















Dravet Syndrome Foundation, Inc.

**Statement of Functional Expenses**

For the Year Ended December 31, 2023

	<b>Patient and Family Services</b>	<b>Professional Education and Meetings</b>	<b>Research</b>	<b>Total Program Services</b>	<b>Management and General</b>	<b>Fundraising</b>	<b>Total</b>
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	<u>\$ 412,525</u>	<u>\$ 150,433</u>	<u>\$ 1,096,459</u>	<u>\$ 1,659,417</u>	<u>\$ 374,423</u>	<u>\$ 129,212</u>	<u>\$ 2,163,052</u>

*The accompanying notes are an integral part of these financial statements.*



Dravet Syndrome Foundation, Inc.

**Statement of Functional Expenses**

For the Year Ended December 31, 2022

	<b>Patient and Family Services</b>	<b>Professional Education and Meetings</b>	<b>Research</b>	<b>Total Program Services</b>	<b>Management and General</b>	<b>Fundraising</b>	<b>Total</b>
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	<u>\$ 631,500</u>	<u>\$ 154,497</u>	<u>\$ 852,551</u>	<u>\$ 1,638,548</u>	<u>\$ 311,273</u>	<u>\$ 79,018</u>	<u>\$ 2,028,839</u>

*The accompanying notes are an integral part of these financial statements.*

# Dravet Syndrome Foundation, Inc.

## Notes to Financial Statements

### 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.

Dravet Syndrome Foundation, Inc.

**Notes to Financial Statements**

**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.

## Notes to Financial Statements

### 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:

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

Dravet Syndrome Foundation, Inc.

**Notes to Financial Statements**

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

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

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

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



## 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

Dravet Syndrome Foundation, Inc.

**Notes to Financial Statements**

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

Changes in endowment net assets is as follows:

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

**Funds with Deficiencies** - From time to time, the fair value of investments associated with donor-restricted 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.

Dravet Syndrome Foundation, Inc.

**Notes to Financial Statements**

**Note 8 - Net Assets**

Net assets consist of the following at December 31:

	<u>2023</u>	<u>2022</u>
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	<u>6,887,248</u>	<u>5,548,913</u>
With donor restrictions:		
Patient assistance	2,488	1,861
Scientific research	25,000	210,000
Total net assets with donor restrictions	<u>27,488</u>	<u>211,861</u>
Total net assets	<u>\$ 6,914,736</u>	<u>\$ 5,760,774</u>

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