

Form **990**
Department of the Treasury
Internal Revenue Service

Return of Organization Exempt From Income Tax

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)

▶ Do not enter social security numbers on this form as it may be made public.

▶ Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047
2020
Open to Public Inspection

A For the 2020 calendar year, or tax year beginning 01-01-2020, and ending 12-31-2020

B Check if applicable:
 Address change
 Name change
 Initial return
 Final return/terminated
 Amended return
 Application pending

C Name of organization
 DRAVET SYNDROME FOUNDATION INC

Doing business as

Number and street (or P.O. box if mail is not delivered to street address) Room/suite
 PO Box 3026

City or town, state or province, country, and ZIP or foreign postal code
 Cherry Hill, NJ 08034

D Employer identification number
 27-0924627

E Telephone number
 (203) 392-1955

F Name and address of principal officer:
 Kathryn Hintz
 PO Box 3026
 Cherry Hill, NJ 08034

G Gross receipts \$ 2,012,610

H(a) Is this a group return for subordinates? Yes No

H(b) Are all subordinates included? Yes No
 If "No," attach a list. (see instructions)

H(c) Group exemption number ▶

I Tax-exempt status: 501(c)(3) 501(c) () ◀ (insert no.) 4947(a)(1) or 527

J Website: ▶ www.dravetfoundation.org

K Form of organization: Corporation Trust Association Other ▶

L Year of formation: 2009 **M** State of legal domicile: CT

Part I Summary

1 Briefly describe the organization's mission or most significant activities:
 The mission of the Dravet Syndrome Foundation is to aggressively raise funds for Dravet syndrome & related epilepsies; support & fund research; increase awareness; & provide support to affected individuals & families.

2 Check this box if the organization discontinued its operations or disposed of more than 25% of its net assets.

3 Number of voting members of the governing body (Part VI, line 1a)	3	7
4 Number of independent voting members of the governing body (Part VI, line 1b)	4	7
5 Total number of individuals employed in calendar year 2020 (Part V, line 2a)	5	6
6 Total number of volunteers (estimate if necessary)	6	20
7a Total unrelated business revenue from Part VIII, column (C), line 12	7a	0
7b Net unrelated business taxable income from Form 990-T, line 39	7b	0

	Prior Year	Current Year
8 Contributions and grants (Part VIII, line 1h)	1,609,408	1,228,571
9 Program service revenue (Part VIII, line 2g)	379,531	654,981
10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)	42,174	16,250
11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	-908	64,315
12 Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)	2,030,205	1,964,117
13 Grants and similar amounts paid (Part IX, column (A), lines 1-3)	672,351	328,994
14 Benefits paid to or for members (Part IX, column (A), line 4)	0	0
15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	298,494	375,684
16a Professional fundraising fees (Part IX, column (A), line 11e)	0	0
b Total fundraising expenses (Part IX, column (D), line 25) ▶ 65,620		
17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	191,288	217,057
18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	1,162,133	921,735
19 Revenue less expenses. Subtract line 18 from line 12	868,072	1,042,382

	Beginning of Current Year	End of Year
20 Total assets (Part X, line 16)	3,618,355	4,882,989
21 Total liabilities (Part X, line 26)	276,857	497,523
22 Net assets or fund balances. Subtract line 21 from line 20	3,341,498	4,385,466

Part II Signature Block

Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete. Declaration of preparer (other than officer) is based on all information of which preparer has any knowledge.

Sign Here

Signature of officer _____ Date 2021-04-30

Kathryn Hintz President
Type or print name and title

Paid Preparer Use Only

Print/Type preparer's name	Preparer's signature	Date	Check <input type="checkbox"/> if self-employed	PTIN
Firm's name ▶			Firm's EIN ▶	
Firm's address ▶			Phone no.	

May the IRS discuss this return with the preparer shown above? (see instructions) Yes No

Part III Statement of Program Service Accomplishments

Check if Schedule O contains a response or note to any line in this Part III

1 Briefly describe the organization's mission:

The mission of the Dravet Syndrome Foundation is to aggressively raise funds for Dravet syndrome & related epilepsies; support & fund research; increase awareness; & provide support to affected individuals & families. We understand the ongoing need to fund innovative research, the urgency in finding better treatments, the motivation of our donors to make an impact specifically in the fields of Dravet syndrome and related epilepsies, the importance of transparency and accountability of not only our organization, but the researchers that we fund, and the need for global collaboration in order to find a cure.

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ? Yes No

If "Yes," describe these new services on Schedule O.

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services? Yes No

If "Yes," describe these changes on Schedule O.

4 Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses. Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.

4a (Code:) (Expenses \$ 344,690 including grants of \$ 320,790) (Revenue \$ 49,183)
See Additional Data

4b (Code:) (Expenses \$ 202,765 including grants of \$ 26,204) (Revenue \$ 500,798)
See Additional Data

4c (Code:) (Expenses \$ 54,085 including grants of \$ 0) (Revenue \$ 105,000)
See Additional Data

4d Other program services (Describe in Schedule O.)
(Expenses \$ 0 including grants of \$ 0) (Revenue \$ 0)

4e Total program service expenses ▶ 601,540

Part IV Checklist of Required Schedules		Yes	No
1	Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? If "Yes," complete Schedule A	Yes	
2	Is the organization required to complete Schedule B, Schedule of Contributors (see instructions)?	Yes	
3	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I		No
4	Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? If "Yes," complete Schedule C, Part II		No
5	Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? If "Yes," complete Schedule C, Part III		No
6	Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? If "Yes," complete Schedule D, Part I		No
7	Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? If "Yes," complete Schedule D, Part II		No
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III		No
9	Did the organization report an amount in Part X, line 21 for escrow or custodial account liability; serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? If "Yes," complete Schedule D, Part IV		No
10	Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi endowments? If "Yes," complete Schedule D, Part V		No
11	If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable.		
a	Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D, Part VI		No
b	Did the organization report an amount for investments—other securities in Part X, line 12 that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VII		No
c	Did the organization report an amount for investments—program related in Part X, line 13 that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VIII		No
d	Did the organization report an amount for other assets in Part X, line 15 that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part IX		No
e	Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X		No
f	Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? If "Yes," complete Schedule D, Part X	Yes	
12a	Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI and XII	Yes	
b	Was the organization included in consolidated, independent audited financial statements for the tax year? If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional		No
13	Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E		No
14a	Did the organization maintain an office, employees, or agents outside of the United States?		No
b	Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? If "Yes," complete Schedule F, Parts I and IV	Yes	
15	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? If "Yes," complete Schedule F, Parts II and IV	Yes	
16	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? If "Yes," complete Schedule F, Parts III and IV		No
17	Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? If "Yes," complete Schedule G, Part I (see instructions)		No
18	Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? If "Yes," complete Schedule G, Part II	Yes	
19	Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? If "Yes," complete Schedule G, Part III		No
20a	Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H		No
b	If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?		
21	Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? If "Yes," complete Schedule I, Parts I and II	Yes	

Part IV Checklist of Required Schedules (continued)

Table with 3 columns: Question ID, Question Text, and Yes/No columns. Rows include questions 22 through 38 regarding organizational reporting, compensation, and tax-exempt status.

Part V Statements Regarding Other IRS Filings and Tax Compliance

Check if Schedule O contains a response or note to any line in this Part V []

Table with 3 columns: Question ID, Question Text, and Yes/No columns. Rows include questions 1a, 1b, and 1c regarding Form 1096, Forms W-2G, and backup withholding rules.

Part V Statements Regarding Other IRS Filings and Tax Compliance (continued)

2a Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return. 2b If at least one is reported on line 2a, did the organization file all required federal employment tax returns? 3a Did the organization have unrelated business gross income of \$1,000 or more during the year? 4a At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country? 5a Was the organization a party to a prohibited tax shelter transaction at any time during the tax year? 6a Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions? 7 Organizations that may receive deductible contributions under section 170(c). 8 Sponsoring organizations maintaining donor advised funds. 9 Sponsoring organizations maintaining donor advised funds. 10 Section 501(c)(7) organizations. 11 Section 501(c)(12) organizations. 12a Section 4947(a)(1) non-exempt charitable trusts. 13 Section 501(c)(29) qualified nonprofit health insurance issuers. 14a Did the organization receive any payments for indoor tanning services during the tax year? 15 Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or excess parachute payment(s) during the year? 16 Is the organization an educational institution subject to the section 4968 excise tax on net investment income?

Part VI Governance, Management, and Disclosure For each "Yes" response to lines 2 through 7b below, and for a "No" response to lines 8a, 8b, or 10b below, describe the circumstances, processes, or changes in Schedule O. See instructions. Check if Schedule O contains a response or note to any line in this Part VI



Section A. Governing Body and Management

Table with 3 columns: Question, Yes, No. Rows include: 1a Enter the number of voting members of the governing body at the end of the tax year; 2 Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee?; 3 Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors or trustees, or key employees to a management company or other person?; 4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?; 5 Did the organization become aware during the year of a significant diversion of the organization's assets?; 6 Did the organization have members or stockholders?; 7a Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body?; 7b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?; 8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following: 8a The governing body? 8b Each committee with authority to act on behalf of the governing body?; 9 Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses in Schedule O.

Section B. Policies (This Section B requests information about policies not required by the Internal Revenue Code.)

Table with 3 columns: Question, Yes, No. Rows include: 10a Did the organization have local chapters, branches, or affiliates? 10b If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes? 11a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? 11b Describe in Schedule O the process, if any, used by the organization to review this Form 990. 12a Did the organization have a written conflict of interest policy? If "No," go to line 13 12b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? 12c Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done 13 Did the organization have a written whistleblower policy? 14 Did the organization have a written document retention and destruction policy? 15 Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision? 15a The organization's CEO, Executive Director, or top management official 15b Other officers or key employees of the organization If "Yes" to line 15a or 15b, describe the process in Schedule O (see instructions). 16a Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year? 16b If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements?

Section C. Disclosure

Table with 3 columns: Question, Yes, No. Rows include: 17 List the states with which a copy of this Form 990 is required to be filed AK, AR, CA, FL, GA, IL, KS, KY, MA, MD, MI, MN, MO, MS, NC, NH, NJ, NM, NY, OR, PA, RI, SC, TN, UT, VA, WI, WV 18 Section 6104 requires an organization to make its Form 1023 (or 1024-A if applicable), 990, and 990-T (501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply. Own website Another's website Upon request Other (explain in Schedule O) 19 Describe in Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year. 20 State the name, address, and telephone number of the person who possesses the organization's books and records: Jamie Cohen 522 Mackin Drive Cherry Hill, NJ 08002 (203) 392-1955

Part VIII Statement of Revenue

Check if Schedule O contains a response or note to any line in this Part VIII

			(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512 - 514	
Contributions, Gifts, Grants and Other Similar Amounts	1a Federated campaigns	1a	0				
	b Membership dues	1b	0				
	c Fundraising events	1c	470,643				
	d Related organizations	1d	0				
	e Government grants (contributions)	1e	0				
	f All other contributions, gifts, grants, and similar amounts not included above	1f	757,928				
	g Noncash contributions included in lines 1a - 1f:\$	1g	0				
	h Total. Add lines 1a-1f			1,228,571			
Program Service Revenue	2a Professional Education & Meetings	Business Code					
		813319	105,000	105,000	0	0	
	b Research Grants	813319	49,183	49,183	0	0	
	c Patient & Family Services	813319	500,798	500,798	0	0	
	d						
	e						
	f All other program service revenue		0	0	0	0	
g Total. Add lines 2a-2f.		654,981					
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)		16,250	0	0	16,250	
	4 Income from investment of tax-exempt bond proceeds		0	0	0	0	
	5 Royalties		0	0	0	0	
	6a Gross rents	(i) Real	(ii) Personal				
		6b Less: rental expenses					
		6c Rental income or (loss)	0	0			
		d Net rental income or (loss)					
	7a Gross amount from sales of assets other than inventory	(i) Securities	(ii) Other				
		7b Less: cost or other basis and sales expenses					
		7c Gain or (loss)	0	0			
		d Net gain or (loss)					
	8a Gross income from fundraising events (not including \$ 470,643 of contributions reported on line 1c). See Part IV, line 18						
		8b Less: direct expenses		112,808	48,493		
		c Net income or (loss) from fundraising events		64,315	0		64,315
	9a Gross income from gaming activities. See Part IV, line 19						
9b Less: direct expenses							
c Net income or (loss) from gaming activities							
10a Gross sales of inventory, less returns and allowances							
	10b Less: cost of goods sold						
	c Net income or (loss) from sales of inventory						
11a Miscellaneous Revenue	Business Code						
	b						
	c						
	d All other revenue						
	e Total. Add lines 11a-11d		0				
12 Total revenue. See instructions		1,964,117	654,981	0	80,565		

Part IX Statement of Functional Expenses

Section 501(c)(3) and 501(c)(4) organizations must complete all columns. All other organizations must complete column (A).

Check if Schedule O contains a response or note to any line in this Part IX

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	162,790	162,790		
2 Grants and other assistance to domestic individuals. See Part IV, line 22	14,526	14,526		
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16.	151,678	151,678		
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	131,900	27,902	97,657	6,341
6 Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)	214,795	92,813	84,828	37,154
7 Other salaries and wages				
8 Pension plan accruals and contributions (include section 401 (k) and 403(b) employer contributions)				
9 Other employee benefits				
10 Payroll taxes	28,989	10,162	15,264	3,563
11 Fees for services (non-employees):				
a Management				
b Legal	7,640		7,640	
c Accounting	4,400		4,400	
d Lobbying				
e Professional fundraising services. See Part IV, line 17				
f Investment management fees				
g Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O)	28,581	24,604	3,977	
12 Advertising and promotion	1,924	1,735	189	
13 Office expenses	22,317	15,382	5,040	1,895
14 Information technology	926		926	
15 Royalties				
16 Occupancy				
17 Travel	3,759	1,456	2,303	
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	67,141	64,429	2,712	
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization				
23 Insurance	4,826	904	2,664	1,258
24 Other expenses. Itemize expenses not covered above (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
a Bank & Credit Card Processing Fees	18,737	258	8,019	10,460
b Charity Registration Fees	5,463	0	5,463	0
c Dues & Subscriptions	20,667	2,225	13,493	4,949
d Other Expenses	30,666	30,666	0	0
e All other expenses	10	10	0	0
25 Total functional expenses. Add lines 1 through 24e	921,735	601,540	254,575	65,620
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here <input type="checkbox"/> if following SOP 98-2 (ASC 958-720).				

Part X Balance Sheet

Check if Schedule O contains a response or note to any line in this Part IX

		(A) Beginning of year		(B) End of year
Assets	1 Cash—non-interest-bearing	264,871	1	314,542
	2 Savings and temporary cash investments	440,752	2	789,919
	3 Pledges and grants receivable, net		3	
	4 Accounts receivable, net	147,905	4	26,142
	5 Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		5	
	6 Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B)		6	
	7 Notes and loans receivable, net		7	
	8 Inventories for sale or use		8	
	9 Prepaid expenses and deferred charges	73,771	9	44,394
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a		
	b Less: accumulated depreciation	10b		10c
	11 Investments—publicly traded securities	2,691,056	11	3,707,992
	12 Investments—other securities. See Part IV, line 11		12	
	13 Investments—program-related. See Part IV, line 11		13	
	14 Intangible assets		14	
	15 Other assets. See Part IV, line 11		15	
16 Total assets. Add lines 1 through 15 (must equal line 33)	3,618,355	16	4,882,989	
Liabilities	17 Accounts payable and accrued expenses	44,357	17	34,006
	18 Grants payable	232,500	18	150,000
	19 Deferred revenue		19	261,960
	20 Tax-exempt bond liabilities		20	
	21 Escrow or custodial account liability. Complete Part IV of Schedule D		21	
	22 Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		22	
	23 Secured mortgages and notes payable to unrelated third parties		23	
	24 Unsecured notes and loans payable to unrelated third parties		24	51,557
	25 Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17 - 24). Complete Part X of Schedule D		25	0
	26 Total liabilities. Add lines 17 through 25	276,857	26	497,523
Net Assets or Fund Balances	Organizations that follow FASB ASC 958, check here <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33.			
	27 Net assets without donor restrictions	3,341,498	27	4,334,842
	28 Net assets with donor restrictions	0	28	50,624
	Organizations that do not follow FASB ASC 958, check here <input type="checkbox"/> and complete lines 29 through 33.			
	29 Capital stock or trust principal, or current funds		29	
	30 Paid-in or capital surplus, or land, building or equipment fund		30	
	31 Retained earnings, endowment, accumulated income, or other funds		31	
32 Total net assets or fund balances	3,341,498	32	4,385,466	
33 Total liabilities and net assets/fund balances	3,618,355	33	4,882,989	

Part XI Reconciliation of Net Assets

Check if Schedule O contains a response or note to any line in this Part XI

1	Total revenue (must equal Part VIII, column (A), line 12)	1	1,964,117
2	Total expenses (must equal Part IX, column (A), line 25)	2	921,735
3	Revenue less expenses. Subtract line 2 from line 1	3	1,042,382
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	3,341,498
5	Net unrealized gains (losses) on investments	5	1,586
6	Donated services and use of facilities	6	0
7	Investment expenses	7	0
8	Prior period adjustments	8	0
9	Other changes in net assets or fund balances (explain in Schedule O)	9	0
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B))	10	4,385,466

Part XII Financial Statements and Reporting

Check if Schedule O contains a response or note to any line in this Part XII

- 1** Accounting method used to prepare the Form 990: Cash Accrual Other _____
 If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule O.
- 2a** Were the organization's financial statements compiled or reviewed by an independent accountant?
 If 'Yes,' check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both:
 Separate basis Consolidated basis Both consolidated and separate basis
- b** Were the organization's financial statements audited by an independent accountant?
 If 'Yes,' check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both:
 Separate basis Consolidated basis Both consolidated and separate basis
- c** If "Yes," to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant?
 If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O.
- 3a** As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133?
- b** If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits.

	Yes	No
2a		No
2b	Yes	
2c	Yes	
3a		No
3b		

Additional Data

Software ID: 20012124

Software Version: v1.00

EIN: 27-0924627

Name: DRAVET SYNDROME FOUNDATION INC

Form 990 (2020)

Form 990, Part III, Line 4a:

DSF funds research for better treatments and a cure for Dravet syndrome and related epilepsies by awarding research grants to qualified scientists and clinicians. These grants fund initial research hypotheses that have not been fully explored. The results extracted from this type of research will help bring untested research to the point that it can qualify for larger governmental funding. Since 2009, DSF has awarded over \$4.5 million to 41 research endeavors. Research areas include SUDEP, gene therapy, drug discovery, screening, treatments, genetics, epidemiology and neuronal networks. In 2020, DSF hired a Scientific Director to serve as the liaison between the medical/scientific community and DSF, developing strategies to support research, manage DSF's involvement in projects, and move projects forward with assistance in project management, manuscript preparation, and other writing opportunities. The Scientific Coordinator acts as a representative of DSF to other institutions including NIH, PDA, pharma and biotechnology companies.

Form 990, Part III, Line 4b:

Receiving a diagnosis of Dravet syndrome can be overwhelming and may leave a family with many unanswered questions. DSF produces a biennial professional and family conference designed to unite community stakeholders to address these questions - families, caregivers, clinicians, researchers, and other professionals. Our 2018 conference welcomed almost 400 parents, children and professionals. The 3-day event featured over 30 speakers who presented on current research, co-morbidities, best care practices, and daily living challenges. Due to the pandemic, our live in-person biennial conference for June 2020 had to be postponed. In its place, we offered a virtual webinar series on new treatments and current research to bridge the educational gap until we can safely meet in person again. In 2017 the DSF Family Network was established to provide regional support to families. As part of this initiative, 5 educational workshops are held across the country each year. Also due to the pandemic, our usual 5 Day of Dravet regional workshops were changed into a single one-day virtual event to connect our caregivers and families and discuss top concerns in the patient community. In addition to these conferences and workshops, DSF has established an international patient assistance grant program to help patients receive medical equipment, therapy devices, and education aides associated with Dravet syndrome that are not covered through private insurance or other assistance programs. Since 2009, DSF has awarded over \$178k in assistance to families.

Form 990, Part III, Line 4c:

DSF produces an annual research roundtable meeting to provide opportunity for researchers and clinicians to collaborate and discuss better treatment options and a roadmap toward a cure and how to best facilitate both. This meeting started in 2010 as a brainstorming session for the few researchers working on Dravet syndrome. DSF hosted its 11th annual Research Roundtable virtually, and had our largest attendance yet, with over 180 participants. In 2020, to address and unmet need in education for healthcare professionals who work with patients with Dravet syndrome, DSF developed a webinar series, Listen+Learn. This CME-accredited series features experts from DSF's Medical Advisory Board who provide guidance and share current treatment approaches with medical professionals who care for patients with Dravet syndrome.

SCHEDULE A
(Form 990 or 990-EZ)

Public Charity Status and Public Support
Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.
▶ Attach to Form 990 or Form 990-EZ.
▶ Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047
2020
Open to Public Inspection

Department of the Treasury
Internal Revenue Service

Name of the organization
DRAVET SYNDROME FOUNDATION INC

Employer identification number
27-0924627

Part I Reason for Public Charity Status (All organizations must complete this part.) See instructions.

The organization is not a private foundation because it is: (For lines 1 through 12, check only one box.)

- 1 A church, convention of churches, or association of churches described in **section 170(b)(1)(A)(i).**
- 2 A school described in **section 170(b)(1)(A)(ii).** (Attach Schedule E (Form 990 or 990-EZ).)
- 3 A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii).**
- 4 A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii).** Enter the hospital's name, city, and state:
- 5 An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv).** (Complete Part II.)
- 6 A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v).**
- 7 An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi).** (Complete Part II.)
- 8 A community trust described in **section 170(b)(1)(A)(vi).** (Complete Part II.)
- 9 An agricultural research organization described in **170(b)(1)(A)(ix)** operated in conjunction with a land-grant college or university or a non-land grant college of agriculture. See instructions. Enter the name, city, and state of the college or university:
- 10 An organization that normally receives: (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions—subject to certain exceptions, and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See **section 509(a)(2).** (Complete Part III.)
- 11 An organization organized and operated exclusively to test for public safety. See **section 509(a)(4).**
- 12 An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in **section 509(a)(1)** or **section 509(a)(2).** See **section 509(a)(3).** Check the box in lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g.
 - a **Type I.** A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization. **You must complete Part IV, Sections A and B.**
 - b **Type II.** A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s). **You must complete Part IV, Sections A and C.**
 - c **Type III functionally integrated.** A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions). **You must complete Part IV, Sections A, D, and E.**
 - d **Type III non-functionally integrated.** A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions). **You must complete Part IV, Sections A and D, and Part V.**
 - e Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization.
 - f Enter the number of supported organizations _____
 - g Provide the following information about the supported organization(s).

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1- 10 above (see instructions))	(iv) Is the organization listed in your governing document?		(v) Amount of monetary support (see instructions)	(vi) Amount of other support (see instructions)
			Yes	No		
Total						

Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)

(Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization failed to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ▶	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grant.") . . .	244,607	997,080	1,459,444	1,609,408	1,228,571	5,539,110
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf. . . .						
3 The value of services or facilities furnished by a governmental unit to the organization without charge..						
4 Total. Add lines 1 through 3	244,607	997,080	1,459,444	1,609,408	1,228,571	5,539,110
5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f) . . .						
6 Public support. Subtract line 5 from line 4.						5,539,110

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
7 Amounts from line 4. . .	244,607	997,080	1,459,444	1,609,408	1,228,571	5,539,110
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources. . . .	477	1,777	523	42,174	16,250	61,201
9 Net income from unrelated business activities, whether or not the business is regularly carried on. . .						
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.). . .						
11 Total support. Add lines 7 through 10						5,600,311
12 Gross receipts from related activities, etc. (see instructions)					12	

13 First 5 years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and **stop here**

Section C. Computation of Public Support Percentage

14 Public support percentage for 2020 (line 6, column (f) divided by line 11, column (f))	14	98.907 %
15 Public support percentage for 2019 Schedule A, Part II, line 14	15	99.067 %

- 16a 33 1/3% support test—2020.** If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and **stop here.** The organization qualifies as a publicly supported organization
- b 33 1/3% support test—2019.** If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and **stop here.** The organization qualifies as a publicly supported organization
- 17a 10%-facts-and-circumstances test—2020.** If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and **stop here.** Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization
- b 10%-facts-and-circumstances test—2019.** If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and **stop here.** Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization
- 18 Private foundation.** If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions

Part III Support Schedule for Organizations Described in Section 509(a)(2)

(Complete only if you checked the box on line 10 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ▶		(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
1	Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") .						
2	Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3	Gross receipts from activities that are not an unrelated trade or business under section 513						
4	Tax revenues levied for the organization's benefit and either paid to or expended on its behalf. . .						
5	The value of services or facilities furnished by a governmental unit to the organization without charge						
6	Total. Add lines 1 through 5						
7a	Amounts included on lines 1, 2, and 3 received from disqualified persons						
b	Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year.						
c	Add lines 7a and 7b.						
8	Public support. (Subtract line 7c from line 6.)						

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶		(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
9	Amounts from line 6.						
10a	Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources. . .						
b	Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975.						
c	Add lines 10a and 10b.						
11	Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on.						
12	Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
13	Total support. (Add lines 9, 10c, 11, and 12.)						

14 First 5 years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and **stop here.**

Section C. Computation of Public Support Percentage

15	Public support percentage for 2020 (line 8, column (f) divided by line 13, column (f))	15	
16	Public support percentage from 2019 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage

17	Investment income percentage for 2020 (line 10c, column (f) divided by line 13, column (f))	17	
18	Investment income percentage from 2019 Schedule A, Part III, line 17	18	

19a 33 1/3% support tests—2020. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and **stop here.** The organization qualifies as a publicly supported organization

b 33 1/3% support tests—2019. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3% and line 18 is not more than 33 1/3%, check this box and **stop here.** The organization qualifies as a publicly supported organization

20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions

Part IV Supporting Organizations

(Complete only if you checked a box on line 12 of Part I. If you checked box 12a, of Part I, complete Sections A and B. If you checked box 12b, of Part I, complete Sections A and C. If you checked box 12c, of Part I, complete Sections A, D, and E. If you checked box 12d, of Part I, complete Sections A and D, and complete Part V.)

Section A. All Supporting Organizations

		Yes	No
1	Are all of the organization's supported organizations listed by name in the organization's governing documents? If "No," describe in Part VI how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.		
2	Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? If "Yes," explain in Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).		
3a	Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? If "Yes," answer lines 3b and 3c below.		
b	Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? If "Yes," describe in Part VI when and how the organization made the determination.		
c	Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? If "Yes," explain in Part VI what controls the organization put in place to ensure such use.		
4a	Was any supported organization not organized in the United States ("foreign supported organization")? If "Yes" and if you checked box 12a or 12b in Part I, answer lines 4b and 4c below.		
b	Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? If "Yes," describe in Part VI how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.		
c	Did the organization support any foreign supported organization that does not have an IRS determination under sections 501(c)(3) and 509(a)(1) or (2)? If "Yes," explain in Part VI what controls the organization used to ensure that all support to the foreign supported organization was used exclusively for section 170(c)(2)(B) purposes.		
5a	Did the organization add, substitute, or remove any supported organizations during the tax year? If "Yes," answer lines 5b and 5c below (if applicable). Also, provide detail in Part VI , including (i) the names and EIN numbers of the supported organizations added, substituted, or removed; (ii) the reasons for each such action; (iii) the authority under the organization's organizing document authorizing such action; and (iv) how the action was accomplished (such as by amendment to the organizing document).		
b	Type I or Type II only. Was any added or substituted supported organization part of a class already designated in the organization's organizing document?		
c	Substitutions only. Was the substitution the result of an event beyond the organization's control?		
6	Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? If "Yes," provide detail in Part VI .		
7	Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).		
8	Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).		
9a	Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons, as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? If "Yes," provide detail in Part VI .		
b	Did one or more disqualified persons (as defined in line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? If "Yes," provide detail in Part VI .		
c	Did a disqualified person (as defined in line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? If "Yes," provide detail in Part VI .		
10a	Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? If "Yes," answer line 10b below.		
b	Did the organization have any excess business holdings in the tax year? (Use Schedule C, Form 4720, to determine whether the organization had excess business holdings).		

Part IV Supporting Organizations (continued)

		Yes	No
11	Has the organization accepted a gift or contribution from any of the following persons?		
a	A person who directly or indirectly controls, either alone or together with persons described in lines 11b and 11c below, the governing body of a supported organization?		
b	A family member of a person described in 11a above?		
c	A 35% controlled entity of a person described in line 11a or 11b above? <i>If "Yes" to 11a, 11b, or 11c, provide detail in Part VI.</i>		

Section B. Type I Supporting Organizations

		Yes	No
1	Did the officers, directors, trustees, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the tax year? <i>If "No," describe in Part VI how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove directors or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.</i>		
2	Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? <i>If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised or controlled the supporting organization.</i>		

Section C. Type II Supporting Organizations

		Yes	No
1	Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)? <i>If "No," describe in Part VI how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s).</i>		

Section D. All Type III Supporting Organizations

		Yes	No
1	Did the organization provide to each of its supported organizations, by the last day of the fifth month of the organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the organization's governing documents in effect on the date of notification, to the extent not previously provided?		
2	Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported organization (s) or (ii) serving on the governing body of a supported organization? <i>If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).</i>		
3	By reason of the relationship described in line 2 above, did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year? <i>If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.</i>		

Section E. Type III Functionally-Integrated Supporting Organizations

1	Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions):		
a	<input type="checkbox"/> The organization satisfied the Activities Test. Complete line 2 below.		
b	<input type="checkbox"/> The organization is the parent of each of its supported organizations. Complete line 3 below.		
c	<input type="checkbox"/> The organization supported a governmental entity. Describe in Part VI how you supported a government entity (see instructions)		
2	Activities Test. Answer lines 2a and 2b below.		
a	Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? <i>If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.</i>	Yes	No
b	Did the activities described in line 2a constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? <i>If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.</i>		
3	Parent of Supported Organizations. Answer lines 3a and 3b below.		
a	Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? <i>If "Yes" or "No" provide details in Part VI.</i>		
b	Did the organization exercise a substantial degree of direction over the policies, programs and activities of each of its supported organizations? <i>If "Yes," describe in Part VI the role played by the organization in this regard.</i>		

Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations

- 1** Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970 (*explain in Part VI*). See instructions. All other Type III non-functionally integrated supporting organizations must complete Sections A through E.

Section A - Adjusted Net Income		(A) Prior Year	(B) Current Year (optional)
1	Net short-term capital gain	1	
2	Recoveries of prior-year distributions	2	
3	Other gross income (see instructions)	3	
4	Add lines 1 through 3	4	
5	Depreciation and depletion	5	
6	Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions)	6	
7	Other expenses (see instructions)	7	
8	Adjusted Net Income (subtract lines 5, 6 and 7 from line 4)	8	
Section B - Minimum Asset Amount		(A) Prior Year	(B) Current Year (optional)
1	Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year):	1	
a	Average monthly value of securities	1a	
b	Average monthly cash balances	1b	
c	Fair market value of other non-exempt-use assets	1c	
d	Total (add lines 1a, 1b, and 1c)	1d	
e	Discount claimed for blockage or other factors (<i>explain in detail in Part VI</i>):		
2	Acquisition indebtedness applicable to non-exempt use assets	2	
3	Subtract line 2 from line 1d	3	
4	Cash deemed held for exempt use. Enter 0.015 of line 3 (for greater amount, see instructions).	4	
5	Net value of non-exempt-use assets (subtract line 4 from line 3)	5	
6	Multiply line 5 by 0.035	6	
7	Recoveries of prior-year distributions	7	
8	Minimum Asset Amount (add line 7 to line 6)	8	
Section C - Distributable Amount			Current Year
1	Adjusted net income for prior year (from Section A, line 8, Column A)	1	
2	Enter 85% of line 1	2	
3	Minimum asset amount for prior year (from Section B, line 8, Column A)	3	
4	Enter greater of line 2 or line 3	4	
5	Income tax imposed in prior year	5	
6	Distributable Amount. Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions)	6	
7	<input type="checkbox"/> Check here if the current year is the organization's first as a non-functionally-integrated Type III supporting organization (see instructions)		

Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations (continued)

Section D - Distributions		Current Year
1 Amounts paid to supported organizations to accomplish exempt purposes	1	
2 Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	2	
3 Administrative expenses paid to accomplish exempt purposes of supported organizations	3	
4 Amounts paid to acquire exempt-use assets	4	
5 Qualified set-aside amounts (<i>prior IRS approval required - provide details in Part VI</i>)	5	
6 Other distributions (<i>describe in Part VI</i>). See instructions	6	
7 Total annual distributions. Add lines 1 through 6.	7	
8 Distributions to attentive supported organizations to which the organization is responsive (<i>provide details in Part VI</i>). See instructions	8	
9 Distributable amount for 2020 from Section C, line 6	9	
10 Line 8 amount divided by Line 9 amount	10	

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2020	(iii) Distributable Amount for 2020
1 Distributable amount for 2020 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2020 (reasonable cause required-- <i>explain in Part VI</i>). See instructions.			
3 Excess distributions carryover, if any, to 2020:			
a From 2015.			
b From 2016.			
c From 2017.			
d From 2018.			
e From 2019.			
f Total of lines 3a through e			
g Applied to underdistributions of prior years			
h Applied to 2020 distributable amount			
i Carryover from 2015 not applied (see instructions)			
j Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
4 Distributions for 2020 from Section D, line 7:			
\$			
a Applied to underdistributions of prior years			
b Applied to 2020 distributable amount			
c Remainder. Subtract lines 4a and 4b from line 4.			
5 Remaining underdistributions for years prior to 2020, if any. Subtract lines 3g and 4a from line 2. If the amount is greater than zero, <i>explain in Part VI</i> . See instructions.			
6 Remaining underdistributions for 2020. Subtract lines 3h and 4b from line 1. If the amount is greater than zero, <i>explain in Part VI</i> . See instructions.			
7 Excess distributions carryover to 2021. Add lines 3j and 4c.			
8 Breakdown of line 7:			
a Excess from 2016.			
b Excess from 2017.			
c Excess from 2018.			
d Excess from 2019.			
e Excess from 2020.			

Part VI **Supplemental Information.** Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; Part III, line 12; Part IV, Section A, lines 1, 2, 3b, 3c, 4b, 4c, 5a, 6, 9a, 9b, 9c, 11a, 11b, and 11c; Part IV, Section B, lines 1 and 2; Part IV, Section C, line 1; Part IV, Section D, lines 2 and 3; Part IV, Section E, lines 1c, 2a, 2b, 3a and 3b; Part V, line 1; Part V, Section B, line 1e; Part V Section D, lines 5, 6, and 8; and Part V, Section E, lines 2, 5, and 6. Also complete this part for any additional information. (See instructions).

Facts And Circumstances Test

SCHEDULE D (Form 990) Department of the Treasury Internal Revenue Service

Supplemental Financial Statements Complete if the organization answered "Yes," on Form 990, Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b. Attach to Form 990. Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047 2020 Open to Public Inspection

Name of the organization DRAVET SYNDROME FOUNDATION INC

Employer identification number 27-0924627

Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts. Complete if the organization answered "Yes" on Form 990, Part IV, line 6.

Table with 2 columns: (a) Donor advised funds, (b) Funds and other accounts. Rows include total number at end of year, aggregate value of contributions, grants, and end of year, and questions about donor/donor advisor notification.

Part II Conservation Easements. Complete if the organization answered "Yes" on Form 990, Part IV, line 7.

Form for Part II Conservation Easements. Includes questions about purpose of easements, number of easements, acreage, and monitoring requirements.

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets. Complete if the organization answered "Yes" on Form 990, Part IV, line 8.

Form for Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets. Includes questions about reporting requirements for art and historical treasures.

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets (continued)

- 3 Using the organization's acquisition, accession, and other records, check any of the following that are a significant use of its collection items (check all that apply):
a Public exhibition
b Scholarly research
c Preservation for future generations
d Loan or exchange programs
e Other
4 Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII.
5 During the year, did the organization solicit or receive donations of art, historical treasures or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection? Yes No

Part IV Escrow and Custodial Arrangements.

Complete if the organization answered "Yes" on Form 990, Part IV, line 9, or reported an amount on Form 990, Part X, line 21.

- 1a Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X? Yes No
b If "Yes," explain the arrangement in Part XIII and complete the following table:
Table with columns: Amount, 1c Beginning balance, 1d Additions during the year, 1e Distributions during the year, 1f Ending balance
2a Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability? Yes No
b If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided in Part XIII

Part V Endowment Funds.

Complete if the organization answered "Yes" on Form 990, Part IV, line 10.

Table with 5 columns: (a) Current year, (b) Prior year, (c) Two years back, (d) Three years back, (e) Four years back. Rows include: 1a Beginning of year balance, b Contributions, c Net investment earnings, gains, and losses, d Grants or scholarships, e Other expenditures for facilities and programs, f Administrative expenses, g End of year balance.

- 2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
a Board designated or quasi-endowment
b Permanent endowment
c Term endowment
The percentages on lines 2a, 2b, and 2c should equal 100%.
3a Are there endowment funds not in the possession of the organization that are held and administered for the organization by:
(i) Unrelated organizations
(ii) Related organizations
b If "Yes" on 3a(ii), are the related organizations listed as required on Schedule R?
4 Describe in Part XIII the intended uses of the organization's endowment funds.

Part VI Land, Buildings, and Equipment.

Complete if the organization answered "Yes" on Form 990, Part IV, line 11a. See Form 990, Part X, line 10.

Table with 4 columns: (a) Cost or other basis (investment), (b) Cost or other basis (other), (c) Accumulated depreciation, (d) Book value. Rows include: 1a Land, b Buildings, c Leasehold improvements, d Equipment, e Other.

Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c).)

Part VII Investments—Other Securities.

Complete if the organization answered "Yes" on Form 990, Part IV, line 11b. See Form 990, Part X, line 12.

(a) Description of security or category (including name of security)	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1) Financial derivatives		
(2) Closely-held equity interests		
(3) Other _____		
(B)		
(C)		
(D)		
(E)		
(F)		
(G)		
(H)		
(I)		
Total. (Column (b) must equal Form 990, Part X, col. (B) line 12.)		

Part VIII Investments—Program Related.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 11c. See Form 990, Part X, line 13.

(a) Description of investment	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1)		
(2)		
(3)		
(4)		
(5)		
(6)		
(7)		
(8)		
(9)		
(10)		
Total. (Column (b) must equal Form 990, Part X, col.(B) line 13.)		

Part IX Other Assets.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 11d. See Form 990, Part X, line 15.

(a) Description	(b) Book value
(1)	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
(10)	
Total. (Column (b) must equal Form 990, Part X, col.(B) line 15.)	

Part X Other Liabilities.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 11e or 11f. See Form 990, Part X, line 25.

1. (a) Description of liability	(b) Book value
(1) Federal income taxes	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (Column (b) must equal Form 990, Part X, col.(B) line 25.)	0

2. Liability for uncertain tax positions. In Part XIII, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FIN 48 (ASC 740). Check here if the text of the footnote has been provided in Part XIII

Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per Return.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 12a.

1	Total revenue, gains, and other support per audited financial statements		1	1,965,703
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
a	Net unrealized gains (losses) on investments	2a	1,586	
b	Donated services and use of facilities	2b	0	
c	Recoveries of prior year grants	2c	0	
d	Other (Describe in Part XIII.)	2d	0	
e	Add lines 2a through 2d			2e 1,586
3	Subtract line 2e from line 1			3 1,964,117
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1 :			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	0	
b	Other (Describe in Part XIII.)	4b	0	
c	Add lines 4a and 4b			4c 0
5	Total revenue. Add lines 3 and 4c . (This must equal Form 990, Part I, line 12.)			5 1,964,117

Part XII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 12a.

1	Total expenses and losses per audited financial statements		1	921,735
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
a	Donated services and use of facilities	2a	0	
b	Prior year adjustments	2b	0	
c	Other losses	2c	0	
d	Other (Describe in Part XIII.)	2d	0	
e	Add lines 2a through 2d			2e 0
3	Subtract line 2e from line 1			3 921,735
4	Amounts included on Form 990, Part IX, line 25, but not on line 1 :			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	0	
b	Other (Describe in Part XIII.)	4b	0	
c	Add lines 4a and 4b			4c 0
5	Total expenses. Add lines 3 and 4c . (This must equal Form 990, Part I, line 18.)			5 921,735

Part XIII Supplemental Information

Provide the descriptions required for Part II, lines 3, 5, and 9; Part III, lines 1a and 4; Part IV, lines 1b and 2b; Part V, line 4; Part X, line 2; Part XI, lines 2d and 4b; and Part XII, lines 2d and 4b. Also complete this part to provide any additional information.

Return Reference	Explanation
See Additional Data Table	

Part XIII Supplemental Information *(continued)*

Return Reference	Explanation

Additional Data

Software ID: 20012124

Software Version: v1.00

EIN: 27-0924627

Name: DRAVET SYNDROME FOUNDATION INC

Supplemental Information

Return Reference	Explanation
Schedule D, Part X, Line 2	DSF recognizes the effect of tax positions only when they are more than likely than not of being sustained. Management has determined that the foundation has no uncertain tax positions that would require financial statement recognition. Tax years dating back to 2017 remain open to examination by federal and state authorities.

**SCHEDULE F
(Form 990)**

Department of the Treasury
Internal Revenue Service

Statement of Activities Outside the United States

▶ Complete if the organization answered "Yes" to Form 990, Part IV, line 14b, 15, or 16.
▶ Attach to Form 990.
▶ Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

2020

Open to Public Inspection

Name of the organization
DRAVET SYNDROME FOUNDATION INC

Employer identification number
27-0924627

Part I **General Information on Activities Outside the United States.** Complete if the organization answered "Yes" on Form 990, Part IV, line 14b.

- 1 For grantmakers.** Does the organization maintain records to substantiate the amount of its grants and other assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? Yes No
- 2 For grantmakers.** Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.
- 3** Activities per Region. (The following Part I, line 3 table can be duplicated if additional space is needed.)

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in the region	(d) Activities conducted in region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in the region	(f) Total expenditures for and investments in the region
North America (including Canada and Mexico, but not the United States)	0	0	Grantmaking	Research grant (e) Specific services provided Help	150,000
3a Sub-total					
b Total from continuation sheets to Part I					
c Totals (add lines 3a and 3b)	0	0			150,000

Part II Grants and Other Assistance to Organizations or Entities Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 15, for any recipient who received more than \$5,000. Part II can be duplicated if additional space is needed.

1 (a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of noncash assistance	(h) Description of noncash assistance	(i) Method of valuation (book, FMV, appraisal, other)
		North America (including Canada and Mexico, but not the United States)	Research Grant. Danielle Andrade, MD, MSc - University of Toronto. Multi-modal assessment of adults with Dravet syndrome. Dr. Andrade plans to better characterize the adult patient with Dravet syndrome. She will study balance, gait, posture, memory, ability to perform day-to-day activities, and genome in a cohort of adults with Dravet syndrome to test the hypothesis that there may be premature brain aging in adult patients. They also plan to explore whether previous use of contraindicated medications influence adult outcome.	150,000	Wire	0		

2 Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as tax-exempt by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter **▶** 0

3 Enter total number of other organizations or entities **▶** 1

Part III Grants and Other Assistance to Individuals Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 16.

Part III can be duplicated if additional space is needed.

(a) Type of grant or assistance	(b) Region	(c) Number of recipients	(d) Amount of cash grant	(e) Manner of cash disbursement	(f) Amount of noncash assistance	(g) Description of noncash assistance	(h) Method of valuation (book, FMV, appraisal, other)

Part IV Foreign Forms

- 1 Was the organization a U.S. transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926)* Yes No
- 2 Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to separately file Form 3520, Annual Return to Report Transactions with Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see Instructions for Forms 3520 and 3520-A; don't file with Form 990)* Yes No
- 3 Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons with Respect to Certain Foreign Corporations. (see Instructions for Form 5471)* Yes No
- 4 Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund. (see Instructions for Form 8621)* . Yes No
- 5 Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons with Respect to Certain Foreign Partnerships (see Instructions for Form 8865)* Yes No
- 6 Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to separately file Form 5713, International Boycott Report (see Instructions for Form 5713; don't file with Form 990).* Yes No

Part V Supplemental Information

Provide the information required by Part I, line 2 (monitoring of funds); Part I, line 3, column (f) (accounting method; amounts of investments vs. expenditures per region); Part II, line 1 (accounting method); Part III (accounting method); and Part III, column (c) (estimated number of recipients), as applicable. Also complete this part to provide any additional information. See instructions.

990 Schedule F, Supplemental Information

Return Reference	Explanation
Schedule F, Part I, Line 2	DSF provides funds for research. The organizations receiving this assistance are required to provide written progress reports on their research into finding a cure for Dravet syndrome and related epilepsies. The Scientific Director of DSF reviews the progress reports and discusses the research projects and progress with the awarded organization. DSF also provides funding to patients with Dravet syndrome and related epilepsies for necessary medical equipment, therapy devices and education aids associated with these conditions that are not covered through private insurance or other assistance programs. Applicants are required to submit an application that includes a recent letter from the child's health care provider explaining the medical necessity of the request and when possible, a letter of denial from the insurance provider.

SCHEDULE G
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Supplemental Information Regarding Fundraising or Gaming Activities

Complete if the organization answered "Yes" on Form 990, Part IV, lines 17, 18, or 19, or if the organization entered more than \$15,000 on Form 990-EZ, line 6a.
▶ Attach to Form 990 or Form 990-EZ.
▶ Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

2020

Open to Public Inspection

Name of the organization
DRAVET SYNDROME FOUNDATION INC

Employer identification number
27-0924627

Part I Fundraising Activities. Complete if the organization answered "Yes" on Form 990, Part IV, line 17. Form 990-EZ filers are not required to complete this part.

- 1** Indicate whether the organization raised funds through any of the following activities. Check all that apply.
- | | |
|--|---|
| a <input type="checkbox"/> Mail solicitations | e <input type="checkbox"/> Solicitation of non-government grants |
| b <input type="checkbox"/> Internet and email solicitations | f <input type="checkbox"/> Solicitation of government grants |
| c <input type="checkbox"/> Phone solicitations | g <input type="checkbox"/> Special fundraising events |
| d <input type="checkbox"/> In-person solicitations | |
- 2a** Did the organization have a written or oral agreement with any individual (including officers, directors, trustees or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services? Yes No
- b** If "Yes," list the 10 highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization.

(i) Name and address of individual or entity (fundraiser)	(ii) Activity	(iii) Did fundraiser have custody or control of contributions?		(iv) Gross receipts from activity	(v) Amount paid to (or retained by) fundraiser listed in col. (i)	(vi) Amount paid to (or retained by) organization
		Yes	No			
Total ▶						

3 List all states in which the organization is registered or licensed to solicit contributions or has been notified it is exempt from registration or licensing.

Part II Fundraising Events. Complete if the organization answered "Yes" on Form 990, Part IV, line 18, or reported more than \$15,000 of fundraising event contributions and gross income on Form 990-EZ, lines 1 and 6b. List events with gross receipts greater than \$5,000.

Revenue	(a) Event #1	(b) Event #2	(c) Other events	(d) Total events	
	<u>Dance for Dravet</u> (event type)	<u>Double Down H-Town</u> (event type)	<u>4</u> (total number)	(add col. (a) through col. (c))	
1 Gross receipts	168,855	128,266	285,053	582,174	
2 Less: Contributions	119,830	97,355	252,526	469,711	
3 Gross income (line 1 minus line 2)	49,025	30,911	32,527	112,463	
Direct Expenses	4 Cash prizes	0	0	0	
	5 Noncash prizes	0	0	0	
	6 Rent/facility costs	0	0	0	
	7 Food and beverages	0	14,360	0	14,360
	8 Entertainment	0	1,688	3,795	5,483
	9 Other direct expenses	2,926	4,916	20,440	28,282
	10 Direct expense summary. Add lines 4 through 9 in column (d) ▶				48,125
11 Net income summary. Subtract line 10 from line 3, column (d) ▶				64,338	

Part III Gaming. Complete if the organization answered "Yes" on Form 990, Part IV, line 19, or reported more than \$15,000 on Form 990-EZ, line 6a.

Revenue	(a) Bingo	(b) Pull tabs/Instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col.(a) through col.(c))
	1 Gross revenue			
Direct Expenses	2 Cash prizes			
	3 Noncash prizes			
	4 Rent/facility costs			
	5 Other direct expenses			
	6 Volunteer labor	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No
7 Direct expense summary. Add lines 2 through 5 in column (d) ▶				
8 Net gaming income summary. Subtract line 7 from line 1, column (d) ▶				

9 Enter the state(s) in which the organization conducts gaming activities: _____

a Is the organization licensed to conduct gaming activities in each of these states? Yes No

b If "No," explain: _____

10a Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year? Yes No

b If "Yes," explain: _____

- 11** Does the organization conduct gaming activities with nonmembers? Yes No
- 12** Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity formed to administer charitable gaming? Yes No
- 13** Indicate the percentage of gaming activity conducted in:

a The organization's facility	13a	%
b An outside facility	13b	%

14 Enter the name and address of the person who prepares the organization's gaming/special events books and records:

Name ▶

Address ▶

15a Does the organization have a contract with a third party from whom the organization receives gaming revenue? Yes No

b If "Yes," enter the amount of gaming revenue received by the organization ▶ \$ _____ and the amount of gaming revenue retained by the third party ▶ \$ _____.

c If "Yes," enter name and address of the third party:

Name ▶

Address ▶

16 Gaming manager information:

Name ▶

Gaming manager compensation ▶ \$

Description of services provided ▶

- Director/officer Employee Independent contractor

17 Mandatory distributions:

a Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license? Yes No

b Enter the amount of distributions required under state law distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year ▶ \$ _____

Part IV Supplemental Information. Provide the explanations required by Part I, line 2b, columns (iii) and (v); and Part III, lines 9, 9b, 10b, 15b, 15c, 16, and 17b, as applicable. Also provide any additional information. See instructions.

Return Reference	Explanation
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Note: To capture the full content of this document, please select landscape mode (11" x 8.5") when printing.

**Schedule I
(Form 990)**

**Grants and Other Assistance to Organizations,
Governments and Individuals in the United States**
Complete if the organization answered "Yes," on Form 990, Part IV, line 21 or 22.
▶ Attach to Form 990.
▶ Go to www.irs.gov/Form990 for the latest information.

OMB No. 1545-0047

2020

**Open to Public
Inspection**

Department of the
Treasury
Internal Revenue Service

Name of the organization
DRAVET SYNDROME FOUNDATION INC

Employer identification number

27-0924627

Part I General Information on Grants and Assistance

- 1** Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? **Yes** **No**
- 2** Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States.

Part II Grants and Other Assistance to Domestic Organizations and Domestic Governments. Complete if the organization answered "Yes" on Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Part II can be duplicated if additional space is needed.

(a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
(1) Northwestern University 633 Clark Street Crown G-547 Evanston, IL 60208	36-2167817	501(c)(3)	150,000				Research Grant - Jennifer Kearney, PHD - Northwestern University. MicroRNA-mediated modification of Dravet syndrome. Dr. Kearney plans to investigate microRNAs (small RNA molecules that regulate expression of gene products) and their modulation of Nav1.1. They have identified two miRNAs that are elevated following seizures and can reduce SCN1A expression and hypothesize that this may contribute to disease progression. She will study this relationship further and evaluate this pathway as a therapeutic target for Dravet syndrome.
(2) Camp Boggy Creek 30500 Brantley Branch Road Eustis, FL 32736	59-3012889	501(c)(3)	10,000				Family Weekend Funding. During weekends in the spring and fall, Camp Boggy welcomes campers and their whole families to camp where parents can relax and find needed support among other families dealing with similar emotional and financial challenges. Brothers and sisters get to participate in the same fun-filled activities since every family member is considered a camper during family weekends. This grant allowed 5 families with Dravet syndrome to attend camp.

2 Enter total number of section 501(c)(3) and government organizations listed in the line 1 table **2**

3 Enter total number of other organizations listed in the line 1 table **0**

Part III Grants and Other Assistance to Domestic Individuals. Complete if the organization answered "Yes" on Form 990, Part IV, line 22.

Part III can be duplicated if additional space is needed.

(a) Type of grant or assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of noncash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance
(1) Patient Assistance Grants The DSF Patient Assistance Grant Program offers grants to patients with Dravet syndrome and related epilepsies for necessary medical equipment, therapy devices, and educational aids associated with these conditions that are not covered through private insurance or other assistance programs. This program is open to all patients worldwide who are members of the DSF Family Network. The DSF Disaster Relief and Recovery Fund was established for patients with Dravet syndrome that have been impacted by natural and other significant natural disaster events in the U.S., such as tornados, hurricanes, earthquakes. Flooding that results from a significant natural disaster event would also qualify. Families that are members of the DSF Family Network may apply for a \$500 Visa card or Amazon E-card to be used for lodging, food, supplies or however needed.	22	6,018	8,508	FMV	Items that are currently covered under this program include: durable medical goods (such as wheelchairs, orthotics, cooling vests, etc.), therapy equipment, communication devices such as iPads, and costs associated with implementation of the ketogenic diet. By awarding these grants, DSF is making no recommendation to the appropriateness or safety of a particular piece of equipment or therapy in treating Dravet syndrome and associated epilepsies and conditions. DSF and its Board of Directors are not responsible for the safety and use of awarded equipment or therapies. Applicants are strongly urged to consult with their medical professionals and therapists regarding equipment and therapies that would be most beneficial for their situation.
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					

Part IV Supplemental Information. Provide the information required in Part I, line 2; Part III, column (b); and any other additional information.

Return Reference	Explanation
Schedule I, Part I, Line 2	DSF provides funds for research. The organizations receiving this assistance are required to provide written progress reports on their research into finding a cure for Dravet syndrome and related epilepsies. The Scientific Director of DSF reviews the progress reports and discusses the research projects and progress with the awarded organization. DSF also provides funding to patients with Dravet syndrome and related epilepsies for necessary medical equipment, therapy devices and education aids associated with these conditions that are not covered through private insurance or other assistance programs. Applicants are required to submit an application that includes a recent letter from the child's health care provider explaining the medical necessity of the request and when possible, a letter of denial from the insurance provider.

SCHEDULE O
(Form 990 or 990-EZ)

Supplemental Information to Form 990 or 990-EZ

Complete to provide information for responses to specific questions on Form 990 or 990-EZ or to provide any additional information.

▶ Attach to Form 990 or 990-EZ.

▶ Go to www.irs.gov/Form990 for the latest information.

OMB No. 1545-0047

2020

Open to Public Inspection

Department of the Treasury

Name of the Organization

DRAVET SYNDROME FOUNDATION INC

Employer identification number

27-0924627

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990, Part VI, Section A, Line 4	<p>On March 23, 2020, DSF's board of directors approved an amendment to the foundation's bylaws. Article II, Board of Directors, Part 2.3 Terms of Office was amended to read, "Each Director shall hold office for a three (3) year term; provided, however, that any Director elected to fill an unexpired term (whether resulting from the death, resignation, or removal of a Director) shall hold office until the expiration of the term of the replaced Director. The terms of Directors shall be staggered such that terms of no more than 1/2 of all Directors shall expire in the same year. Each Director shall be elected for an initial term of three (3) years; provided that such initial term may be truncated to as necessary to meet the requirements of the immediately preceding sentence. Directors shall serve no more than two (2) consecutive terms, and, once termed-off, such Directors shall not be eligible for re-election to the Board until one year thereafter. A Director shall continue to serve after such Director's term of office has expired until a successor is duly elected. The provisions of this section shall not apply to ex officio Directors, each of whom shall continue in office so long as, but no longer than, (s)he holds the office from which his/her ex officio status derives. Unless otherwise provided in the Certificate of Incorporation, ex officio Directors shall not be entitled to vote, nor shall they be counted when determining quorum." Article IV Officers, Part 4.5 was amended to read, "The Treasurer shall review the financial operations of the Corporation and should possess thorough knowledge and understanding of the organization's financial reports and important financial ratios. The Treasurer shall keep the board apprised of the corporation's financial performance and balance sheet, key financial events, trends, and concerns. The Treasurer shall also be responsible for ensuring the completion of required financial reporting forms (including the IRS Form 990) in a timely manner and making these forms available for the board's review." Lastly, Article IX, General Provisions added section 9.4 to read, "Document Retention and Destruction Policy. The Board of Directors shall adopt and ensure compliance with a Document Retention and Destruction Policy."</p>

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990, Part VI, Section B, Line 11b	A copy of Form 990 and all related schedules is provided to the executive committee of the board of directors for review prior to filing with the Internal Revenue Service.

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990, Part VI, Section B, Line 12c	A conflict of interest disclosures statement is distributed and signed by each board member annually. Conflicts are dealt with on a case-by-case basis.

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990, Part VI, Section C, Line 19	DSF makes its governing documents and conflict of interest policy available to the public upon prior written request from the president. Financial statements are available for public view on the organization's website.