# **Dravet Syndrome** Foundation

Dravet Syndrome Foundation, Inc.

# Financial Statements with Independent Auditor's Report

Years Ended December 31, 2023 and 2022

# **Table of Contents**

# Page Independent Auditor's Report 1 - 2 Financial Statements: 1 - 2 Statements of Financial Position at December 31, 2023 and 2022 3 Statements of Activities for the Years Ended December 31, 2023 and 2022 4 Statements of Cash Flows for the Years Ended December 31, 2023 and 2022 5 Statements of Functional Expenses for the Years Ended December 31, 2023 and 2022 6 - 7 Notes to Financial Statements 8 - 17



#### Independent Auditor's Report

To the Board of Directors of Dravet Syndrome Foundation, Inc. Cherry Hill, New Jersey

#### Opinion

We have audited the accompanying financial statements of Dravet Syndrome Foundation, Inc. (a nonprofit organization), which comprise the statements of financial position as of December 31, 2023 and 2022, 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 Dravet Syndrome Foundation, Inc. as of December 31, 2023 and 2022, 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 Dravet Syndrome Foundation, Inc. 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 conditions or events, considered in the aggregate, that raise substantial doubt about Dravet Syndrome Foundation, Inc.'s ability to continue as a going concern within one year after the date that the financial statements are available to be issued.

123 South Main Street • Suite 140 • Newtown, CT 06470

#### 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 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 Dravet Syndrome Foundation, Inc.'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 Dravet Syndrome Foundation, Inc.'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.

Nanavaty, Davenport, Studley & White, LLP

March 18, 2024

# **Statements of Financial Position**

At December 31,

Assets	2023	2022			
Cash and cash equivalents	\$ 940,715	\$	1,008,939		
Investments	6,443,876		5,167,263		
Contributions receivable	36,608		54,682		
Prepaid expenses	83,285		11,792		
Other assets	5,418		6,472		
Total Assets	\$ 7,509,902	\$	6,249,148		
Liabilities and Net Assets					
Liabilities:					
Accounts payable	\$ 531,404	\$	337,231		
Deferred revenue	 63,762		151,143		
Total Liabilities	 595,166		488,374		
Net Assets:					
Net assets without donor restrictions	6,887,248		5,548,913		
Net assets with donor restrictions	27,488		211,861		
Total Net Assets	 6,914,736		5,760,774		
Total Liabilities and Net Assets	\$ 7,509,902	\$	6,249,148		

# Statements of Activities

For the Years Ended December 31,

Net Assets Without Donor Restrictions	2023	2022			
Revenues and Other Support:					
Special events - revenue	<b>\$ 1,629,770</b>	\$ 1,010,374			
- expenses	(283,205)	(217,673)			
- net	1,346,565	792,701			
Program service revenue	471,472	662,596			
Contributions and grants	1,158,864	758,180			
Investment return, net	278,332	35,591			
Total Unrestricted Revenues and Other Support	3,255,233	2,249,068			
Net Assets Released from Restrictions	246,154	103,310			
Total Revenues and Other Support	3,501,387	2,352,378			
Expenses:					
Program services	1,659,417	1,638,548			
Management and general	374,423	311,273			
Fundraising	129,212	79,018			
Total expenses	2,163,052	2,028,839			
Change in net assets without donor restrictions	1,338,335	323,539			
Net Assets With Donor Restrictions					
Contributions	61,781	213,941			
Net assets released from restriction	(246,154)	(103,310)			
Change in net assets with donor retrictions	(184,373)	110,631			
Change in net assets	1,153,962	434,170			
Net assets at beginning of year	5,760,774	5,326,604			
Net assets at end of year	\$ 6,914,736	\$ 5,760,774			

# Statements of Cash Flows

# For the Years Ended December 31,

	2023	2022			
Cash Flows from Operating Activities:					
Change in net assets	\$ 1,153,962	\$	434,170		
Adjustments to reconcile change in net assets to					
net cash provided by operating activities					
Net realized and unrealized (gain) loss on investments	(59,918)		52,772		
Changes in operating assets and liabiliies:					
(Increase) decrease in:					
Contributions receivable	18,074		(6,152)		
Prepaid expenses	(71,493)		49,313		
Other assets	1,054		(6,472)		
Increase (decrease) in:					
Accounts payable	194,173		84,932		
Deferred revenue	 (87,381)		(188,881)		
Net cash provided by operating activities	 1,148,471		419,682		
Cash Flows from Investing Activities:					
Purchase of investments	 (1,216,695)		(837,482)		
Net cash used in investing activities	 (1,216,695)		(837,482)		
Net decrease in cash and cash equivalents	(68,224)		(417,800)		
Cash and cash equivalents at beginning of year	1,008,939		1,426,739		
Cash and cash equivalents at end of year	\$ 940,715	\$	1,008,939		

#### Statement of Functional Expenses

For the Year Ended December 31, 2023

	Patient and Family			Professional Education and		Total Program		Mana	agement and						
	5	Services	Ν	Aeetings	R	lesearch		ervices		General	Fur	Fundraising		Total	
Salaries	\$	140,093	\$	42,178	\$	127,582	\$	309,853	\$	246,504	\$	90,040	\$	646,397	
Payroll taxes		11,338		3,130		9,231		23,699		18,996		6,893		49,588	
Grants		400		-		918,166		918,566		-		-		918,566	
Conferences and meetings		98,893		77,414		18,101		194,408		14,912		6,422		215,742	
Professional fees		109,331		26,202		23,250		158,783		48,762		247		207,792	
Dues and subscriptions		1,623		243		93		1,959		14,622		11,719		28,300	
Bank charges		228		108		22		358		14,204		101		14,663	
Patient assistance		36,572		-		-		36,572		-		-		36,572	
Postage		4,772		471		-		5,243		1,423		561		7,227	
Office supplies		8,076		514		-		8,590		6,739		4,612		19,941	
Taxes, licenses and fees		-		-		-		-		4,588		-		4,588	
Insurance		1,055		29		14		1,098		2,270		2,066		5,434	
Advertising		-		-		-		-		-		514		514	
Printing		-		-		-		-		1,247		5,893		7,140	
Telephone		144	_	144		-		288		156		144		588	
Total expenses	\$	412,525	\$	150,433	\$	1,096,459	\$	1,659,417	\$	374,423	\$	129,212	\$	2,163,052	

#### Statement of Functional Expenses

For the Year Ended December 31, 2022

	]	tient and Family ervices	Ed	ofessional ucation and Meetings	Total Program Research Services		m Management and			ndraising	Total		
Salaries	\$	52,501	\$	22,839	\$ 135,603	\$	210,943	\$	200,812	\$	55,509	\$	467,264
Payroll taxes		4,398		1,714	10,145		16,257		15,778		4,406		36,441
Grants		140		-	667,345		667,485		-		-		667,485
Conferences and meetings		333,500		96,634	4,586		434,720		6,595		2,298		443,613
Professional fees		140,827		30,888	34,088		205,803		48,929		-		254,732
Dues and subscriptions		1,060		728	273		2,061		9,428		4,513		16,002
Bank charges		1,539		3	3		1,545		5,689		3,597		10,831
Patient assistance		26,213		-	-		26,213		-		-		26,213
Postage		9,189		-	-		9,189		2,040		723		11,952
Office supplies		9,541		1,417	137		11,095		11,383		3,441		25,919
Taxes, licenses and fees		-		-	-		-		4,635		-		4,635
Insurance		1,169		64	371		1,604		1,580		2,210		5,394
Advertising		6,581		-	-		6,581		332		333		7,246
Printing		3,166		-	-		3,166		3,862		1,776		8,804
Telephone		210		210	-		420		210		212		842
Other expenses		41,466		-	-		41,466		-		-		41,466
Total expenses	\$	631,500	\$	154,497	\$ 852,551	\$	1,638,548	\$	311,273	\$	79,018	\$	2,028,839

#### Note 1 - Organization

The Dravet Syndrome Foundation, Inc. (DSF) was incorporated as a nonprofit, publicly supported corporation on September 24, 2009 under the laws of the State of Connecticut. DSF was formed to promote and support research regarding Dravet syndrome and related epilepsies. DSF funds research towards better treatments and a cure of Dravet syndrome and related epilepsies by awarding research grants to qualified scientists and doctors. DSF produces an annual Research Roundtable Meeting to provide the opportunity for researchers and clinicians to collaborate and discuss better treatment options and a roadmap toward a cure and how to best facilitate both. Through the International Patience Assistance Grant Program, DSF provides grants to cover expenses not covered by medical insurance.

#### Note 2 - Summary of Significant Accounting Policies

#### **Basis of Accounting and Presentation**

The accompanying financial statements have been prepared on the accrual basis of accounting in accordance with accounting principles generally accepted in the United States of America. Accordingly the accounts of DSF are reported in the following net assets classifications:

**Net assets without donor restrictions** – Net assets without donor restrictions are not subject to donor-imposed restrictions and may be expended for any purpose in performing the primary objectives of DSF. These net assets may be used at the discretion of DSF's management and Board of Directors.

**Net assets with donor restrictions** – Net assets with donor restrictions are subject to stipulations imposed by donors and grantors. Some donor restrictions are temporary in nature; those restrictions will be met by actions of DSF or by the passage of time. Other donor restrictions are perpetual in nature, where by the donor has stipulated the funds be maintained in perpetuity.

Donor restricted contributions are reported as increases in net assets with donor restrictions. When a restriction expires, net assets are reclassified from net assets with donor restrictions to net assets without donor restrictions in the statements of activities.

#### Note 2 - Summary of Significant Accounting Policies (continued)

#### Cash and Cash Equivalents

For financial statement purposes, DSF considers funds in demand deposits, certificates of deposit, money market funds and all highly liquid debt instruments purchased with a maturity of three months or less to be cash equivalents.

#### **Contributions Receivable**

Accounts receivable are stated at the amount management expects to collect from outstanding balances. Management believes all amounts are collectible from the donors.

#### Income Taxes

DSF is exempt from income taxes under Section 501(c)(3) of the Internal Revenue Code. A ruling from the Internal Revenue Service has determined that DSF will be treated as a publicly supported organization, and not a private foundation. This qualifies DSF for the 50% charitable contribution deduction for individual donors. Consequently, the accompanying financial statements do not include any provision for income taxes.

DSF recognizes the effect of tax positions only when they are more than likely than not of being sustained. Management has determined that DSF had no uncertain tax positions that qualify for either recognition or disclosure in the financial statements. In the normal course of business DSF's tax filings are subject to examination by federal and state authorities. The tax returns for the years ended December 31, 2020 and forward are subject to examination by taxing authorities.

#### **Functional Expenses**

DSF allocates its expenses on a functional basis among its various programs. Expenses that can be identified with a specific program are allocated directly according to their natural expense classification. Common expenses that benefit all functional areas of DSF (personnel costs, professional fees, supplies, office expenses) are allocated to the various programs based on a percentage of payroll costs charged to the specific program in relation to total payroll costs of DSF as a whole. Other costs have been allocated between the program and supporting services benefited. Such allocations are determined by management on an equitable basis.

# Notes to Financial Statements

#### Note 2 - Summary of Significant Accounting Policies (continued)

#### Use of Estimates

The preparation of financial statements in conformity with generally accepted accounting principles requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities and disclosures of contingent assets and liabilities at the date of the financial statements. They also affect the reported amounts of revenues and expenses during the reporting period. Actual results could differ from those estimates.

#### Investments

Investments in equity securities with readily determinable fair market values and all investments in debt instruments are reported at fair value in the statement of financial position. Realized gains or losses and unrealized appreciation or depreciation are reflected in the accompanying statement of activities. If received as a donation, the investment is stated at fair value at the date of donation.

#### **Revenue and Revenue Recognition**

DSF recognizes contributions when cash, securities or other assets; an unconditional promise to give; or a 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 are met.

In accordance with financial accounting standards, DSF records contributions received as without donor restrictions or with donor restrictions depending on the existence and or nature of any donor restrictions. Restricted net assets are reclassified to net assets without donor restrictions upon the satisfaction of the time or purpose restrictions.

All contributions are considered to be available for unrestricted use unless specifically restricted by the donor. Support that is restricted by the donor for particular operating purposes or for fixed asset acquisitions is reported as an increase in net assets without donor restrictions if the restriction expires in the reporting period in which the support is recognized.

DSF recognizes program/grant revenue in the year the program takes place. Any revenue received during the fiscal year for a program/grant that has not taken place is considered deferred revenue. DSF records special events revenue equal to the fair value of direct benefits to donors and contribution income for the excess received when the event takes place.

#### Note 2 - Summary of Significant Accounting Policies (continued)

Contributed services are recognized in the financial statements if they enhance nonfinancial assets or require specialized skills, are provided by individuals possessing those skills, and would typically need to be purchased if not provided by donation. While many individuals volunteer their time, and perform a variety of tasks that assist DSF, no amounts have been recognized in the accompanying financial statements for such services because the criteria for recognition of such volunteer efforts have not been met.

#### Subsequent Events

In preparing these financial statements, management has evaluated subsequent events through March 18, 2024, which represents the date the financial statements were available to be issued. There were no subsequent events that require disclosure.

#### Note 3 - Donated Services, Materials, Facilities

DSF received donated services from unpaid volunteers. No amounts have been recognized in the accompanying statement of activities because the criteria for recognition of such volunteer effort under Accounting Standards Codification (ASC) 958 have not been satisfied. The contributions of services are recognized if the services received (a) create or enhance nonfinancial assets or (b) require specialized skills that are provided by individuals possessing those skills and would typically need to be purchased if not provided by donation.

#### Note 4 - Concentrations of Credit and Market Risk

#### **Cash Balances**

DSF maintains its cash and cash equivalents in one financial institution. The balances are insured by the Federal Deposit Insurance Corporation at each institution up to \$250,000. The balances may at times during the year exceed the FDIC limit; however, DSF does not feel that there is any significant credit risk.

#### Investments

Investments in marketable securities with readily determinable fair values are reported at their fair values in the statement of financial position. Realized gains or losses and unrealized appreciation or depreciation are reflected in the accompanying statement of activities. The value of these investments is subject to fluctuations due to general market conditions and interest rates.

# Notes to Financial Statements

#### Note 5 - Fair Value Measurements

The Financial Accounting Standards Board ("FASB") Topic 820, under the FASB Accounting Standards Codification ("ASC") defines fair value, establishes a framework for measuring fair value, and expands disclosures about fair value measurements. This standard provides a consistent definition of fair value, which focuses on an exit price between market participants in an orderly transaction.

The standard also prioritizes the use of observable inputs and minimizes the use of unobservable inputs by requiring that observable inputs be used when available.

Observable inputs are inputs that market participants would use in pricing the respective asset or liability based on market data obtained from independent sources. Unobservable inputs reflect assumptions that market participants would use in pricing the asset or liability based on the best information available in the circumstances. The hierarchy is categorized into three levels based on the transparency of inputs as follows:

- Level 1 Quoted prices are available in active markets for identical assets or liabilities as of the report date. A quoted price for an identical asset or liability in an active market provides the most reliable fair value measurement because it is directly observable to the market.
- Level 2 Pricing inputs are other than quoted prices in active markets, which are either directly or indirectly observable as of the report date. The nature of these securities includes investments for which quoted prices are available but traded less frequently and investments that are fair valued using other securities, the parameters of which can be directly observed. Also included in Level 2 are investments measured using a net asset value ("NAV") per share, or its equivalent, that may be redeemed at NAV at the date of the statement of financial position or in the near term, which DSF has determined to be within 90 days.
- Level 3 Investments that have little to no pricing observability as of the report date. These investments are measured using management's best estimate of fair value, where the inputs into the determination of fair value are not observable and require significant management judgment or estimation.

# Notes to Financial Statements

#### Note 5 - Fair Value Measurements (continued)

Inputs are used in applying the various valuation techniques and broadly refer to the assumptions that market participants use to make valuation decisions, including assumptions about risk. Inputs may include price information, volatility statistics, specific and broad credit data, liquidity statistics, and other factors. A financial instrument's level within the fair value hierarchy is based on the lowest level of any input that is significant to the fair value measurement. However, the determination of what constitutes "observable" requires significant judgment by DSF.

DSF considers observable data to be market data that is readily available, regularly distributed or updated, reliable and verifiable, not proprietary, and provided by independent sources that are actively involved in the relevant market.

The categorization of a financial instrument within the hierarchy is based upon the pricing transparency of the instrument and does not necessarily correspond to DSFs' perceived risk of that instrument.

DSF's policy is to recognize transfers in and transfers out of levels at the end of the reporting period.

The following is a description of the valuation methodologies used for assets measured at fair value:

**Common Stocks and Mutual Funds** - These items are valued at the closing price reported in the active market in which the individual securities are traded.

There have been no changes in the methodologies used at December 31, 2023.

Assets Measured at Fair-Value on a Recurring Basis - The following is a summary of the source of fair-value measurements for assets that are measured at fair-value on a recurring basis as of December 31:

	2023	2022
Investment	Level 1	Level 1
Mutual funds	\$ 6,443,876	\$ 5,167,263
Total investments at fair value	\$ 6,443,876	\$ 5,167,263

#### Notes to Financial Statements

#### Note 5 - Fair Value Measurements (continued)

Investment return, net is comprised of the following at December 31:

	2023		 2022
Dividends and interest	\$	218,414	\$ 88,363
Unrealized gain (loss)		59,918	 (52,772)
Investment return, net	\$	278,332	\$ 35,591

#### Note 6 - Availability and Liquidity

The following represents DSF's financial assets at December 31:

DSF's goal is generally to maintain financial assets by receiving support from various sources including individual, corporate, foundation and Board contributions, fundraising events, as well as income from investment sources.

Financial Assets at year-end:	2023	2022
Cash and cash equivalents	\$ 940,715	\$ 1,008,939
Investments	6,443,876	5,167,263
Contributions receivable	36,608	54,682
	7,421,199	6,230,884
Less: Net assets with donor restrictions	(27,488)	(211,861)
Financial assets to meet general expenditures over the next twelve		
months	\$ 7,393,711	\$ 6,019,023

# Notes to Financial Statements

#### Note 7 - Board Designated Endowment

DSF's endowment consists of funds established for the purpose is to provide an alternative source of funds to support the operations of DSF. Its endowment includes funds designated by the Board of Directors to function as endowment. As required by accounting principles generally accepted in the United States of America, net assets associated with endowment funds, including funds designated by the Board of Directors to function as endowment, are classified and reported based on the existence or absence of donor-imposed restrictions.

**Interpretation of Relevant Law** - The Board of Directors of DSF has interpreted the Connecticut Prudent Management of Institutional Funds Act (CTPMIFA) as requiring the preservation of the fair value of the original gift as of the gift date of the donor-restricted endowment funds, absent explicit donor stipulations to the contrary. As a result of this interpretation, DSF classifies as permanently restricted net assets (a) the original value of gifts donated to the permanent endowment, (b) the original value of subsequent gifts to the permanent endowment, and (c) accumulations to the permanent endowment made in accordance with the direction of the applicable donor gift instrument at the time the accumulation is added to the fund. The remaining portion of the donor-restricted endowment fund that is not classified in permanently restricted net assets is classified as temporarily restricted net assets until those amounts are appropriated for expenditure by DSF in a manner consistent with the standard of prudence prescribed by CTPMIFA.

In accordance with CTPMIFA, DSF considers the following factors in making a determination to appropriate or accumulate donor-restricted endowment funds:

- The duration and preservation of the fund
- The purposes of the organization and the donor-restricted endowment fund
- The investment policies of the organization
- General economic conditions
- The possible effect of inflation and deflation
- The expected total return from income and the appreciation of investments
- Other resources of the organization

#### Note 7 - Board Designated Endowment (continued)

Changes in endowment net assets is as follows:

	Without
	Donor
	Restrictions
Endowment net assets December 31, 2021	275,171
Investment income, net	(46,491)
Endowment net assets December 31, 2022	228,680
Contributions and investment income	320,899
Endowment net assets December 31, 2023	\$ 549,579

**Funds with Deficiencies** - From time to time, the fair value of investments associated with donorrestricted endowment funds may fall below the level that the donor or CTPMIFA requires DSF to retain as a fund of perpetual duration. In accordance with GAAP, deficiencies of this nature are reported in unrestricted net assets. There were no funds with deficiencies as of December 31,2023, and December 31, 2022.

**Return Objectives and Risk Parameters** - DSF has adopted an investment policy for endowment assets that attempts to provide a predictable stream of funding to programs supported by its endowment while seeking to maintain the purchasing power of the endowment assets. Endowment assets include board designated assets that DSF must hold in perpetuity. Under this policy, as approved by the Board of Directors, endowment assets are invested in a manner that is intended to meet DSF's primary objective of preservation of their capital investments and the secondary objective of long-term capital appreciation.

**Strategies Employed for Achieving Objectives** - To satisfy its long-term rate-of-return objectives, DSF currently relies on a strategy of investing in mutual funds in which investment returns are achieved through capital appreciation (realized and unrealized).

**Spending Policy and How the Investment Objectives Relate to Spending Policy** – DSF's Board of Directors evaluates each fiscal year any investment returns will be considered eligible for a contribution to DSF's operating expenses budget at the discretion of the Board of Director's. This policy will be regularly reviewed by the Board of Directors. DSF has an investment objective to maintain the purchasing power of the endowment assets held in perpetuity, as well as to provide additional real growth through new gifts and investment return.

# Notes to Financial Statements

#### Note 8 - Net Assets

Net assets consist of the following at December 31:

0		
	2023	2022
Without donor restrictions:		
Funds available for current operations	\$ 6,337,669	\$ 5,320,233
Board designated endowment	549,579	228,680
Total net assets without donor restrictions	6,887,248	5,548,913
With donor restrictions: Patient assistance	2,488	1,861
Scientific research	25,000	210,000
Total net assets with donor restrictions	27,488	211,861
Total net assets	\$ 6,914,736	\$ 5,760,774