

**DYSTONIA MEDICAL RESEARCH FOUNDATION**

**FINANCIAL STATEMENTS**

**for the years ending December 31, 2024 and 2023**

# **DYSTONIA MEDICAL RESEARCH FOUNDATION**

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# BARNES, GIVENS & BARNES, LTD.

CERTIFIED PUBLIC ACCOUNTANTS  
200 EAST EVERGREEN AVENUE, SUITE 117  
MOUNT PROSPECT, ILLINOIS 60056-3240  
224-764-2442 FAX: 224-764-2448  
bgbcpas.com

## 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, 2024 and 2023, 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, 2024 and 2023, 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 15, 2025

**DYSTONIA MEDICAL RESEARCH FOUNDATION**

## Statements of Financial Position

December 31, 2024 and 2023

	<b>2024</b>	<b>2023</b>
<b><u>ASSETS</u></b>		
Current Assets		
Cash and cash equivalents including segregated Dystonia Coalition cash of \$505,776 in 2024 and \$601,276 in 2023	\$ 838,865	\$ 689,422
Unconditional promises to give	84,931	529,047
Other current assets	36,658	24,573
Financing lease right-of-use asset, current	3,070	4,819
Operating lease right-of-use asset, current	43,687	42,681
Total Current Assets	<u>1,007,211</u>	<u>1,290,542</u>
Noncurrent Assets		
Investments	5,284,811	4,975,677
Equipment and leasehold improvements, less \$35,632 in 2024 and \$35,194 in 2023, of accumulated depreciation	7,953	8,263
Financing lease right-of-use, noncurrent	686	3,756
Operating lease right-of-use asset, noncurrent	121,769	165,456
Total Non-Current Assets	<u>5,415,219</u>	<u>5,153,152</u>
Total Assets	<u><u>\$ 6,422,430</u></u>	<u><u>\$ 6,443,694</u></u>

See Accompanying Notes to Financial Statements

**DYSTONIA MEDICAL RESEARCH FOUNDATION**

## Statements of Financial Position

December 31, 2024 and 2023

	<u>2024</u>	<u>2023</u>
<b><u>LIABILITIES AND NET ASSETS</u></b>		
Current Liabilities		
Grants and fellowships payable	\$ 499,428	\$ 563,470
Accounts payable and accrued expenses	88,967	93,240
Deferred revenue	-	75,000
Dystonia Coalition agency liability funds	505,776	601,276
Financing lease liability, current	3,070	4,818
Operating lease liability, current	51,548	49,299
Total Current Liabilities	<u>1,148,789</u>	<u>1,387,103</u>
Noncurrent Liabilities		
Financing lease liability, noncurrent	686	3,756
Operating lease liability, noncurrent	148,667	200,216
Total Noncurrent Liabilities	<u>149,353</u>	<u>203,972</u>
Total Liabilities	<u>1,298,142</u>	<u>1,591,075</u>
Net Assets		
Without donor restrictions:		
Undesignated	1,649,091	1,299,728
Board designated for science	1,500,000	1,500,000
Total net assets without donor restrictions	<u>3,149,091</u>	<u>2,799,728</u>
With donor restrictions:		
Purpose restricted	1,975,197	2,052,891
Total net assets with donor restrictions	<u>1,975,197</u>	<u>2,052,891</u>
Total Net Assets	<u>5,124,288</u>	<u>4,852,619</u>
Total Liabilities and Net Assets	<u><u>\$ 6,422,430</u></u>	<u><u>\$ 6,443,694</u></u>

See Accompanying Notes to Financial Statements

# DYSTONIA MEDICAL RESEARCH FOUNDATION

## Statements of Activities

For the Years Ended December 31, 2024 and 2023

	2024			2023		
	Without Donor Restrictions	With Donor Restrictions	Total	Without Donor Restrictions	With Donor Restrictions	Total
Revenue, Gains and Support						
Donations and grants	\$ 1,199,402	\$ 349,069	\$ 1,548,471	\$ 2,009,404	\$ 262,760	\$ 2,272,164
Registrations	-	-	-	128,610	-	128,610
Cure Dystonia Now funds received	-	-	-	78,446	-	78,446
Bequests	941,117	-	941,117	34,937	-	34,937
Special events, net of direct benefits to donors of \$50,599 and \$75,899 respectively	430,916	-	430,916	452,324	-	452,324
Investment income (loss)	315,567	-	315,567	493,677	-	493,677
Other income	2,056	-	2,056	3,776	-	3,776
Net assets released from restrictions	426,763	(426,763)	-	363,731	(363,731)	-
Total Revenue, Gains and Support	3,315,821	(77,694)	3,238,127	3,564,905	(100,971)	3,463,934
Expenses						
Program services-						
Science and mental health	1,618,141	-	1,618,141	2,215,520	-	2,215,520
Awareness and education	597,110	-	597,110	506,313	-	506,313
Membership and support	110,242	-	110,242	101,745	-	101,745
Advocacy	72,862	-	72,862	71,903	-	71,903
Total program services	2,398,355	-	2,398,355	2,895,481	-	2,895,481
Supporting services-						
Administrative	317,617	-	317,617	286,313	-	286,313
Fundraising	250,486	-	250,486	225,674	-	225,674
Total Expenses	2,966,458	-	2,966,458	3,407,468	-	3,407,468
Change in Net Assets	349,363	(77,694)	271,669	157,437	(100,971)	56,466
Net Assets, Beginning of Year	2,799,728	2,052,891	4,852,619	2,642,291	2,153,862	4,796,153
Net Assets, End of Year	\$ 3,149,091	\$ 1,975,197	\$ 5,124,288	\$ 2,799,728	\$ 2,052,891	\$ 4,852,619

See Accompanying Notes to Financial Statements

# DYSTONIA MEDICAL RESEARCH FOUNDATION

## Statement of Functional Expenses For the Year Ended December 31, 2024

	Program Services					Supporting Services		
	Science	Awareness and Education	Membership and Support	Advocacy	Total Program Services	Adminis- trative	Fund Raising	Total
Medical research	\$ 1,008,881	\$ -	\$ -	\$ -	\$ 1,008,881	\$ -	\$ -	\$ 1,008,881
Compensation	222,951	284,271	74,199	12,586	594,007	174,063	102,511	870,581
Consultants/Professional fees	165,848	68,025	912	52,368	287,153	71,164	42,715	401,032
Occupancy	28,918	33,420	12,620	1,374	76,332	18,931	11,447	106,710
Meetings and workshops	79,159	8,395	2,682	257	90,493	3,413	2,954	96,860
Computer	30,259	26,358	8,610	612	65,839	11,919	18,383	96,141
Postage/Delivery	5,653	65,148	2,913	324	74,038	3,706	13,020	90,764
Printing/Media	2,560	50,980	6	56	53,602	64	30,150	83,816
Travel	55,559	7,022	789	4,298	67,668	1,024	6,747	75,439
Miscellaneous	5,490	3,116	759	485	9,850	25,473	10,902	46,225
Supplies	3,141	27,656	2,225	132	33,154	2,060	6,049	41,263
Communications	5,759	8,188	2,731	224	16,902	3,515	3,198	23,615
Insurance - property/liability	2,337	3,431	1,205	98	7,071	1,533	1,765	10,369
Website	480	9,454	-	-	9,934	-	-	9,934
Depreciation	1,146	1,646	591	48	3,431	752	645	4,828
Total	<u>\$ 1,618,141</u>	<u>\$ 597,110</u>	<u>\$ 110,242</u>	<u>\$ 72,862</u>	<u>\$ 2,398,355</u>	<u>\$ 317,617</u>	<u>\$ 250,486</u>	<u>\$ 2,966,458</u>

See Accompanying Notes to Financial Statements



**DYSTONIA MEDICAL RESEARCH FOUNDATION**

Statement of Functional Expenses  
For the Year Ended December 31, 2023

	Program Services					Supporting Services		
	Science	Awareness and Education	Membership and Support	Advocacy	Total Program Services	Adminis- trative	Fund Raising	Total
Medical research	\$ 1,064,462	\$ -	\$ -	\$ -	\$ 1,064,462	\$ -	\$ -	\$ 1,064,462
Compensation	228,678	244,283	72,075	15,899	560,935	185,064	115,893	861,892
Meetings, workshops and symposia	451,907	3,362	1,277	379	456,925	2,619	1,560	461,104
Consultants/Professional fees	174,996	31,836	598	51,990	259,420	26,165	8,988	294,573
Travel	201,963	4,476	519	449	207,407	1,064	6,650	215,121
Occupancy	26,732	32,599	12,083	1,802	73,216	18,062	12,430	103,708
Printing/Media	35	60,693	14	1	60,743	29	26,746	87,518
Computer	27,100	20,907	6,492	569	55,068	11,661	18,577	85,306
Postage/Delivery	4,015	55,935	1,630	166	61,746	3,519	12,685	77,950
Miscellaneous	19,943	2,415	1,076	73	23,507	26,304	14,727	64,538
Supplies	4,440	29,504	1,847	156	35,947	3,329	2,357	41,633
Communications	6,491	6,212	2,396	243	15,342	4,934	2,940	23,216
Insurance - property/liability	2,823	3,501	1,147	116	7,587	2,351	1,400	11,338
Website	529	9,110	20	2	9,661	41	24	9,726
Depreciation	1,406	1,480	571	58	3,515	1,171	697	5,383
Total	<u>\$ 2,215,520</u>	<u>\$ 506,313</u>	<u>\$ 101,745</u>	<u>\$ 71,903</u>	<u>\$ 2,895,481</u>	<u>\$ 286,313</u>	<u>\$ 225,674</u>	<u>\$ 3,407,468</u>

See Accompanying Notes to Financial Statements

# DYSTONIA MEDICAL RESEARCH FOUNDATION

## Statements of Cash Flows For the Years Ended December 31, 2024 and 2023

	<u>2024</u>	<u>2023</u>
Cash Flows from Operating Activities		
Change in net assets	\$ 271,669	\$ 56,466
Adjustments to reconcile change in net assets to net cash provided by (used in) operating activities-		
Realized and unrealized loss (gain) on investments	(178,950)	(381,735)
Depreciation	4,828	5,383
(Increase) decrease in assets-		
Unconditional promises to give	444,116	(455,608)
Other current assets	(12,085)	32,618
Right-of-use asset	47,500	46,440
Increase (decrease) in liabilities-		
Grants and fellowships payable	(64,042)	35,495
Accounts payable and accrued expenses	(4,273)	18,662
Deferred rent payable	-	-
Deferred revenue	(75,000)	(93,573)
Dystonia Coalition agency liability funds	(95,500)	222,421
Operating lease liability	(49,300)	(47,093)
Net Cash Provided by (Used in) Operating Activities	<u>288,963</u>	<u>(560,524)</u>
Cash Flows from Investing Activities:		
Sale of investments	887,657	602,166
Purchase of investments	(1,017,841)	(474)
Purchase of equipment	(4,518)	(4,324)
Net Cash Provided by (Used in) Investing Activities	<u>(134,702)</u>	<u>597,368</u>
Cash Flows from Financing Activities		
Financing lease liability	(4,818)	(4,722)
Net Increase in Cash and Cash Equivalents	149,443	32,122
Cash and Cash Equivalents - Beginning of Year	<u>689,422</u>	<u>657,300</u>
Cash and Cash Equivalents - End of Year	<u>\$ 838,865</u>	<u>\$ 689,422</u>

\* \* \* \* \*

### Supplemental Disclosure of Cash Flow Information

Cash paid during the year for:

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

See Accompanying Notes to Financial Statements

## **DYSTONIA MEDICAL RESEARCH FOUNDATION**

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

December 31, 2024 and 2023

#### **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 85% in 2024 and 80% in 2023 of the Foundation’s operational support came from donations and grants. The balance is from investment income, special events, and other revenue. In 2024, 32% of the Foundation’s support came from two bequests greater than \$100,000 and 16% of the Foundation’s support came from four donors who contributed greater than \$100,000. In 2023, 31% of the Foundation’s support came from five donors who 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. During the year ended December 31, 2023, the final \$78,446 of CDN funds were transferred to the Foundation.

#### **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, 2024 and 2023**

#### **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, 2024 and 2023

#### **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, 2024 and 2023.

##### 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.

## DYSTONIA MEDICAL RESEARCH FOUNDATION

Notes to the Financial Statements  
December 31, 2024 and 2023

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

#### **Revenue Recognition (continued)**

The following table provides information about significant changes in the contract liabilities for the years ended December 31, 2024 and 2023:

	2024	2023
Deferred revenue, beginning of year:	\$ 75,000	\$ 168,573
Revenue recognized that was included in deferred revenue at the beginning of the year	(75,000)	(168,573)
Increase in deferred revenue due to cash received during the period	-	75,000
Total	\$ -	\$ 75,000

#### **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, 2024 and 2023**

#### **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.

##### **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, 2024 and 2023. 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, 2024 and 2023.

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.

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, 2024, 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.

## **DYSTONIA MEDICAL RESEARCH FOUNDATION**

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

December 31, 2024 and 2023

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

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

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.

#### **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, 2024. The Foundation has evaluated its tax positions and determined it has no uncertain tax positions at December 31, 2024. The Foundation's 2021-2024 tax years are open for examination by the IRS and State of Illinois and 2020-2024 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.



## DYSTONIA MEDICAL RESEARCH FOUNDATION

### Notes to the Financial Statements

December 31, 2024 and 2023

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

Donations include \$689,579 and \$739,985 from Directors of the Foundation and organizations they control for the years ended December 31, 2024 and 2023, respectively. Net special event revenue includes \$258,963 and \$269,467 raised by groups or individuals who fund raise on behalf of the Foundation for the years ended December 31, 2024 and 2023, respectively. In addition, the Foundation received \$35,768 in 2024 and \$39,242 in 2023 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.

#### **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, 2024 and 2023, which are available for the following purposes:

	2023	Increase	Decrease	2024
Scientific Research	\$ 589,431	\$ 23,050	\$ -	\$ 612,481
Cure Dystonia Now Fund	417,922	51,287	99,978	369,231
Clinical Fellowships	78,120	-	78,120	-
Cure Dystonia Initiative – Acceleration Fund	291,093	-	-	291,093
Dystonia Coalition Project II	215,455	-	17,283	198,172
Myoclonus Dystonia Research	11,709	-	-	11,709
Myoclonus Dystonia Program	240,156	-	-	240,156
Dorothy Feiss Research Fund	93,018	26,680	8,000	111,698
David Rudolph Research Fund	84,290	26,767	16,097	94,960
Neurocrine Biosciences	-	15,000	-	15,000
Patient/Physician Communication Kits	7,200	-	-	7,200
Other	24,497	2,500	3,500	23,497
Total	<u>\$ 2,052,891</u>	<u>\$ 145,284</u>	<u>\$ 222,978</u>	<u>\$ 1,975,197</u>

# **DYSTONIA MEDICAL RESEARCH FOUNDATION**

## Notes to the Financial Statements

December 31, 2024 and 2023

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

	2022	Increase	Decrease	2023
Scientific Research	\$ 608,429	\$ 25,000	\$ 43,998	\$ 589,431
Cure Dystonia Now Fund	446,017	128,756	156,851	417,922
Clinical Fellowships	154,593	-	76,473	78,120
Cure Dystonia Initiative – Acceleration Fund	291,093	-	-	291,093
Dystonia Coalition Project II	215,455	-	-	215,455
Myoclonus Dystonia Research	82,681	-	70,972	11,709
Myoclonus Dystonia Program	240,156	-	-	240,156
Dorothy Feiss Research Fund	28,350	80,105	15,437	93,018
David Rudolph Research Fund	57,891	26,399	-	84,290
Patient/Physician Communication Kits	7,200	-	-	7,200
Other	21,997	2,500	-	24,497
Total	<u>\$ 2,153,862</u>	<u>\$ 262,760</u>	<u>\$ 363,731</u>	<u>\$ 2,052,891</u>

Net assets with donor restrictions consist of:

	2024	2023
Cash, cash equivalents and short-term investments	\$ 2,364,175	\$ 2,272,726
Grants and fellowships payable	<u>(388,978)</u>	<u>(219,835)</u>
Total	<u>\$ 1,975,197</u>	<u>\$ 2,052,891</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.

## **DYSTONIA MEDICAL RESEARCH FOUNDATION**

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

**December 31, 2024 and 2023**

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

- 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.

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, 2024.

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.

## DYSTONIA MEDICAL RESEARCH FOUNDATION

### Notes to the Financial Statements

December 31, 2024 and 2023

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

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, 2024 and 2023.

At December 31, 2024, 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	\$ 636,013	\$ -	\$ -	\$ 636,013
Certificates of Deposit	-	5,500	-	5,500
US Equity Mtl. Funds	-	1,920,380	-	1,920,380
US Fixed Inc. Mtl. Funds	-	2,360,900	-	2,360,900
Int'l Equity Mtl. Funds	-	225,961	-	225,961
Int'l Fixed Inc. Mtl. Funds	-	136,057	-	136,057
Total	<u>\$ 636,013</u>	<u>\$ 4,648,798</u>	<u>\$ -</u>	<u>\$ 5,284,811</u>

At December 31, 2023, 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	\$ 341,241	\$ -	\$ -	\$ 341,241
Certificates of Deposit	-	5,500	-	5,500
US Equity Mtl. Funds	-	2,135,149	-	2,135,149
US Fixed Inc. Mtl. Funds	-	2,096,270	-	2,096,270
Int'l Equity Mtl. Funds	-	263,298	-	263,298
Int'l Fixed Inc. Mtl. Funds	-	134,219	-	134,219
Total	<u>\$ 341,241</u>	<u>\$ 4,634,436</u>	<u>\$ -</u>	<u>\$ 4,975,677</u>

**DYSTONIA MEDICAL RESEARCH FOUNDATION**

## Notes to the Financial Statements

December 31, 2024 and 2023

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

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

	2024		2023	
	Cost	Fair Value	Cost	Fair Value
Money Market Funds	\$ 636,013	\$ 636,013	\$ 341,241	\$ 341,241
Certificates of Deposit	5,500	5,500	5,500	5,500
US Equity Mutual Funds	1,356,084	1,920,380	1,623,290	2,135,149
US Fixed Inc. Mutual Funds	2,519,188	2,360,900	2,224,819	2,096,270
Int'l Equity Mutual Funds	203,941	225,961	252,950	263,298
Int'l Fixed Inc. Mutual Funds	151,198	136,057	131,231	134,219
	<u>\$ 4,871,924</u>	<u>\$ 5,284,811</u>	<u>\$ 4,579,031</u>	<u>\$ 4,975,677</u>

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

	2024	2023
Interest and dividends	\$ 165,250	\$ 137,703
Net realized and unrealized gain (loss)	178,950	381,735
Advisory fees	(28,633)	(25,761)
	<u>\$ 315,567</u>	<u>\$ 493,677</u>

**Note H – Unconditional Promises to Give**

Unconditional promises to give consists of the following:

	2024	2023
Amounts due in:		
Greater than one year	\$ 5,000	\$ 10,000
Less than one year	79,931	519,047
Total	<u>\$ 84,931</u>	<u>\$ 529,047</u>

# **DYSTONIA MEDICAL RESEARCH FOUNDATION**

## Notes to the Financial Statements

December 31, 2024 and 2023

### **Note I - Leases**

The Foundation is party, 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, 2024, consist of the following:

<u>Cost element</u>	<u>Amount</u>
Operating lease cost	
Amortization of right-of-use assets	\$ 42,681
Interest on lease liabilities	4,542
Total operating lease cost	<u>\$ 47,223</u>
Finance lease cost	
Amortization of right-of-use assets	\$ 4,819
Interest on lease liabilities	144
Total finance lease cost	<u>\$ 4,963</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, 2024, are as follows:

<u>Year Ending December 31,</u>	<u>Operating Leases</u>	<u>Finance Leases</u>
2025	\$ 55,084	\$ 3,124
2026	56,327	689
2027	57,569	-
2028	38,932	-
2029	-	-
Total future minimum lease payments	207,912	3,813
Less: imputed interest included therein	(7,697)	(57)
Net	<u>\$ 200,215</u>	<u>\$ 3,756</u>

The following table provides additional information related to the Foundation's leases as of December 31, 2024:

	<u>Operating Leases</u>	<u>Finance Leases</u>
Current portion of lease liabilities	\$ 51,548	\$ 3,070
Long-term portion of lease liabilities	148,667	686
Total lease liabilities	<u>\$ 200,215</u>	<u>\$ 3,756</u>
Weighted average remaining lease term	4 years	1.5 years
Weighted average discount rate	2.00%	2.00%

## DYSTONIA MEDICAL RESEARCH FOUNDATION

### Notes to the Financial Statements

December 31, 2024 and 2023

#### **Note I – Leases (continued)**

The Foundation has a sublease agreement for a portion of their office space for a term ending June 30, 2026. The sublease agreement requires the sublessee to pay the Foundation monthly rent of \$200 through June 30, 2026.

Rent expense was \$100,987, net of sublease income of \$2,400 and \$98,889, net of sublease income of \$6,000 for the years ended December 31, 2024 and 2023, 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, 2024 and 2023 were \$20,587 and \$24,373, respectively. There were no employer discretionary contributions in 2024 and 2023.

#### **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.

	2024	2023
Financial assets, at year-end:		
Cash and cash equivalents	\$ 838,865	\$ 689,422
Investments	5,284,811	4,975,677
Unconditional promises to give	84,931	529,047
Less contractual or donor-imposed restrictions:		
Cash restricted for Dystonia Coalition	(505,776)	(601,276)
Donor restrictions for specific purposes	(1,975,197)	(2,052,891)
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>\$ 2,227,634</u>	<u>\$ 2,039,979</u>

## **DYSTONIA MEDICAL RESEARCH FOUNDATION**

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

**December 31, 2024 and 2023**

#### **Note L - 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 \$114,984 in 2024 and \$131,579 in 2023.

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 \$15,498 in 2024 and \$19,472 in 2023.

The Foundation also serves as the administrative center for various Dystonia Community Projects. Total receipts for Dystonia Community Projects were \$24,619 in 2024 and \$19,487 in 2023. Total disbursements for Dystonia Community Projects were \$22,500 and \$21,487 in 2024 and 2025. As of December 31, 2024 and 2023, \$0- and \$2,000, 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, 2024 and 2023 was an agency liability of \$505,776 and \$601,276, respectively, for Coalition funds held. The Foundation holds these funds in segregated cash accounts. Agency liabilities for Dystonia Community Projects at December 31, 2024 and 2023 were \$4,456 and \$4,500, respectively.



## **DYSTONIA MEDICAL RESEARCH FOUNDATION**

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

**December 31, 2024 and 2023**

#### **Note M – 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, 2024 and 2023, the Foundation had \$1,460,580 and \$525,473, 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.

#### **Note N – Subsequent Events**

The Foundation has determined that no material events or transactions occurred subsequent to December 31, 2024 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.