

Dravet Syndrome Foundation, Inc.

Financial Statements

December 31, 2019 and December 31, 2018

**DRAVET SYNDROME FOUNDATION, INC.**  
**Financial Statements**  
**December 31, 2019**

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April 3, 2020

## **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 statement of financial position as of December 31, 2019 and 2018, 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 audit. We conducted our audit in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audit 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, 2019 and December 31, 2018, 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

**DRAVET SYNDROME FOUNDATION, INC.**  
**Statements of Financial Position**  
**December 31,**

	<b>2019</b>	<b>2018</b>
<b>Assets</b>		
<u>Assets</u>		
Cash and cash equivalents	\$ 705,623	\$ 2,559,221
Investments	2,691,056	-
Accounts receivable	147,905	58,638
Prepaid expenses	73,771	39,041
<b>Total Assets</b>	<b>\$ 3,618,355</b>	<b>\$ 2,656,900</b>
<b>Liabilities and Net Assets</b>		
<u>Liabilities</u>		
Accounts payable	\$ 276,857	\$ 183,739
<b>Total Liabilities</b>	<b>276,857</b>	<b>183,739</b>
<u>Net Assets</u>		
Net assets without donor restrictions	3,341,498	2,473,161
<b>Total Net Assets</b>	<b>3,341,498</b>	<b>2,473,161</b>
<b>Total Liabilities and Net Assets</b>	<b>\$ 3,618,355</b>	<b>\$ 2,656,900</b>

**DRAVET SYNDROME FOUNDATION, INC.**  
**Statements of Activities**  
**For the Year Ended December 31,**

	<b>2019</b>	<b>2018</b>
<b>Change in Net Assets</b>		
<u>Revenues and Other Support</u>		
Special events	\$ 1,214,847	\$ 923,496
- revenue		
- expenses	(173,468)	(79,494)
- net	1,041,379	844,002
Program service revenue	379,531	511,463
Contributions and grants	566,255	657,764
Investment return, net	42,174	523
Other income	1,131	3,468
<b>Total Revenues and Other Support</b>	<b>2,030,470</b>	<b>2,017,220</b>
 <u>Expenses</u>		
<u>Program Services:</u>		
Patient and family services	118,861	263,616
Professional education and meetings	78,153	75,850
Research	660,894	426,512
Total Program Services	857,908	765,978
<u>Support Services:</u>		
Management and general	216,575	199,207
Fundraising	87,650	77,176
Total Support Services	304,225	276,383
<b>Total Expenses</b>	<b>1,162,133</b>	<b>1,042,361</b>
<b>Increase in net assets</b>	<b>868,337</b>	<b>974,859</b>
<b>Net assets at beginning of year</b>	<b>2,473,161</b>	<b>1,498,302</b>
<b>Net assets at end of year</b>	<b>\$ 3,341,498</b>	<b>\$ 2,473,161</b>

**DRAVET SYNDROME FOUNDATION, INC.**  
**Statements of Cash Flows**  
**For the Year Ended December 31,**

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	<b>2019</b>	<b>2018</b>
<b>Cash Flows from Operating Activities:</b>		
Increase in net assets	\$ 868,337	\$ 974,005
	868,337	974,005
Changes in assets and liabilities:		
(Increase) decrease in:		
Accounts receivable	(89,267)	8,996
Prepaid expenses	(34,730)	(20,879)
	(123,997)	(11,883)
Increase (decrease) in:		
Accounts payable and accrued expenses	93,118	(77,105)
	93,118	(77,105)
<b>Net cash provided by operating activities</b>	<b>837,458</b>	<b>885,017</b>
<b>Cash Flows from Investing Activities:</b>		
Purchase of investments	(2,691,056)	1,899
<b>Net cash (used in) provided by investing activities</b>	<b>(2,691,056)</b>	<b>1,899</b>
<b>Net (decrease) increase in cash and cash equivalents</b>	<b>(1,853,598)</b>	<b>886,916</b>
<b>Cash and cash equivalents at beginning of year</b>	<b>2,559,221</b>	<b>1,672,305</b>
<b>Cash and cash equivalents at end of year</b>	<b>\$ 705,623</b>	<b>\$ 2,559,221</b>

**DRAVET SYNDROME FOUNDATION, INC.**  
**Statement of Functional Expenses**  
**For the Year Ended December 31, 2019**

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

**DRAVET SYNDROME FOUNDATION, INC.**  
**Statement of Functional Expenses**  
**For the Year Ended December 31, 2018**

	Patient and Family Services	Professional Education and Meetings	Research	Management and General	Fund Raising	Total
Professional fees	\$ -	-	\$ -	\$ 3,500	\$ -	\$ 3,500
Salaries	27,804	8,668	3,555	156,420	36,313	232,760
Payroll taxes	2,560	685	294	12,907	2,842	19,288
Telephone	100	100	-	100	100	400
Office supplies	3,700	669	-	2,592	2,284	9,245
Insurance	437	28	11	2,119	813	3,408
Postage	-	-	-	1,088	690	1,778
Printing	935	-	-	2,754	1,819	5,508
Patient assistance	31,458	-	-	-	-	31,458
Dues and subscriptions	943	700	-	6,369	1,834	9,846
Advertising	-	295	-	296	66	657
Bank charges	2,699	-	45	5,108	25,538	33,390
Taxes, Licenses and Fees	-	-	-	4,432	-	4,432
Grants	-	-	422,607	-	-	422,607
Conferences and meetings	192,980	64,705	-	1,522	-	259,207
Other expenses	-	-	-	-	4,877	4,877
Total expenses before fund raising	<u>\$ 263,616</u>	<u>\$ 75,850</u>	<u>\$ 426,512</u>	<u>\$ 199,207</u>	<u>\$ 77,176</u>	<u>\$ 1,042,361</u>

**DRAVET SYNDROME FOUNDATION, INC.**  
**Notes to Financial Statements**  
**December 31, 2019**

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**Note 1 - Summary of Significant Accounting Policies**

**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.

**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 the Organization 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 the organization. These net assets may be used at the discretion of the Organization'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 the Organization 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**  
**December 31, 2019**

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**Note 1 - Summary of Significant Accounting Policies (continued)**

**New Accounting Pronouncement**

On August 18, 2016, the FASB issued ASU 2016-14, Not-for-Profit Entities (Topic 958) – Presentation of Financial Statements of Not-for-Profit Entities. The update addresses the complexity and understandability of net asset classification, deficiencies in information about liquidity and availability of resources, and the lack of consistency in the type of information provided about expenses and investment return. The Organization has adjusted the presentation of these financial statements accordingly. The ASU has been applied retrospectively to all periods presented.

**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.

**Income Taxes**

The Dravet Syndrome Foundation, Inc. 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 the Organization will be treated as a publicly supported organization, and not a private foundation. This qualifies the Organization for the 50% charitable contribution deduction for individual donors. Consequently, the accompanying financial statements do not include any provision for income taxes.

The Foundation recognizes the effect of tax positions only when they are more than likely that not of being sustained. Management has determined that the Foundation had no uncertain tax positions that qualify for either recognition or disclosure in the financial statements. In the normal course of business the Foundation's tax filings are subject to examination by federal and state authorities. The tax returns for the years ended December 31, 2016 and forward are subject to examination by taxing authorities.

**DRAVET SYNDROME FOUNDATION, INC.**  
**Notes to Financial Statements**  
**December 31, 2019**

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**Note 1 - Summary of Significant Accounting Policies (continued)**

**Functional Expenses**

The Foundation allocates expenses on a functional basis among programs and support services. Expenses that can be specifically identified are charged directly to the related program or support service. Other expenses that are common to several functions are allocated based on estimates made by management.

**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**

The Foundation 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.

The Foundation has adopted Accounting Standards Update ( ASU ) No. 2018-08 *Not -for-Profit Entities: Clarifying the Scope and the Accounting Guidance for Contributions received and Contributions Made ( Topic 605)* as management believes the standard improves the usefulness and understandability of the Foundation's financial reporting.

**DRAVET SYNDROME FOUNDATION, INC.**  
**Notes to Financial Statements**  
**December 31, 2019**

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**Note 1 - Summary of Significant Accounting Policies (continued)**

Analysis of various provisions of this standard resulted in no significant changes in the way the Foundation recognizes revenue, therefore no changes to the previously issued audited financial statements were required on a retrospective basis. The presentation and disclosures of revenue have been enhanced in accordance with the standard.

**Contributions**

In accordance with financial accounting standards, the Organization 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 3, 2020, which represents the date the financial statements were available to be issued.

**Note 2 - Donated Services, Materials, Facilities**

The Foundation 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 3 – Concentrations of Credit Risk**

**Cash Balances**

The Foundation 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, the Foundation does not feel that there is any significant credit risk.

**DRAVET SYNDROME FOUNDATION, INC.**  
**Notes to Financial Statements**  
**December 31, 2019**

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**Note 3 – Concentrations of Credit Risk (continued)**

**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 4 - Research**

The Foundation has entered into agreements with several universities to fund research in 2019 and 2020.

**Note 5 – Other**

The Foundation has been named the beneficiary of the Dravet Syndrome Foundation Endowment Fund. The Endowment Fund will pay out annually to the Foundation to support syndrome specific research to find better treatments and a cure while assisting afflicted individuals and their families living in Iowa. The endowment fund is administered by the Community Foundation of Dubuque, Iowa as Trustee. Distributions may be made annually from the net income of the fund.

**Note 6 – Fair Value of Financial Instruments**

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.

**DRAVET SYNDROME FOUNDATION, INC.**  
**Notes to Financial Statements**  
**December 31, 2019**

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**Note 6 – Fair Value of Financial Instruments (continued)**

**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.

**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:

**Exchange Traded Funds, 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, 2019.

**DRAVET SYNDROME FOUNDATION, INC.**  
**Notes to Financial Statements**  
**December 31, 2019**

**Note 6– Fair Value of Financial Instruments (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 Description	2019			Total
	Level 1	Level 2	Level 3	
Mutual funds	\$ -	\$ -	\$ -	\$ -
	2,691,056	-	-	2,691,056
	-	-	-	-
Total investments at fair value	<u>\$2,691,056</u>	<u>\$ -</u>	<u>\$ -</u>	<u>\$2,691,056</u>

Investment return, net is comprised of the following:

	December 31, 2019
Dividends and interest	\$ 42,174
	<u>\$ 42,174</u>

**Note 7 – Availability and Liquidity**

The following represents the Organizations financial assets at December 31, 2019 and 2018

	2019	2018
<b>Financial Assets at year end:</b>		
Cash and cash equivalents	\$ 3,396,679	\$ 2,559,221
Accounts receivable	147,905	58,638
Total financial assets	<u>3,544,584</u>	<u>2,617,859</u>
Financial assets available to meet general expenditures over the next twelve months	<u>\$ 3,544,584</u>	<u>\$ 2,617,859</u>

**DRAVET SYNDROME FOUNDATION, INC.**  
**Notes to Financial Statements**  
**December 31, 2019**

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**Note 7 – Availability and Liquidity (continued)**

The foundation'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.

**Note 8 – Subsequent Events**

The COVID-19 outbreak in the United States has caused business interruption through mandated and voluntary closings of businesses and schools. While the interruption is currently expected to be temporary, there is considerable uncertainty around the duration of the closings. The Foundation expects this matter to negatively impact both financial and operating results. However, the related financial impact and duration cannot be reasonably estimated at this time.