

Dravet Syndrome Foundation, Inc.

Financial Statements

December 31, 2018 and December 31, 2017

Studley - White, P.C.

ACCOUNTING - TAX - AUDITING - CONSULTING

**DRAVET SYNDROME FOUNDATION, INC.**  
**Financial Statements**  
**December 31, 2018**

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March 22, 2019

## **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, 2018 and 2017, 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, 2018 and December 31, 2017, 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.

*Studley-White, P.C.*

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

	<b>2018</b>	<b>2017</b>
<b>Assets</b>		
<u>Assets</u>		
Cash and cash equivalents	\$ 2,559,221	\$ 1,672,305
Accounts receivable	58,638	67,634
Prepaid expenses	39,041	18,162
Beneficial interest in charitable trust	11,412	13,312
<b>Total Assets</b>	<b>\$ 2,668,312</b>	<b>\$ 1,771,413</b>
<b>Liabilities and Net Assets</b>		
<u>Liabilities</u>		
Accounts payable	\$ 183,739	\$ 260,845
<b>Total Liabilities</b>	<b>183,739</b>	<b>260,845</b>
<u>Net Assets</u>		
Net assets without donor restrictions	2,473,104	1,497,256
Net Assets with donor restrictions	11,469	13,312
<b>Total Net Assets</b>	<b>2,484,573</b>	<b>1,510,568</b>
<b>Total Liabilities and Net Assets</b>	<b>\$ 2,668,312</b>	<b>\$ 1,771,413</b>

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

	<b>2018</b>	<b>2017</b>
<b>Change in Unrestricted Net Assets</b>		
<u>Revenues and Other Support</u>		
Special events	\$ 923,496	\$ 939,334
- revenue		
- expenses	(79,494)	(124,747)
- net	844,002	814,587
Program Service Revenue	511,463	142,722
Contributions and grants	657,764	630,749
Other income	3,137	2,501
Unrestricted revenues and other support	2,016,366	1,590,559
Net assets released from restriction	854	861
<b>Total Revenues and Other Support</b>	<b>2,017,220</b>	<b>1,591,420</b>
 <u>Expenses</u>		
<u>Program Services:</u>		
Patient and family services	263,616	90,222
Professional Education and Meetings	75,850	45,716
Research	426,512	724,644
Total Program Services	765,978	860,582
<u>Support Services:</u>		
Management and general	199,207	140,723
Fund raising	77,176	103,360
Total Support Services	276,383	244,083
<b>Total Expenses</b>	<b>1,042,361</b>	<b>1,104,665</b>
<b>Increase in net assets without donor restrictions</b>	<b>974,859</b>	<b>486,755</b>
<b>Net Assets with Donor Restrictions</b>		
Investment income	-	1,777
Net assets released from restriction	(854)	(861)
<b>Increase (decrease) in net assets with donor restrictions</b>	<b>(854)</b>	<b>916</b>
<b>Increase in net assets</b>	<b>974,005</b>	<b>487,671</b>
<b>Net assets at beginning of year</b>	<b>1,510,568</b>	<b>1,022,897</b>
<b>Net assets at end of year</b>	<b>\$ 2,484,573</b>	<b>\$ 1,510,568</b>

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

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	<b>2018</b>	<b>2017</b>
<b>Cash Flows from Operating Activities:</b>		
Increase in net assets	\$ 974,005	\$ 487,671
	974,005	487,671
Changes in assets and liabilities:		
(Increase) decrease in:		
Accounts receivable	8,996	(42,897)
Prepaid expenses	(20,879)	(4,241)
	(11,883)	(47,138)
Increase (decrease) in:		
Accounts payable and accrued expenses	(77,105)	255,192
	(77,105)	255,192
 <b>Net cash provided by operating activities</b>	 <b>885,017</b>	 <b>695,725</b>
Investment (income)loss, net assets with donor restrictions	1,899	(902)
<b>Net increase in cash and cash equivalents</b>	<b>886,916</b>	<b>694,823</b>
<b>Cash and cash equivalents at beginning of year</b>	<b>1,672,305</b>	<b>977,482</b>
<b>Cash and cash equivalents at end of year</b>	<b>\$ 2,559,221</b>	<b>\$ 1,672,305</b>

**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.**  
**Statement of Functional Expenses**  
**For the Year Ended December 31, 2017**

	Patient and Family Services	Professional Education and Meetings	Research	Management and General	Fund Raising	Total
Professional fees	\$ -	-	\$ -	\$ 4,760	\$ -	\$ 4,760
Salaries	6,024	6,601	4,389	111,065	46,883	174,962
Payroll taxes	499	547	364	9,198	3,883	14,490
Telephone	49	49	-	49	49	194
Office supplies	-	-	-	1,634	3,756	5,390
Insurance	41	45	30	2,492	995	3,602
Postage	-	1,163	-	1,025	1,025	3,213
Printing	2,517	1,055	-	814	1,524	5,910
Patient assistance	16,778	-	-	-	-	16,778
Dues and subscriptions	774	1,010	-	5,258	4,638	11,680
Advertising	1,523	337	-	-	1,523	3,383
Bank charges	-	-	-	-	36,331	36,331
Taxes, Licenses and Fees	-	-	-	3,845	-	3,845
Grants	-	-	719,861	-	-	719,861
Conferences and meetings	61,427	34,910	-	584	242	97,163
Other expenses	591	-	-	-	2,512	3,103
Total expenses before fund raising	<u>\$ 90,222</u>	<u>\$ 45,716</u>	<u>\$ 724,644</u>	<u>\$ 140,723</u>	<u>\$ 103,360</u>	<u>\$ 1,104,665</u>

**DRAVET SYNDROME FOUNDATION, INC.**  
**Notes to Financial Statements**  
**December 31, 2018**

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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, 2018**

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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.

**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.

**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.

**DRAVET SYNDROME FOUNDATION, INC.**  
**Notes to Financial Statements**  
**December 31, 2018**

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

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, 2015 and forward are subject to examination by taxing authorities.

**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.

**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, 2018**

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**Note 4 - Research**

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

**Note 5 –Net Assets with Donor Restrictions**

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. The assets of the trust are recorded as net assets with donor restrictions. Distributions may be made annually from the net income of the fund. Net assets held in perpetuity at December 31 2018 and 2017 was \$11,469.

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

Financial Accounting Standards Board ( FASB) Accounting Standards Codification (ASC) 820 defines fair value, requires certain disclosures about fair value measurements, and establishes a three level hierarchy for fair value measurements based on observable inputs to the valuation of an asset or liability at the measurement date. Fair value is defined as the price that would be received to sell an asset or paid to transfer a liability in an orderly transaction between market participants at the measurement date.

The carrying amounts reflected in the accompanying statements of financial position for cash and cash equivalents approximate their respective fair values due to the short maturities of those instruments.

**Note 7 – Availability and Liquidity**

The following represents the Organizations financial assets at December 31, 2018 and 2017

	<u>2018</u>	<u>2017</u>
<b>Financial Assets at year end:</b>		
Cash and cash equivalents	\$ 2,559,221	\$ 1,672,305
Accounts receivable	58,638	67,634
Total financial assets	<u>2,617,859</u>	<u>1,739,939</u>
Less amounts not available to be used within one year:		
Net assets with donor restrictions	<u>11,469</u>	<u>13,312</u>
Financial assets available to meet general expenditures over the next twelve months	<u>\$ 2,606,390</u>	<u>\$ 1,726,627</u>

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

**DRAVET SYNDROME FOUNDATION, INC.**  
**Notes to Financial Statements**  
**December 31, 2018**

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**Note 8 – Subsequent Events**

Management has evaluated events and transactions occurring after December 31, 2018 through March 22, 2019, the date of the financial statements were available to be issued and has determined there are no material events that would require disclosure in the financial statements.