$ -	\$ 863,373
Compensation	207,866	215,508	111,564	21,108	556,046	156,520	126,997	839,563
Consultants/Professional fees	165,211	13,040	810	50,454	229,515	24,923	3,317	257,755
Occupancy	22,845	24,105	13,017	2,006	61,973	14,704	13,259	89,936
Printing/Media	400	45,958	505	-	46,863	-	33,688	80,551
Computer	27,189	19,119	7,461	678	54,447	7,442	13,812	75,701
Postage/Delivery	3,762	52,690	2,367	209	59,028	2,328	8,959	70,315
Miscellaneous	6,204	2,951	1,382	94	10,631	18,645	26,900	56,176
Supplies	5,060	35,714	3,377	267	44,418	2,929	2,642	49,989
Travel	16,043	7,488	57	603	24,191	141	8,312	32,644
Website	480	29,593	-	-	30,073	472	13	30,558
Communications	6,421	5,942	3,412	344	16,119	3,877	3,409	23,405
Meetings, workshops and symposia	16,890	217	-	-	17,107	-	-	17,107
Insurance	2,997	2,877	1,771	181	7,826	1,980	2,086	11,892
Depreciation	2,034	1,952	1,201	123	5,310	1,343	1,212	7,865
Total	<u>\$ 1,346,775</u>	<u>\$ 457,154</u>	<u>\$ 146,924</u>	<u>\$ 76,067</u>	<u>\$ 2,026,920</u>	<u>\$ 235,304</u>	<u>\$ 244,606</u>	<u>\$ 2,506,830</u>

See Accompanying Notes to Financial Statements



# **DYSTONIA MEDICAL RESEARCH FOUNDATION**

## Statement of Functional Expenses For the Year Ended December 31, 2021

	Program Services					Supporting Services		
	Science	Awareness and Education	Membership and Support	Advocacy	Total Program Services	Adminis- trative	Fund Raising	Total
Medical research	\$ 932,777	\$ -	\$ -	\$ -	\$ 932,777	\$ -	\$ -	\$ 932,777
Compensation	222,561	200,975	106,371	19,488	549,395	169,727	136,199	855,321
Consultants/Professional fees	150,948	13,834	666	50,458	215,906	24,738	6,816	247,460
Occupancy	21,718	21,890	12,578	1,734	57,920	16,013	13,535	87,468
Printing/Media	243	40,578	504	8	41,333	123	33,040	74,496
Postage/Delivery	4,856	47,829	4,139	307	57,131	4,771	11,876	73,778
Computer	19,943	10,900	4,707	296	35,846	4,810	10,170	50,826
Supplies	3,321	28,401	2,442	183	34,347	2,966	2,867	40,180
Miscellaneous	4,179	2,048	836	233	7,296	17,592	13,115	38,003
Communications	4,960	7,486	2,880	264	15,590	4,245	3,265	23,100
Insurance - property/liability	6,130	2,439	1,464	133	10,166	2,158	1,780	14,104
Meetings, workshops and symposia	2,952	2,672	1,779	143	7,546	2,348	1,703	11,597
Website	73	8,501	32	89	8,695	47	35	8,777
Depreciation	1,455	1,649	990	87	4,181	1,459	1,078	6,718
Travel	2,017	687	194	18	2,916	287	1,404	4,607
Total	<u>\$ 1,378,133</u>	<u>\$ 389,889</u>	<u>\$ 139,582</u>	<u>\$ 73,441</u>	<u>\$ 1,981,045</u>	<u>\$ 251,284</u>	<u>\$ 236,883</u>	<u>\$ 2,469,212</u>

See Accompanying Notes to Financial Statements

# DYSTONIA MEDICAL RESEARCH FOUNDATION

## Statements of Cash Flows

For the Years Ended December 31, 2022 and 2021

	<u>2022</u>	<u>2021</u>
Cash Flows from Operating Activities		
Change in net assets	\$ (644,093)	\$ 720,813
Adjustments to reconcile change in net assets to net cash provided by (used in) operating activities-		
Realized and unrealized loss (gain) on investments	698,345	(284,604)
Depreciation	7,865	6,718
(Increase) decrease in assets-		
Unconditional promises to give	(37,442)	(2,516)
Other current assets	16,278	(855)
Right-of-use asset	(263,152)	-
Increase (decrease) in liabilities-		
Grants and fellowships payable	(289,779)	1,565
Accounts payable and accrued expenses	13,098	(5,096)
Deferred rent payable	(50,886)	(4,163)
Deferred revenue	(41,927)	119,000
Dystonia Coalition agency liability funds	60,802	(4,966)
Operating lease liability	296,608	-
Net Cash Provided by (Used in) Operating Activities	<u>(234,283)</u>	<u>545,896</u>
Cash Flows from Investing Activities:		
Sale of investments	1,181,288	860,917
Purchase of investments	(1,314,471)	(1,084,874)
Purchase of equipment	(5,611)	(6,743)
Net Cash Provided by (Used in) Investing Activities	<u>(138,794)</u>	<u>(230,700)</u>
Cash Flows from Financing Activities		
Financing lease liability	13,296	-
Net Increase (Decrease) in Cash and Cash Equivalents	(359,781)	315,196
Cash and Cash Equivalents - Beginning of Year	<u>1,017,081</u>	<u>701,885</u>
Cash and Cash Equivalents - End of Year	<u>\$ 657,300</u>	<u>\$ 1,017,081</u>

\* \* \* \* \*

### Supplemental Disclosure of Cash Flow Information

Cash paid during the year for:

Income tax	\$ -	\$ -
Interest	<u>\$ -</u>	<u>\$ -</u>

See Accompanying Notes to Financial Statements

## **DYSTONIA MEDICAL RESEARCH FOUNDATION**

### **Notes to the Financial Statements**

December 31, 2022 and 2021

#### **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 81% in 2022 and 77% in 2021 of the Foundation’s operational support came from donations and grants. The balance is from investment income, special events, and other revenue. In 2022, 27% of the Foundation’s support came from five donors who individually contributed greater than \$100,000 during the year. In 2021, 30% of the Foundation’s support came from five donors who individually contributed greater than \$100,000 during the year.

#### *Cure Dystonia Now*

The Foundation and Cure Dystonia Now (“CDN”) have been long-standing partners in supporting dystonia research. CDN joined with the Foundation in 2022 to enhance support for funding the best research to advance understanding of dystonia and accelerate progress toward a cure. On December 31, 2021 CDN ceased its operations and transferred \$400,000 to the Foundation to establish the DMRF CDN Fund that will support research.

#### **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.

## DYSTONIA MEDICAL RESEARCH FOUNDATION

### Notes to the Financial Statements

December 31, 2022 and 2021

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

##### 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.

##### 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 or are satisfied 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 or is satisfied, 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.

## **DYSTONIA MEDICAL RESEARCH FOUNDATION**

### **Notes to the Financial Statements**

**December 31, 2022 and 2021**

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

##### Unconditional Promises to Give (continued)

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, 2021 and 2020.

##### 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. 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 event occurs.

##### Revenue Recognition

The Foundation has adopted Accounting Standards Update (ASU) No. 2014-19 – Revenue from Contracts with Customers (Topic 606), as amended. The standard contains principles that an organization applies to determine the measurement of revenue and the timing of when it is recognized. The adoption of this accounting pronouncement did not result in significant changes in the timing of the Foundation's revenue recognition.

Donations, Grants and Bequests – A majority of the Foundation's revenue is derived from donations, grants and bequests. The Foundation recognizes contributions of cash and securities when received.

Special Events and Fundraising – The Foundation receives revenue from Special Events and Fundraising. Revenue is recognized at the time the event takes place.

##### 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:

## DYSTONIA MEDICAL RESEARCH FOUNDATION

### Notes to the Financial Statements

December 31, 2022 and 2021

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

##### Net Assets (continued)

*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.

##### 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.

##### Adoption of New Accounting Policy

Due to amendments to U.S. generally accepted accounting principles (US GAAP), commencing January 1, 2022, all of the Foundation's real estate and equipment leases that have lease terms exceeding 12 months will now be required to be recorded on the Statement of Financial Position as right-of-use assets accompanied by liabilities for the present value of the lease payments that the Foundation is obligated to make in order to obtain control of the leased assets for the duration of each lease term.

## **DYSTONIA MEDICAL RESEARCH FOUNDATION**

### **Notes to the Financial Statements**

**December 31, 2022 and 2021**

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

##### **Adoption of New Accounting Policy (continued)**

Lease-related expense, under these amendments, will be recognized in different patterns depending on whether the underlying lease is classified as an operating lease or a finance lease. Total lease expense for operating leases will be recognized as a single expense using the straight-line method over the term of the lease, which includes options to renew the lease that the Foundation is reasonably certain to exercise. Finance lease expense will consist of two components, interest expense on the lease obligation payable and straight-line amortization of the right-of-use asset.

Implementation of these amendments is reflected retrospectively as of January 1, 2022, the effective date of the amendments. As a result of implementation, the Foundation recorded additional lease assets of \$263,152, liabilities of \$309,904 and a change in beginning net assets of \$53,876 as of January 1, 2022. To ease the burden of implementation, the Foundation elected an available package of practical expedients permitted under the transition guidance included in the amended US GAAP that permits the Foundation to carry forward the historical lease identification, classification and initial direct costs associated with its pre-existing leases. The implementation of these amendments did not materially impact net income or cash flows (see following caption "Leases" for further details). Apart from these amendments, there have been no other changes in significant accounting policies during the year ended December 31, 2022, as compared to the significant accounting policies described in the Foundation's financial statements for the year ended December 31, 2021.

##### **Leases**

The Foundation determines if an arrangement is a lease or contains a lease at the inception of the contract. Operating leases are presented under the captions operating lease right-of-use (ROU) assets, current portion of operating lease liabilities, and long-term portion of operating lease liabilities in the accompanying Statement of Financial Position as of December 31, 2022. Finance leases are presented under the captions finance lease right-of-use (ROU) assets, current portion of finance lease liabilities, and long-term portion of finance lease liabilities in the accompanying Statement of Financial Position as of December 31, 2022.

Both operating lease and finance lease ROU assets and lease liabilities are initially measured at the present value of future lease payments over the lease term as determined at each lease's commencement date. In measuring assets and liabilities for certain classes of underlying assets, the Foundation has elected a practical expedient to account for lease and nonlease components together as a single lease component. The Foundation has used U.S. treasury instruments with a maturity of similar length to the lease term as the interest rate to discount lease payments.

## **DYSTONIA MEDICAL RESEARCH FOUNDATION**

### **Notes to the Financial Statements**

**December 31, 2022 and 2021**

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

##### **Leases (continued)**

Operating lease expense is recognized on a straight-line basis over the term of each lease. Finance lease expense is recognized in two separate components, interest expense on the lease liability and amortization of the right-of-use (ROU) asset. In the accompanying Statement of Activities for the year ended December 31, 2022, the interest expense on the lease liabilities has been combined with other interest expense and displayed as a single number under the caption, other income (expenses), and the amortization of the ROU assets has been combined with other depreciation and amortization and displayed as components of cost of revenues and general and administrative expenses, respectively.

Operating lease ROU assets include all fixed contractual lease payments and initial direct costs incurred, less any lease incentives received from the lessor. Facility leases generally obligate the Foundation for lease expense, but nonlease reimbursements to the lessor of the proportionate share of common area maintenance (CAM), and non-component reimbursements to the lessor of certain of the lessor's costs such as real estate taxes and lessor insurance premiums applicable to the leased property are not included because the CAM is a variable rate that depends on current market price and are expensed as incurred. As permitted by US GAAP, we have elected not to apply these new lease accounting policies to leases with a term of less than one year at the lease's commencement date. Expenses associated with these short-term leases are recognized on a straight-line basis over the term of the lease.

The lease for commercial real estate contains options granting the Foundation the right to renew or extend the term of the lease for specified option periods. The decision as to whether the Foundation will exercise lease renewal options is generally at the Foundation's sole discretion. The Foundation includes lease extensions in the lease term when it is reasonably certain that the Foundation will exercise the extension. The Foundation's lease agreements do not contain any material variable lease payments, residual value guarantees, options to purchase leased assets, or restrictive covenants.

##### **COVID-19 Impact**

Management has evaluated the impact of the COVID-19 pandemic and have concluded that the net effect on the Foundation's financial position, results of its operations and cash flows was not significantly adversely affected. The Foundation successfully managed to meet its revenue and programmatic benchmarks in 2022. However, compliance with the COVID-19 protocols limited the Foundation's opportunities to provide in-person educational, support and community events as well as limited the opportunity for the scientific networking that occurs when hosting in-person scientific meetings. All programs were offered virtually. Management is grateful for the loyal donors who have supported the Foundation throughout the pandemic allowing it to continue to provide needed programs without interruption.



## **DYSTONIA MEDICAL RESEARCH FOUNDATION**

### **Notes to the Financial Statements**

December 31, 2022 and 2021

#### **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. The Foundation also files Form AG990-IL, Illinois Charitable Organization Annual Report with the Attorney General of the State of Illinois and Form 109, California Exempt Organization Business Income Tax Return with the State of California. Management has determined that the Foundation has no income tax liability as of December 31, 2022. The Foundation has evaluated its tax positions and determined it has no uncertain tax positions at December 31, 2022. The Foundation's 2019-2022 tax years are open for examination by the IRS and State of Illinois and 2018-2022 for the State of California. 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 \$819,229 and \$636,574 from Directors of the Foundation and organizations they control for the years ended December 31, 2022 and 2021, respectively. Net special event revenue includes \$219,733 and \$274,272 raised by groups or individuals who fund raise on behalf of the Foundation for the years ended December 31, 2022 and 2021, respectively. In addition, the Foundation received \$36,675 in 2022 and \$23,034 in 2021 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, 2022 and 2021

### **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, 2022 and 2021, which are available for the following purposes:

	<u>2021</u>	<u>Increase</u>	<u>Decrease</u>	<u>2022</u>
Scientific Research	\$ 589,257	\$ 25,100	\$ 5,928	\$ 608,429
Cure Dystonia Now Fund	400,000	175,661	129,644	446,017
Clinical Fellowships	189,364	40,000	74,771	154,593
Cure Dystonia Initiative – Acceleration Fund	291,093	-	-	291,093
Dystonia Coalition Project II	215,455	-	-	215,455
Dystonia Journal	15,031	-	15,031	-
Myoclonus Dystonia Research	82,681	-	-	82,681
Myoclonus Dystonia Program	240,156	-	-	240,156
Cure Dystonia Now	54,569	-	54,569	-
Dorothy Feiss Research Fund	98,704	34,078	104,432	28,350
David Rudolph Research Fund	32,762	25,129	-	57,891
Patient/Physician Communication Kits	7,200	-	-	7,200
Other	19,497	2,500	-	21,997
<b>Total</b>	<b>\$ 2,235,769</b>	<b>\$ 302,468</b>	<b>\$ 384,375</b>	<b>\$ 2,153,862</b>

	<u>2020</u>	<u>Increase</u>	<u>Decrease</u>	<u>2021</u>
Scientific Research	\$ 570,452	\$ 28,805	\$ 10,000	\$ 589,257
Cure Dystonia Now Fund	-	400,000	-	400,000
Clinical Fellowships	193,264	65,000	68,900	189,364
Cure Dystonia Initiative – Acceleration Fund	291,064	29	-	291,093
Dystonia Coalition Project II	215,455	-	-	215,455
Dystonia Journal	-	15,031	-	15,031
Myoclonus Dystonia Research	153,653	-	70,972	82,681
Myoclonus Dystonia Program	240,156	-	-	240,156
Cure Dystonia Now	17,069	50,000	12,500	54,569
Dorothy Feiss Research Fund	74,582	69,122	45,000	98,704
David Rudolph Research Fund	6,509	26,253	-	32,762
Education Programs and Dystonia Dialogue	7,200	-	-	7,200
Other	11,997	7,500	-	19,497
<b>Total</b>	<b>\$ 1,781,401</b>	<b>\$ 661,740</b>	<b>\$ 207,372</b>	<b>\$ 2,235,769</b>

## DYSTONIA MEDICAL RESEARCH FOUNDATION

### Notes to the Financial Statements

December 31, 2022 and 2021

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

Net assets with donor restrictions consist of:

	2022	2021
Cash, cash equivalents and short-term investments	\$ 2,263,827	\$ 2,513,193
Grants and fellowships payable	(109,965)	(277,424)
Total	\$ 2,153,862	\$ 2,235,769

#### **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, 2022 and 2021**

#### **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, 2022.

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.

Alternative Investment Funds – These investments are subject to the terms and conditions of the respective funds' offering documents and categorized as level 3 in the hierarchy, unless the investment is valued at NAV, as a practical expedient for fair value and excluded from the fair value hierarchy.

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, 2022 and 2021.

# **DYSTONIA MEDICAL RESEARCH FOUNDATION**

## Notes to the Financial Statements

December 31, 2022 and 2021

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

At December 31, 2022, 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>Valued @ NAV</u>	<u>Total</u>
Money Market	\$ 1,059,907	\$ -	\$ -	\$ -	\$ 1,059,907
Certificates of Deposit	-	5,500	-	-	5,500
US Equity Mtl. Funds	-	1,636,101	-	-	1,636,101
US Fixed Inc. Mtl. Funds	-	1,998,894	-	-	1,998,894
Int'l Equity Mtl. Funds	-	264,263	-	-	264,263
Int'l Fixed Inc. Mtl. Funds	-	209,881	-	-	209,881
Alternative Invest. Funds	-	-	-	21,088	21,088
 Total	 \$ 1,059,907	 \$ 4,114,639	 \$ -	 \$ 21,088	 \$ 5,195,634

At December 31, 2021, 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>Valued @ NAV</u>	<u>Total</u>
Money Market	\$ 1,016,932	\$ -	\$ -	\$ -	\$ 1,016,932
Certificates of Deposit	-	6,434	-	-	6,434
US Equity Mtl. Funds	-	1,789,319	-	-	1,789,319
US Fixed Inc. Mtl. Funds	-	2,050,743	-	-	2,050,743
Int'l Equity Mtl. Funds	-	233,531	-	-	233,531
Int'l Fixed Inc. Mtl. Funds	-	234,597	-	-	234,597
Alternative Invest. Funds	-	-	-	429,240	429,240
 Total	 \$ 1,016,932	 \$ 4,314,624	 \$ -	 \$ 429,240	 \$ 5,760,796

**DYSTONIA MEDICAL RESEARCH FOUNDATION**

## Notes to the Financial Statements

December 31, 2022 and 2021

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

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

	2022		2021	
	Cost	Fair Value	Cost	Fair Value
Money Market Funds	\$ 1,059,907	\$ 1,059,907	\$ 1,016,932	\$ 1,016,932
Certificates of Deposit	5,500	5,500	5,500	6,434
US Equity Mutual Funds	1,410,904	1,636,101	1,232,319	1,789,319
US Fixed Inc. Mutual Funds	2,208,370	1,998,894	2,005,747	2,050,743
Int'l Equity Mutual Funds	283,026	264,263	208,208	233,531
Int'l Fixed Inc. Mutual Funds	273,786	209,881	241,190	234,597
Alternative Investment Funds	21,088	21,088	400,000	429,240
	<u>\$ 5,262,581</u>	<u>\$ 5,195,634</u>	<u>\$ 5,109,896</u>	<u>\$ 5,760,796</u>

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

	2022	2021
Interest and Dividends	\$ 114,512	\$ 99,596
Net Realized and Unrealized Gain (Loss)	(698,345)	284,604
Advisory Fees	(26,136)	(26,346)
	<u>\$ (609,969)</u>	<u>\$ 357,854</u>

**Note H – Unconditional Promises to Give**

Unconditional promises to give consists of the following:

	2022	2021
Amounts due in:		
Greater than one year	\$ 15,000	\$ -
Less than one year	58,439	35,997
Total	<u>\$ 73,439</u>	<u>\$ 35,997</u>

# **DYSTONIA MEDICAL RESEARCH FOUNDATION**

## Notes to the Financial Statements

December 31, 2022 and 2021

### **Note I - Leases**

The Foundation are parties, as lessee, to various operating leases and finance leases for corporate facilities and equipment. The components of lease expense for the year ended December 31, 2022, consist of the following:

<u>Cost element</u>	<u>Amount</u>
Operating lease cost	
Amortization of right-of-use assets	\$ 40,800
Interest on lease liabilities	6,423
Total operating lease cost	<u>\$ 47,223</u>
Finance lease cost	
Amortization of right-of-use assets	\$ 4,005
Interest on lease liabilities	268
Total finance lease cost	<u>\$ 4,273</u>

Future minimum lease payments for the next five years and in the aggregate under all noncancelable leases with a term of one year or greater as of December 31, 2022, are as follows:

<u>Year Ending December 31,</u>	<u>Operating Leases</u>	<u>Finance Leases</u>
2023	\$ 52,599	\$ 4,963
2024	53,842	4,963
2025	55,084	3,124
2026	56,327	689
2027	57,569	-
Thereafter	38,932	-
Total future minimum lease payments	314,353	13,739
Less: imputed interest included therein	(17,745)	(443)
Net	<u>\$ 296,608</u>	<u>\$ 13,296</u>

The following table provides additional information related to our leases as of December 31, 2022:

	<u>Operating Leases</u>	<u>Finance Leases</u>
Current portion of lease liabilities	\$ 47,094	\$ 4,721
Long-term portion of lease liabilities	249,514	8,575
Total lease liabilities	<u>\$ 296,608</u>	<u>\$ 13,296</u>
Weighted average remaining lease term	6 years	2.5 years
Weighted average discount rate	2.00%	2.00%

## DYSTONIA MEDICAL RESEARCH FOUNDATION

### Notes to the Financial Statements

December 31, 2022 and 2021

#### **Note I – Leases (continued)**

The Foundation has a sublease agreement for a portion of their office space for a term ending June 30, 2023. The sublease is expected to be extended for one year. The sublease agreement requires the sub lessee to pay the Foundation monthly rent of \$775 through June 30, 2022 and increases to \$800 per month thereafter.

Rent expense was \$86,105, net of sublease income of \$9,450 and \$83,778, net of sublease income of \$9,150 for the years ended December 31, 2022 and 2021, respectively.

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, 2022 and 2021 were \$25,894 and \$26,047, respectively. There were no employer discretionary contributions in 2022 and 2021.

#### **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.

	2022	2021
Financial assets, at year-end:		
Cash and cash equivalents	\$ 657,300	\$ 1,017,081
Investments	5,195,634	5,760,796
Unconditional promises to give	73,439	35,997
Less contractual or donor-imposed restrictions:		
Cash restricted for Dystonia Coalition	(378,855)	(318,053)
Donor restrictions for specific purposes	(2,153,862)	(2,235,769)
Board designated fund for science	(1,500,000)	(1,500,000)
Financial assets available to meet cash needs for general expenditure within one year	<u>\$ 1,893,656</u>	<u>\$ 2,760,052</u>



## **DYSTONIA MEDICAL RESEARCH FOUNDATION**

### **Notes to the Financial Statements**

December 31, 2022 and 2021

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

On January 28, 2021, the Foundation was granted a loan from Hinsdale Bank & Trust Company, N.A. in the aggregate amount of \$144,660, 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 October 8, 2021, the Foundation was granted full forgiveness for this loan and has recorded \$144,660 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 dystonia 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 \$214,851 in 2022 and \$221,262 in 2021.

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 \$22,102 in 2022 and \$42,756 in 2021.

## **DYSTONIA MEDICAL RESEARCH FOUNDATION**

### **Notes to the Financial Statements**

**December 31, 2022 and 2021**

#### **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 \$22,500 in 2022 and \$24,297 in 2021. Total disbursements for Dystonia Community Projects were \$18,000 and \$27,717 in 2022 and 2021. As of December 31, 2022 and 2021, \$-0- and \$750, respectively, 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, 2022 and 2021 was an agency liability of \$378,855 and \$318,053, respectively, for Coalition funds held. The Foundation holds these funds in segregated cash accounts. Agency liabilities for Dystonia Community Projects at December 31, 2022 and 2021 were \$4,500 and \$-0-, respectively.

#### **Note N – Insurance Settlement**

As a result of the Foundation having to cancel the Samuel Belzberg 6th International Dystonia Symposium ("SBIDS6") due to the global pandemic, a claim was made against the event cancellation insurance policy. The policy reimburses the Foundation for the costs incurred in planning the cancelled SBIDS6. On September 29, 2021 it was determined that the Foundation's related expenses previously incurred in planning the event totaled \$43,936. Insurance proceeds of \$43,936 were received in 2021 and have been recognized as Other Income on the Statement of Activities.

#### **Note O – Concentration of Custodial Risk**

Financial instruments that potentially subject the Foundation to concentration of custodial 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, 2022 and 2021, the Foundation had \$276,861 and \$700,561, respectively on deposit in excess of the FDIC insured limit. To mitigate this custodial 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 banks chartered in Illinois and Wisconsin.

## **DYSTONIA MEDICAL RESEARCH FOUNDATION**

### **Notes to the Financial Statements**

**December 31, 2022 and 2021**

#### **Note P – Subsequent Events**

On January 5, 2023, the Foundation received a payment of \$78,446 from Cure Dystonia as a final payment to officially transfer operations to the Foundation.

Other than the matter above, the Foundation has determined that no material events or transactions occurred subsequent to December 31, 2022 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.