

MOEBIUS SYNDROME FOUNDATION

FINANCIAL STATEMENTS

DECEMBER 31, 2021 AND 2020



Certified Public Accountants

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Certified Public Accountants

Independent Auditor's Report

To the Board of Directors
Moebius Syndrome Foundation

Opinion

We have audited the accompanying financial statements of the **Moebius Syndrome Foundation** (a nonprofit organization), which comprise the statements of financial position as of December 31, 2021 and 2020, 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 **Moebius Syndrome Foundation** as of December 31, 2021 and 2020, 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 audits 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 **Moebius Syndrome Foundation** and to meet our other ethical responsibilities in accordance with the relevant ethical requirements relating to our audits. 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 condition or events, considered in the aggregate, that raise substantial doubt about the **Moebius Syndrome 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 are considered material if there is a substantial likelihood that individually or in the aggregate, they would influence the judgement made by a reasonable user based on the financial statements.

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

- Exercise professional judgement 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 **Moebius Syndrome 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 judgement, there are conditions or events, considered in the aggregate, that raise substantial doubt about the Moebius Syndrome 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.

Kositzka, Wicks and Company

Alexandria, Virginia
December 14, 2022

Moebius Syndrome Foundation

Statements of Financial Position December 31,

2021**2020****Assets****Current assets**

Cash and cash equivalents	\$ 128,954	\$ 34,712
Investments	2,195,388	1,553,870
Prepaid expenses	69,492	423
Total assets	<u>\$ 2,393,834</u>	<u>\$ 1,589,005</u>

Liabilities and net assets**Current liabilities**

Accounts payable and accrued expenses	\$ -	\$ 2,388
Grants payable, current portion	71,000	60,000
	<u>71,000</u>	<u>62,388</u>

Long-term liabilities

Grants payable	-	111,000
Total liabilities	<u>71,000</u>	<u>173,388</u>

Net assets

Without donor restrictions	2,180,398	1,413,617
With donor restrictions	142,436	2,000
Total net assets	<u>2,322,834</u>	<u>1,415,617</u>
Total liabilities and net assets	<u>\$ 2,393,834</u>	<u>\$ 1,589,005</u>

The accompanying independent auditor's report and notes are an integral part of the financial statements.

Moebius Syndrome Foundation

Statement of Activities for the year ended December 31, 2021

	Without donor restrictions	With donor restrictions	Total
Revenue			
Contributions	\$ 848,452	\$ 140,436	\$ 988,888
Investment income, net	102,071	-	102,071
	<u>950,523</u>	<u>140,436</u>	<u>1,090,959</u>
Expenses			
Program services			
Conference expenses	60,875	-	60,875
Research and support	71,219	-	71,219
Administrative expenses	45,365	-	45,365
Fundraising	6,283	-	6,283
	<u>183,742</u>	<u>-</u>	<u>183,742</u>
Change in net assets	766,781	140,436	907,217
Net assets, beginning of year	1,413,617	2,000	1,415,617
Net assets, end of year	<u>\$ 2,180,398</u>	<u>\$ 142,436</u>	<u>\$ 2,322,834</u>

The accompanying independent auditor's report and notes are an integral part of the financial statements.

Moebius Syndrome Foundation

Statement of Activities for the year ended December 31, 2020

	Without donor restrictions	With donor restrictions	Total
Revenue			
Contributions	64,075	2,150	66,225
Investment income, net	125,550	-	125,550
Other income	100	-	100
Net assets released	1,150	(1,150)	-
	<u>190,875</u>	<u>1,000</u>	<u>191,875</u>
Expenses			
Program services			
Conference expenses	52,357	-	52,357
Research and support	324,070	-	324,070
Administrative expenses	46,165	-	46,165
Fundraising	4,915	-	4,915
	<u>427,507</u>	<u>-</u>	<u>427,507</u>
Change in net assets	(236,632)	1,000	(235,632)
Net assets, beginning of year	1,650,249	1,000	1,651,249
Net assets, end of year	<u>\$ 1,413,617</u>	<u>\$ 2,000</u>	<u>\$ 1,415,617</u>

The accompanying independent auditor's report and notes are an integral part of the financial statements.

Moebius Syndrome Foundation

Statement of Functional Expenses for the year ended December 31, 2021

	Program expenses			Administrative	Fundraising	Total expenses
	Conference	Research and support	Total			
Administrative expenses	\$ 10,918	\$ 12,903	\$ 23,821	\$ 13,801	\$ -	\$ 37,622
Insurance	-	99	99	1,217	-	1,316
Professional fees	-	-	-	14,050	-	14,050
Promotional marketing and newsletter	6,379	10,288	16,667	126	-	16,793
Scholarships	-	8,000	8,000	-	-	8,000
Salaries	42,330	39,929	82,259	16,171	6,283	104,713
Travel	1,248	-	1,248	-	-	1,248
Total functional expenses	\$ 60,875	\$ 71,219	\$ 132,094	\$ 45,365	\$ 6,283	\$ 183,742

The accompanying independent auditor's report and notes are an integral part of the financial statements.

Moebius Syndrome Foundation

Statement of Functional Expenses for the year ended December 31, 2020

	Program expenses			Administrative	Fundraising	Total expenses
	Conference	Research and support	Total			
Administrative expenses	\$ 10,529	\$ 8,930	\$ 19,459	\$ 14,532	\$ -	\$ 33,991
Board expenses	328	1,073	1,401	3,000	-	4,401
Conference expenses	3,844	1,751	5,595	-	-	5,595
Insurance	-	-	-	1,407	-	1,407
Moebius Awareness Day	-	1,000	1,000	-	-	1,000
Computer expenses	200	5,900	6,100	-	-	6,100
Professional fees	-	-	-	14,500	-	14,500
Promotional marketing and newsletter	10,810	21,765	32,575	-	-	32,575
Research awards	-	234,344	234,344	-	-	234,344
Scholarships	-	10,000	10,000	-	-	10,000
Salaries	24,962	39,307	64,269	12,726	4,915	81,910
Travel	1,684	-	1,684	-	-	1,684
Total functional expenses	\$ 52,357	\$ 324,070	\$ 376,427	\$ 46,165	\$ 4,915	\$ 427,507

The accompanying independent auditor's report and notes are an integral part of the financial statements.

Moebius Syndrome Foundation

Statements of Cash Flows for the years ended December 31,

2021**2020****Cash flows from operating activities**

Change in net assets	\$ 907,217	\$ (235,632)
Adjustments to reconcile change in net assets to net cash used in operating activities		
Unrealized gains on investments	(64,420)	(109,839)
(Increase) decrease in operating assets		
Prepaid expenses	(69,069)	17,844
Increase (decrease) in operating liabilities		
Accrued expenses	(2,388)	2,023
Grants payable	(100,000)	(20,000)
Net cash provided by (used in) operating activities	<u>671,340</u>	<u>(345,604)</u>

Cash flows from investing activities

Purchases of investments and reinvestments	(1,137,098)	-
Proceeds from investments	<u>560,000</u>	<u>5,037</u>
Net cash (used in) provided by investing activities	<u>(577,098)</u>	<u>5,037</u>

Net change in cash and cash equivalents

94,242 (340,567)

Cash and cash equivalents, beginning of year

34,712 375,279

Cash and cash equivalents, end of year\$ 128,954 \$ 34,712**Supplemental disclosure of cash flow information**

Cash paid for interest	<u>\$ -</u>	<u>\$ -</u>
Income taxes paid	<u>\$ -</u>	<u>\$ -</u>

The accompanying independent auditor's report and notes are an integral part of the financial statements.

Moebius Syndrome Foundation

Notes to Financial Statements December 31, 2021 and 2020

1. Organization

The Moebius Syndrome Foundation (the Foundation) is a 501(c)(3) nonprofit organization, founded in 1994. The Foundation strives to provide information and support to individuals with Moebius syndrome and their families, promote greater awareness and understanding of Moebius syndrome, and to advocate for scientific research to advance the diagnosis and treatment of Moebius syndrome and its associated conditions. The Foundation's revenue is generated from contributions and conferences. In 2021, the conferences were postponed due to the COVID-19 pandemic.

2. Significant accounting policies

Basis of accounting

The accompanying financial statements are prepared on the accrual method of accounting in conformity with accounting principles generally accepted in the United States of America (U.S. GAAP).

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 in two categories as described below.

Net assets without donor restrictions are net assets available for use in general operations and not subject to donor restrictions.

Net assets with donor restrictions are net assets subject to donor-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.

Revenue recognition

The Foundation recognizes contributions when cash, securities or other assets, an unconditional promise to give, or notification of a beneficial interest is received. Conditional promises to give, that is, those with a measurable performance or other barrier, and a right of return, are not recognized until the conditions on which they depend have been substantially met.

The Foundation records conference revenue as an exchange transaction. The benefit is transferred when the conference occurs, at a point in time. Payments received before the event are recorded as deferred revenue.

Cash and cash equivalents

For purposes of the statements of cash flows, Moebius Syndrome Foundation considers all cash and unrestricted highly liquid investments with an initial maturity of three months or less to be cash equivalents. FDIC insurance is \$250,000 per depositor, per insured bank. At December 31, 2021 and 2020, cash did not exceed the FDIC limit.

Investments

The Foundation records investment purchases at cost, or if donated, at fair value on the date of donation. Thereafter, investments are reported at their fair values in the statements of financial position. Net investment income is reported in the statements of activities and consists of interest and dividend income, realized and unrealized capital gains and losses, and external and direct internal investment expenses.

See independent auditor's report.

Moebius Syndrome Foundation

Notes to Financial Statements December 31, 2021 and 2020

Income tax status

Moebius Syndrome Foundation is exempt from income taxes under Section 501(c)(3) of the Internal Revenue Code. Income from certain activities not directly related to the Organization's exempt purpose is subject to taxation as unrelated business income. The Foundation had no unrelated business income for the years ended December 31, 2021 and 2020.

The material jurisdictions subject to potential examination by taxing authorities are the United States and Missouri. The Board does not believe that the ultimate outcome of any future examinations of open tax years will have a material impact on Moebius Syndrome Foundation's results of operations. Tax years that remain subject to examination by the IRS are fiscal years 2018 through 2021.

Use of estimates

The preparation of financial statements in conformity with U.S. GAAP requires management to make estimates and assumptions that affect certain reported amounts of assets and liabilities and disclosures of contingent assets and liabilities and the reported amounts of revenues and expenses. Management believes that the estimates and assumptions are reasonable in the circumstances; however, actual results could differ from those estimates.

Contributions

The Foundation receives contributions, with and without restrictions, as a main source of revenue. Contributions are considered an exchange transaction based on the value of benefits provided. For the year ended December 31, 2021, one member's contribution accounted for 51 percent of total contributions received.

Other financial assets and liabilities

Financial assets with carrying values approximating fair value include cash and cash equivalents and prepaid expenses. Financial liabilities with carrying values approximating fair value include accounts payable, accrued expenses and grants payable. The carrying value of these financial assets and liabilities approximates fair value due to their short maturities.

Functional classification of expenses

The costs of program and supporting services have been summarized on a functional basis in the statements of activities. The statement of functional expenses present the natural classification detail of expenses by function. Expenses are charged to programs and supporting services based on a combination of specific identification and allocation by management. Certain categories of expenses are attributed to more than one function and have been allocated on a reasonable basis that is consistently applied. Expenses that are allocated on a time-and-effort basis include salaries and administrative expenses.

Grants payable

Grants authorized but unpaid at year-end are reported as liabilities. Grants to be paid over the course of more than one year will be discounted based on the Foundation's borrowing rate determined by the timing of grant payments. Any discount recorded would be amortized and reported with the research awards on the statements of functional expenses. Management assessed the discount to be recorded for the years ended December 31, 2021 and 2020 and determined it was immaterial to the financial statements as a whole and therefore not reported.

See independent auditor's report.

Moebius Syndrome Foundation

Notes to Financial Statements December 31, 2021 and 2020

3. Liquidity and availability

Financial assets available for general expenditure, that is, without donor or other restrictions limiting their use, within one year of the statement of financial position date, include the following assets at December 31, 2021 and 2020:

	2021	2020
Cash and cash equivalents	\$ 128,954	\$ 33,712
Investments	2,195,388	1,553,870
	<u>2,324,342</u>	<u>1,587,582</u>
Less amounts with restrictions	(142,436)	(2,000)
	<u>\$ 2,181,906</u>	<u>\$ 1,585,582</u>

The Foundation's goal is to maintain financial assets at a level equal to 90-180 days of their operating expenses.

4. Investments and fair value measurements

The Foundation maintains its investments at fair market value, based on quoted prices in active markets, and accordingly, recognizes the gains or losses that result from market fluctuations for the period in which fluctuations occur. Purchased investments are initially recorded at cost and donated investments at fair value on date of receipt. Unrealized gains and losses are included in the statements of activities.

Moebius Syndrome Foundation classifies its investment into Level 1, which refers to securities valued using quoted prices from active markets for identical assets; Level 2, which refers to securities not traded on an active market but for which observable market inputs are readily available; and Level 3, which refers to securities valued based on significant unobservable inputs. Assets and liabilities are classified in their entirety based on the lowest level of input that is significant to the fair value measurement.

Investments consisted of the following on December 31, 2021:

	Level 1	Level 2	Level 3	Total
Cash and money market funds	\$ 123,952	\$ -	\$ -	\$ 123,952
Bond funds	756,684	-	-	756,684
Equity funds	675,025	-	-	675,025
Exchange traded funds	639,727	-	-	639,727
	<u>\$ 2,195,388</u>	<u>\$ -</u>	<u>\$ -</u>	<u>\$ 2,195,388</u>

See independent auditor's report.

Moebius Syndrome Foundation

Notes to Financial Statements December 31, 2021 and 2020

Investments consisted of the following on December 31, 2020:

	<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>	<u>Total</u>
Cash and money market funds	\$ 179,351	\$ -	\$ -	\$ 179,351
Bond funds	294,742	-	-	294,742
Equity funds	534,017	-	-	534,017
Exchange traded funds	545,760	-	-	545,760
	<u>\$ 1,553,870</u>	<u>\$ -</u>	<u>\$ -</u>	<u>\$ 1,553,870</u>

Investment income consisted of the following for the years ended December 31, 2021 and 2020:

	<u>2021</u>	<u>2020</u>
Interest and dividends	\$ 49,048	\$ 26,816
Unrealized gain	64,420	109,839
Fees	(11,397)	(11,105)
	<u>\$ 102,071</u>	<u>\$ 125,550</u>

5. Net assets with donor restrictions

Contributions received are recorded as revenue with or without donor restrictions depending on the existence and/or nature of any donor restrictions. Donor-restricted revenue is reported as an increase in net assets with donor restrictions. When a restriction expires (that is, when a stipulated time restriction ends or purpose restriction is accomplished), net assets with donor restrictions are reclassified to net assets without donor restrictions and reported in the statements of activities as net assets released from restrictions.

At December 31, 2021 and 2020, the Foundation had net assets with donor restrictions totaling \$140,436 and \$2,000, respectively.

	<u>12/31/2020</u>	<u>Additions</u>	<u>Releases</u>	<u>12/31/2021</u>
Restricted for specific purposes				
Conference	\$ -	\$ 4,691	\$ -	\$ 4,691
Research	-	124,746	-	124,746
Educational	-	6,500	-	6,500
Sponsorship	2,000	2,500	-	4,500
	<u>\$ 2,000</u>	<u>\$ 138,436</u>	<u>\$ -</u>	<u>\$ 140,436</u>
	<u>12/31/2019</u>	<u>Additions</u>	<u>Releases</u>	<u>12/31/2020</u>
Restricted for specific purposes				
Sponsorship	\$ 1,000	\$ 2,150	\$ (1,150)	\$ 2,000

See independent auditor's report.

Moebius Syndrome Foundation

Notes to Financial Statements December 31, 2021 and 2020

6. Grants payable

The Moebius Syndrome Foundation is committed to funding research related to Moebius syndrome and its associated conditions, per the mission statement. As of 2020 the Foundation has provided research funding for six Research Symposiums (2007, 2010, 2012, 2014, 2016 and 2018) as well as numerous grants to researchers. Funding priorities of the Moebius Syndrome Foundation include:

- To advance the diagnosis, treatment, and/or quality of life of people with Moebius syndrome and its associated conditions.
- To promote sustainable and comprehensive programs of research focused on Moebius syndrome by providing “seed funds” for larger research programs and grant submissions to larger funding organizations.

Hospital for Sick Children, Toronto, ON

In 2016, Gregory Borschel, MD and Ronald Zuker, MD were awarded \$124,000 to research the long-term outcomes of facial reanimation in young adults with Moebius syndrome. The final installment of \$31,000 was paid in 2021.

Hospital for Sick Children, Toronto, ON

In 2020, Gregory Borschel, MD was awarded \$210,000 to research surgical treatment to enhance dynamic eyelid closure in patients with Moebius syndrome. \$70,000 was paid in 2021 and 2020. Dr. Borschel’s research project was transferred and the final payment will be made to Riley Hospital for Children in Indiana in 2022.

7. Subsequent events

Moebius Syndrome Foundation assessed events occurring subsequent to December 31, 2021 through December 14, 2022, the date the financial statements were available to be issued, for potential recognition and disclosure in the financial statements. In April 2022, the Foundation’s board designated approximately \$500,000 for the CranioFacial Endowment. No other events have occurred that would require adjustment to or disclosure in the financial statements.