



Dravet Syndrome Foundation, Inc.

Financial Statements with Independent Auditor's Report

Years Ended December 31, 2020 and 2019

Dravet Syndrome Foundation, Inc.

Table of Contents

	<u>Page</u>
Independent Auditor's Report.....	1 - 2
Financial Statements:	
Statements of Financial Position at December 31, 2020 and 2019	3
Statements of Activities for the Years Ended December 31, 2020 and 2019	4
Statements of Cash Flows for the Years Ended December 31, 2020 and 2019	5
Statement of Functional Expenses for the Year Ended December 31, 2020 and 2019.....	6 - 7
Notes to Financial Statements.....	8 - 16

INDEPENDENT AUDITOR'S REPORT

To The Board of Directors of
Dravet Syndrome Foundation, Inc.

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, 2020 and 2019, and the related statements of activities, functional expenses and cash flows for the years then ended, and the related notes to the financial statements.

Management's Responsibility for the Financial Statements

Management is responsible for the preparation and fair presentation of these financial statements in accordance with accounting principles generally accepted in the United States of America; this includes 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.

Auditor's Responsibility

Our responsibility is to express an opinion on these financial statements based on our audits. We conducted our audits in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audits to obtain reasonable assurance about whether the financial statements are free of material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or errors. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial statements 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 entity's internal control. Accordingly, we express no such opinion. An audit also evaluating the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Opinion

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, 2020 and 2019, 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.

Nanavaty, Davenport, Studley & White, LLP

April 16, 2021

Dravet Syndrome Foundation, Inc.

Statements of Financial Position

At December 31,

Assets	2020	2019
Cash and cash equivalents	\$ 1,104,461	\$ 705,623
Investments	3,707,992	2,691,056
Accounts receivable	26,142	147,905
Prepaid expenses	44,394	73,771
Total Assets	<u>\$ 4,882,989</u>	<u>\$ 3,618,355</u>
Liabilities and Net Assets		
Liabilities:		
Accounts payable	\$ 184,006	\$ 276,857
Deferred revenue	261,960	-
Refundable advance	51,557	-
Total Liabilities	<u>497,523</u>	<u>276,857</u>
Net Assets:		
Net assets without donor restrictions	4,334,842	3,341,498
Net assets with donor restrictions	50,624	-
Total Net Assets	<u>4,385,466</u>	<u>3,341,498</u>
Total Liabilities and Net Assets	<u>\$ 4,882,989</u>	<u>\$ 3,618,355</u>

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

Dravet Syndrome Foundation, Inc.

Statements of Activities

For the Years Ended December 31,

Net Assets Without Donor Restrictions	<u>2020</u>	<u>2019</u>
Revenues and Other Support:		
Special events - revenue	\$ 583,451	\$ 1,214,847
- expenses	(48,493)	(173,468)
- net	<u>534,958</u>	<u>1,041,379</u>
Program service revenue	654,981	379,531
Contributions and grants	707,304	566,255
Investment return, net	17,836	42,174
Other income	-	1,133
Total revenues and other support	<u>1,915,079</u>	<u>2,030,472</u>
Expenses:		
Program services		
Program services	601,541	857,908
Management and general	254,574	216,575
Fundraising	65,620	87,650
Total expenses	<u>921,735</u>	<u>1,162,133</u>
Change in net assets	<u>993,344</u>	<u>868,339</u>
Net assets with donor restrictions		
Contributions	50,624	-
Change in net assets with donor restrictions	<u>50,624</u>	<u>-</u>
Change in net assets	1,043,968	868,339
Net assets at beginning of year	<u>3,341,498</u>	<u>2,473,159</u>
Net assets at end of year	<u>\$ 4,385,466</u>	<u>\$ 3,341,498</u>

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

Dravet Syndrome Foundatioin, Inc.

Statements of Cash Flows

For the Years Ended December 31,

	<u>2020</u>	<u>2019</u>
Cash Flows from Operating Activities:		
Change in net assets	\$ 1,043,968	\$ 868,339
Adjustments to reconcile change in net assets to net cash provided by operating activities		
Net realized and unrealized (gain) investments	(1,585)	
Changes in assets and liabilities:		
(Increase) decrease in:		
Accounts receivable	121,763	(89,267)
Prepaid expenses	29,377	(34,730)
Increase (decrease) in:		
Accounts payable and accrued expenses	(92,851)	93,116
Deferred revenue	261,960	-
Reundable advance	51,557	-
Net cash provided by operating activities	<u>1,414,189</u>	<u>837,458</u>
Cash Flows from Investing Activities:		
Purchase of investments	(1,015,351)	(2,691,056)
Net cash used in investing activities	<u>(1,015,351)</u>	<u>(2,691,056)</u>
Net increase (decrease) in cash and cash equivalents	398,838	(1,853,598)
Cash and cash equivalents at beginning of year	705,623	2,559,221
Cash and cash equivalents at end of year	<u>\$ 1,104,461</u>	<u>\$ 705,623</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, 2020

	Patient and Family Services	Professional Education and Meetings	Research	Total Program Expenses	Management and General	Fundraising	Total
Salaries	\$ 68,961	\$ 15,039	\$ 36,714	\$ 120,714	\$ 182,485	\$ 43,495	\$ 346,694
Payroll taxes	5,970	1,016	3,176	10,162	15,263	3,563	28,988
Grants	10,000	-	302,800	312,800	-	-	312,800
Conferences and meetings	28,567	36,794	523	65,884	5,016	-	70,900
Professional fees	24,604	-	-	24,604	16,017	-	40,621
Dues and subscriptions	1,136	945	145	2,226	13,493	4,949	20,668
Bank charges	258	-	-	258	8,019	10,460	18,737
Patient assistance	16,205	-	-	16,205	-	-	16,205
Postage	9,291	-	-	9,291	1,561	259	11,111
Office supplies	5,386	-	132	5,518	3,788	452	9,758
Taxes, Licenses and Fees	-	-	-	-	5,463	-	5,463
Insurance	773	60	72	905	2,664	1,258	4,827
Advertising	606	-	1,129	1,735	189	-	1,924
Printing	111	-	-	111	385	953	1,449
Telephone	231	231	-	462	231	231	924
Other expenses	30,666	-	-	30,666	-	-	30,666
Total expenses	<u>\$ 202,765</u>	<u>\$ 54,085</u>	<u>\$ 344,691</u>	<u>\$ 601,541</u>	<u>\$ 254,574</u>	<u>\$ 65,620</u>	<u>\$ 921,735</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, 2019

	Patient and Family Services	Professional Education and Meetings	Research	Total Program Expenses	Management and General	Fundraising	Total
Salaries	\$ 47,352	\$ 9,497	\$ 3,808	\$ 60,657	\$ 166,400	\$ 48,422	\$ 275,479
Payroll taxes	4,215	773	313	5,301	13,777	3,937	23,015
Grants	400	-	656,610	657,010	-	-	657,010
Conferences and meetings	39,465	66,716	-	106,181	5,345	-	111,526
Bank charges	195	-	150	345	6,096	25,462	31,903
Patient assistance	19,906	-	-	19,906	-	-	19,906
Dues and subscriptions	519	919	-	1,438	10,380	3,214	15,032
Office supplies	3,853	-	-	3,853	2,428	2,422	8,703
Professional fees	-	-	-	-	4,000	-	4,000
Taxes, licenses and fees	-	-	-	-	4,605	-	4,605
Printing	969	-	-	969	699	2,177	3,845
Insurance	527	32	13	572	2,163	896	3,631
Postage	1,272	28	-	1,300	494	505	2,299
Telephone	188	188	-	376	188	188	752
Other expenses	-	-	-	-	-	427	427
Total expenses	<u>\$ 118,861</u>	<u>\$ 78,153</u>	<u>\$ 660,894</u>	<u>\$ 857,908</u>	<u>\$ 216,575</u>	<u>\$ 87,650</u>	<u>\$ 1,162,133</u>

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

Dravet Syndrome Foundation, Inc.

Notes to Financial Statements

Note 1 - Organization

General

The Dravet Syndrome Foundation, Inc. (DSF) was incorporated as a not-for-profit, 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 toward better treatments and a cure of Dravet Syndrome and related epilepsies by awarding research grants to qualified scientists and doctors. The 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

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.

Basis of Presentation

The financial statements of DSF comply with the Financial Statements of Not-for-Profit Organizations topic of the FASB Codification. Under this topic, the Organization reports information regarding its financial position and activities according to the following net assets classifications:

Net assets without donor restrictions— Net assets that 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 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.

Accounts 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, 2017 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 (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.

Reclassifications

Certain accounts in the prior-year financial statements have been reclassified for comparative purposes to conform with the presentation in the current-year financial statements.

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, grantor or other outside party 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.

Subsequent Events

In preparing these financial statements, management has evaluated subsequent events through April 16, 2021 which represents the date the financial statements were available to be issued. There were no subsequent events that require disclosure.

Notes to Financial Statements

Note 2 - Summary of Significant Accounting Policies (continued)

Risks and Uncertainties

The recent COVID-19 outbreak has caused economic disruptions through mandated voluntary closings of businesses and organizations throughout the United States. The extent of the impact of COVID-19 on DSF's operational and financial performance will depend on certain developments, including the duration and spread of the outbreak and its impact on DSF's donors, employees, investments and vendors, all of which at present cannot be determined. Accordingly, the extent to which COVID-19 may impact DSF's financial position and changes in net assets and cash flows is uncertain and the accompanying financial statements include no adjustments relating to the effects of the pandemic.

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 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.

Note 5 – Research

DSF has entered into agreements with several universities to fund research to investigate the cause of DRAVET Syndrome in children and adults and potential remedies to end this disease.

Notes to Financial Statements

Note 6 - 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 future, which DSF has determined to be within 90 days.

Notes to Financial Statements

Note 6 - Fair Value Measurements (continued)

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.

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 that 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, 2020.

Dravet Syndrome Foundation, Inc.

Notes to Financial Statements

Note 6 - Fair Value Measurements (continued)

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:

Investment	2020			Total
	Level 1	Level 2	Level 3	
Mutual funds	\$ 3,707,992	\$ -	\$ -	\$ 3,707,992
Total investments at fair value	\$ 3,707,992	\$ -	\$ -	\$ 3,707,992

Investment	2019			Total
	Level 1	Level 2	Level 3	
Mutual funds	\$ 2,691,056	\$ -	\$ -	\$ 2,691,056
Total investments at fair value	\$ 2,691,056	\$ -	\$ -	\$ 2,691,056

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

	2020	2019
Dividends and interest	\$ 17,836	\$ 42,174

Note 7 - Availability and Liquidity

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

	2020	2019
Financial Assets at year end:		
Cash and cash equivalents	\$ 1,104,461	\$ 705,623
Investments	3,707,992	2,691,056
Accounts receivable	26,142	147,905
	<u>4,838,595</u>	<u>3,544,584</u>
Less		
Net assets with donor restrictions	<u>(50,624)</u>	<u>-</u>
Financial assets to meet general expenditures over the next twelve months	\$ <u>4,787,971</u>	\$ <u>3,544,584</u>

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

Notes to Financial Statements

Note 8 - Board Designated Endowment

DSF's endowment consists of a 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 8 - Board Designated Endowment (continued)

Endowment Net Assets - Endowment net assets composition by type of fund is as follows as of December 21, 2020

	Without Donor Restrictions	Total
Board-designated endowment funds	\$ 101,887	\$ 101,887

Note 9 - Net Assets

Net assets consist of the following at December 31:

	2020	2019
Without donor restrictions		
Funds available for current operations	\$ 4,232,955	\$ 3,341,498
Board designated for endowment	101,887	-
Total net assets without donor restrictions	<u>4,334,842</u>	<u>3,341,498</u>
With donor restrictions		
Scientific research	50,624	-
Total net assets with donor restrictions	<u>50,624</u>	<u>-</u>
Total net assets	<u>\$ 4,385,466</u>	<u>\$ 3,341,498</u>