

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.**2024****Open to Public
Inspection**

A For the 2024 calendar year, or tax year beginning 01/01/2024 and ending 12/31/2024																							
B Check if applicable: <input type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial return <input type="checkbox"/> Final return/terminated <input type="checkbox"/> Amended return <input type="checkbox"/> Application pending	<table><tr><td colspan="2">C Name of organization DRAVET SYNDROME FOUNDATION INC</td><td>D Employer identification number 27-0924627</td></tr><tr><td colspan="2">Doing business as</td><td rowspan="3">E Telephone number 203-392-1955</td></tr><tr><td colspan="2">Number and street (or P.O. box if mail is not delivered to street address) Room/suite PO Box 3026</td></tr><tr><td colspan="2">City or town, state or province, country, and ZIP or foreign postal code Cherry Hill, NJ 08034</td></tr><tr><td colspan="2">F Name and address of principal officer: Ross Nicholas PO Box 3026, Cherry Hill, NJ 08034</td><td>G Gross receipts \$ 4,523,327</td></tr><tr><td colspan="2">I Tax-exempt status: <input checked="" type="checkbox"/> 501(c)(3) <input type="checkbox"/> 501(c) () (insert no.) <input type="checkbox"/> 4947(a)(1) or <input type="checkbox"/> 527</td><td>H(a) Is this a group return for subordinates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No H(b) Are all subordinates included? <input type="checkbox"/> Yes <input type="checkbox"/> No If "No," attach a list. See instructions. H(c) Group exemption number</td></tr><tr><td colspan="2">J Website: www.dravetfoundation.org</td><td></td></tr><tr><td colspan="2">K Form of organization: <input checked="" type="checkbox"/> Corporation <input type="checkbox"/> Trust <input type="checkbox"/> Association <input type="checkbox"/> Other</td><td>L Year of formation: 2009 M State of legal domicile: CT</td></tr></table>	C Name of organization DRAVET SYNDROME FOUNDATION INC		D Employer identification number 27-0924627	Doing business as		E Telephone number 203-392-1955	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		F Name and address of principal officer: Ross Nicholas PO Box 3026, Cherry Hill, NJ 08034		G Gross receipts \$ 4,523,327	I Tax-exempt status: <input checked="" type="checkbox"/> 501(c)(3) <input type="checkbox"/> 501(c) () (insert no.) <input type="checkbox"/> 4947(a)(1) or <input type="checkbox"/> 527		H(a) Is this a group return for subordinates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No H(b) Are all subordinates included? <input type="checkbox"/> Yes <input type="checkbox"/> No If "No," attach a list. See instructions. H(c) Group exemption number	J Website: www.dravetfoundation.org			K Form of organization: <input checked="" type="checkbox"/> Corporation <input type="checkbox"/> Trust <input type="checkbox"/> Association <input type="checkbox"/> Other		L Year of formation: 2009 M State of legal domicile: CT
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Part I Summary

Activities & Governance	1	Briefly describe the organization's mission or most significant activities: <u>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.</u>		
	2	Check this box <input type="checkbox"/> 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	9
	4	Number of independent voting members of the governing body (Part VI, line 1b)	4	9
	5	Total number of individuals employed in calendar year 2024 (Part V, line 2a)	5	13
	6	Total number of volunteers (estimate if necessary)	6	100
		7a	Total unrelated business revenue from Part VIII, column (C), line 12	7a
b		Net unrelated business taxable income from Form 990-T, Part I, line 11	7b	0
Revenue	8	Contributions and grants (Part VIII, line 1h)	Prior Year 2,530,133	Current Year 3,106,931
	9	Program service revenue (Part VIII, line 2g)	471,472	734,789
	10	Investment income (Part VIII, column (A), lines 3, 4, and 7d)	218,414	304,376
	11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	37,077	75,526
	12	Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)	3,257,096	4,221,622
	Expenses	13	Grants and similar amounts paid (Part IX, column (A), lines 1–3)	955,138
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)	695,982	841,275
16a		Professional fundraising fees (Part IX, column (A), line 11e)	0	0
b		Total fundraising expenses (Part IX, column (D), line 25)	237,361	
17		Other expenses (Part IX, column (A), lines 11a–11d, 11f–24e)	511,932	908,777
18		Total expenses. Add lines 13–17 (must equal Part IX, column (A), line 25)	2,163,052	4,259,172
Net Assets or Fund Balances	19	Revenue less expenses. Subtract line 18 from line 12	1,094,044	-37,550
	20	Total assets (Part X, line 16)	Beginning of Current Year 7,509,902	End of Year 8,536,916
	21	Total liabilities (Part X, line 26)	595,166	1,560,863
	22	Net assets or fund balances. Subtract line 21 from line 20	6,914,736	6,976,053

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

04/23/2025

Ross Nicholas, President

Type or print name and title

**Paid
Preparer
Use Only**

Preparer's name

Preparer's signature

Date

Check ☐ 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 AccomplishmentsCheck 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
(Continued on Schedule O, Statement 1)
- 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 \$ 2,672,460 including grants of \$ 2,485,115) (Revenue \$ 0)
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 \$10.5 million to 71 research endeavors. Research areas include SUDEP, gene therapy, drug discovery, screening, treatments, genetics, epidemiology and neuronal networks. DSF has also supported the development of a commercial line of iPSC cells for researchers and the biotechnology industry. DSF's Scientific Director serves 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 Director acts as a representative of DSF to other institutions including NIH, FDA, pharma and biotechnology companies.

4b (Code:) (Expenses \$ 764,750 including grants of \$ 24,006) (Revenue \$ 637,288)
Receiving a diagnosis of Dravet syndrome (DS) can be overwhelming, leaving families with many unanswered questions. To support our patient community, DSF provides a variety of educational, advocacy, and support resources: These initiatives are part of DSF's commitment to providing vital resources and fostering a strong, supportive community for those affected by Dravet syndrome. DSF Family Network: Open to any parent, legal guardian, or sibling interested in our advocacy services and programs, the Family Network keeps members informed about new advocacy tools, clinical trials, educational opportunities, and fundraising events. It also includes moderated private Facebook support groups for parents and caregivers of individuals with Dravet syndrome. Membership is limited to those legally responsible for making medical decisions for the patient. In 2024, 347 people joined the Family Network. Newly Diagnosed Kits: DSF provides newly diagnosed families with a kit that includes a guidebook for navigating life after diagnosis, a medication bag, and other materials to ensure they have the knowledge and tools needed for their child's care. In 2024, DSF distributed 131 kits. Patient Assistance Grants: The DSF Patient Assistance Grant Program offers financial support to patients with Dravet syndrome and related SCN1A epilepsies for medical equipment, therapy devices, and
 (Continued on Schedule O, Statement 2)

4c (Code:) (Expenses \$ 165,700 including grants of \$ 0) (Revenue \$ 97,500)
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 15th annual Research Roundtable with nearly 190 participants.

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

4e Total program service expenses 3,602,910

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	1 ✓	
2 Is the organization required to complete Schedule B, Schedule of Contributors? See instructions	2 ✓	
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	3	✓
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	4 ✓	
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 Rev. Proc. 98-19? If "Yes," complete Schedule C, Part III	5	✓
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	6	✓
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	7	✓
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III	8	✓
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	9	✓
10 Did the organization, directly or through a related organization, hold assets in donor-restricted endowments or in quasi-endowments? If "Yes," complete Schedule D, Part V	10 ✓	
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	11a	✓
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	11b	✓
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	11c	✓
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	11d	✓
e Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X	11e	✓
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	11f ✓	
12a Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI and XII	12a ✓	
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	12b	✓
13 Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E	13	✓
14a Did the organization maintain an office, employees, or agents outside of the United States?	14a	✓
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	14b ✓	
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	15 ✓	
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	16	✓
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	17	✓
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	18 ✓	
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	19	✓
20a Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H	20a	✓
b If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?	20b	
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	21 ✓	

Part IV Checklist of Required Schedules (continued)

	Yes	No
22 Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? If "Yes," complete Schedule I, Parts I and III	22 ✓	
23 Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5, about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? If "Yes," complete Schedule J	23 ✓	
24a Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a	24a	✓
b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b	
c Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?	24c	
d Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d	
25a Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? If "Yes," complete Schedule L, Part I	25a	✓
b Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? If "Yes," complete Schedule L, Part I	25b	✓
26 Did the organization report any amount on Part X, line 5 or 22, for receivables from or 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? If "Yes," complete Schedule L, Part II	26	✓
27 Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity (including an employee thereof) or family member of any of these persons? If "Yes," complete Schedule L, Part III	27	✓
28 Was the organization a party to a business transaction with one of the following parties? (See the Schedule L, Part IV, instructions for applicable filing thresholds, conditions, and exceptions).		
a A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? If "Yes," complete Schedule L, Part IV	28a ✓	
b A family member of any individual described in line 28a? If "Yes," complete Schedule L, Part IV	28b	✓
c A 35% controlled entity of one or more individuals and/or organizations described in line 28a or 28b? If "Yes," complete Schedule L, Part IV	28c	✓
29 Did the organization receive more than \$25,000 in noncash contributions? If "Yes," complete Schedule M	29	✓
30 Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? If "Yes," complete Schedule M	30	✓
31 Did the organization liquidate, terminate, or dissolve and cease operations? If "Yes," complete Schedule N, Part I	31	✓
32 Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If "Yes," complete Schedule N, Part II	32	✓
33 Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? If "Yes," complete Schedule R, Part I	33	✓
34 Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1	34	✓
35a Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a	✓
b If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? If "Yes," complete Schedule R, Part V, line 2	35b	
36 Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? If "Yes," complete Schedule R, Part V, line 2	36	✓
37 Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? If "Yes," complete Schedule R, Part VI	37	✓
38 Did the organization complete Schedule O and provide explanations on Schedule O for Part VI, lines 11b and 19? Note: All Form 990 filers are required to complete Schedule O	38 ✓	

Part V Statements Regarding Other IRS Filings and Tax ComplianceCheck if Schedule O contains a response or note to any line in this Part V ☐

	Yes	No
1a Enter the number reported in box 3 of Form 1096. Enter -0- if not applicable	1a 13	
b Enter the number of Forms W-2G included on line 1a. Enter -0- if not applicable	1b 0	
c Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	1c ✓	

Part V Statements Regarding Other IRS Filings and Tax Compliance (continued)			Yes	No
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	2a 13		
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	2b	✓	
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?	3a		✓
b	If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation on Schedule O	3b		
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 (such as a bank account, securities account, or other financial account)?	4a		✓
b	If "Yes," enter the name of the foreign country _____ See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).			
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5a		✓
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5b		✓
c	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?	5c		
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?	6a		✓
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	6b		
7	Organizations that may receive deductible contributions under section 170(c).			
a	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?	7a	✓	
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?	7b	✓	
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?	7c		✓
d	If "Yes," indicate the number of Forms 8282 filed during the year	7d		
e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	7e		✓
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7f		✓
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	7g		
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?	7h		
8	Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?	8		
9	Sponsoring organizations maintaining donor advised funds.			
a	Did the sponsoring organization make any taxable distributions under section 4966?	9a		
b	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?	9b		
10	Section 501(c)(7) organizations. Enter:			
a	Initiation fees and capital contributions included on Part VIII, line 12	10a		
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities	10b		
11	Section 501(c)(12) organizations. Enter:			
a	Gross income from members or shareholders	11a		
b	Gross income from other sources. (Do not net amounts due or paid to other sources against amounts due or received from them.)	11b		
12a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?	12a		
b	If "Yes," enter the amount of tax-exempt interest received or accrued during the year	12b		
13	Section 501(c)(29) qualified nonprofit health insurance issuers.			
a	Is the organization licensed to issue qualified health plans in more than one state? Note: See the instructions for additional information the organization must report on Schedule O.	13a		
b	Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans	13b		
c	Enter the amount of reserves on hand	13c		
14a	Did the organization receive any payments for indoor tanning services during the tax year?	14a		✓
b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation on Schedule O	14b		
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? If "Yes," see the instructions and file Form 4720, Schedule N.	15		✓
16	Is the organization an educational institution subject to the section 4968 excise tax on net investment income? If "Yes," complete Form 4720, Schedule O.	16		✓
17	Section 501(c)(21) organizations. Did the trust, or any disqualified or other person, engage in any activities that would result in the imposition of an excise tax under section 4951, 4952, or 4953? If "Yes," complete Form 6069.	17		

Part VI Governance, Management, and Disclosure. For each "Yes" response to lines 2 through 7b below, and for a "No" response to line 8a, 8b, or 10b below, describe the circumstances, processes, or changes on 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

		Yes	No
1a Enter the number of voting members of the governing body at the end of the tax year . . .	1a 9		
If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain on Schedule O.			
b Enter the number of voting members included on line 1a, above, who are independent . . .	1b 9		
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? . . .	2		<input checked="" type="checkbox"/>
3 Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors, trustees, or key employees to a management company or other person? . . .	3		<input checked="" type="checkbox"/>
4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed? . . .	4		<input checked="" type="checkbox"/>
5 Did the organization become aware during the year of a significant diversion of the organization's assets? . . .	5		<input checked="" type="checkbox"/>
6 Did the organization have members or stockholders? . . .	6		<input checked="" type="checkbox"/>
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? . . .	7a		<input checked="" type="checkbox"/>
b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body? . . .	7b		<input checked="" type="checkbox"/>
8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:			
a The governing body? . . .	8a	<input checked="" type="checkbox"/>	
b Each committee with authority to act on behalf of the governing body? . . .	8b	<input checked="" type="checkbox"/>	
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 on Schedule O . . .	9		<input checked="" type="checkbox"/>

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

	Yes	No
10a Did the organization have local chapters, branches, or affiliates? . . .	10a	<input checked="" type="checkbox"/>
b 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? . . .	10b	
11a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? . . .	11a	<input checked="" type="checkbox"/>
b Describe on 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 . . .	12a	<input checked="" type="checkbox"/>
b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? . . .	12b	<input checked="" type="checkbox"/>
c Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe on Schedule O how this was done . . .	12c	<input checked="" type="checkbox"/>
13 Did the organization have a written whistleblower policy? . . .	13	<input checked="" type="checkbox"/>
14 Did the organization have a written document retention and destruction policy? . . .	14	<input checked="" type="checkbox"/>
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?		
a The organization's CEO, Executive Director, or top management official . . .	15a	<input checked="" type="checkbox"/>
b Other officers or key employees of the organization . . .	15b	<input checked="" type="checkbox"/>
If "Yes" to line 15a or 15b, describe the process on 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? . . .	16a	<input checked="" type="checkbox"/>
b 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? . . .	16b	

Section C. Disclosure

- 17** List the states with which a copy of this Form 990 is required to be filed [See Schedule O, Statement 3](#)
- 18** Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, and 990-T (section 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 on Schedule O)
- 19** Describe on 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, (203)392-1955

522 Mackin Drive, Cherry Hill, NJ 08002

Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent ContractorsCheck if Schedule O contains a response or note to any line in this Part VII ☐**Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees****1a** Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year.

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.

- List all of the organization's **current** key employees, if any. See the instructions for definition of "key employee."

- List the organization's five **current** highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (box 5 of Form W-2, box 6 of Form 1099-MISC, and/or box 1 of Form 1099-NEC) of more than \$100,000 from the organization and any related organizations.

- List all of the organization's **former** officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.

- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations.

See the instructions for the order in which to list the persons above.

☐ Check this box if neither the organization nor any related organization compensated any current officer, director, or trustee.

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/ 1099-MISC/ 1099-NEC)	(E) Reportable compensation from related organizations (W-2/ 1099-MISC/ 1099-NEC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
Mary Anne Meskis Executive Director	40.00 0.00			✓				172,586	0	0
Veronica Hood Scientific Director	40.00 0.00					✓		165,459	0	0
Jamie Cohen Finance & Program Director	40.00 0.00			✓				108,866	0	0
Ted Odlaug PhD President	1.00 0.00	✓		✓				0	0	0
Ross Nicholas Vice President	1.00 0.00	✓		✓				0	0	0
Claire Carey Secretary	1.00 0.00	✓		✓				0	0	0
Josh Goldman Treasurer	1.00 0.00	✓		✓				0	0	0
Nathan Batt Trustee	1.00 0.00	✓						0	0	0
Ashley Kerns Trustee	1.00 0.00	✓						0	0	0
Joseph Sullivan MD Trustee	1.00 0.00	✓						0	0	0
Bill Kirshner Trustee	1.00 0.00	✓						0	0	0
Gail Farfel Trustee	1.00 0.00	✓						0	0	0
Amanda Prather Trustee	1.00 0.00	✓						0	0	0

[illegible]

		Yes	No
3	Did the organization list any former officer, director, trustee, key employee, or highest compensated employee on line 1a? <i>If "Yes," complete Schedule J for such individual</i>	3	✓
4	For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? <i>If "Yes," complete Schedule J for such individual</i>	4	✓
5	Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? <i>If "Yes," complete Schedule J for such person</i>	5	✓

1 Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax year.

2	Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization	1
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Part VIII Statement of RevenueCheck 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	1,412,646				
	d	Related organizations	1d	0				
	e	Government grants (contributions)	1e	0				
	f	All other contributions, gifts, grants, and similar amounts not included above	1f	1,694,285				
	g	Noncash contributions included in lines 1a-1f	1g	\$ 0				
	h	Total. Add lines 1a-1f		3,106,931				
	Program Service Revenue			Business Code				
2a		Professional Education & Meetings	813319	97,500	97,500	0	0	
b		Patient & Family Services	813319	637,289	637,289	0	0	
c								
d								
e								
f		All other program service revenue . .		0	0	0	0	
g		Total. Add lines 2a-2f		734,789				
Other Revenue	3	Investment income (including dividends, interest, and other similar amounts)		304,376	0	0	304,376	
	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				
			6a					
			6b					
	b	Less: rental expenses	6b					
	c	Rental income or (loss)	6c	0	0			
	d	Net rental income or (loss)						
	7a	Gross amount from sales of assets other than inventory	(i) Securities	(ii) Other				
			7a					
			7b					
	b	Less: cost or other basis and sales expenses	7b					
	c	Gain or (loss)	7c	0	0			
	d	Net gain or (loss)						
	8a	Gross income from fundraising events (not including \$ 1,412,646 of contributions reported on line 1c). See Part IV, line 18						
			8a	377,231				
			8b	301,705				
	b	Less: direct expenses	8b					
	c	Net income or (loss) from fundraising events		75,526		0	75,526	
9a	Gross income from gaming activities. See Part IV, line 19							
		9a						
		9b						
b	Less: direct expenses	9b						
c	Net income or (loss) from gaming activities							
10a	Gross sales of inventory, less returns and allowances							
		10a						
		10b						
b	Less: cost of goods sold	10b						
c	Net income or (loss) from sales of inventory							
Miscellaneous Revenue			Business Code					
	11a							
	b							
	c							
	d	All other revenue						
e	Total. Add lines 11a-11d		0					
12	Total revenue. See instructions			4,221,622	734,789	0	379,902	

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	1,987,617	1,987,617		
2 Grants and other assistance to domestic individuals. See Part IV, line 22	22,540	22,540		
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16	498,963	498,963		
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	281,793	42,846	231,432	7,515
6 Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)				
7 Other salaries and wages	471,622	283,914	38,016	149,692
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	26,890	11,920	10,688	4,282
9 Other employee benefits				
10 Payroll taxes	60,970	26,239	21,782	12,949
11 Fees for services (nonemployees):				
a Management				
b Legal				
c Accounting	10,000		10,000	
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.)	158,070	122,450	35,620	0
12 Advertising and promotion				
13 Office expenses	52,271	10,895	19,603	21,773
14 Information technology	6,824	3,266	2,469	1,089
15 Royalties				
16 Occupancy	2,643	881	881	881
17 Travel	84,526	69,884	7,370	7,272
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	526,603	512,011	10,661	3,931
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization				
23 Insurance	5,863	1,747	1,512	2,604
24 Other expenses. Itemize expenses not covered above. (List miscellaneous expenses on 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 Fees	21,737	1,366	14,522	5,849
b Charity Registration Fees	5,031	0	5,031	0
c Dues & Subscriptions	35,209	6,371	9,314	19,524
d				
e All other expenses				
25 Total functional expenses. Add lines 1 through 24e	4,259,172	3,602,910	418,901	237,361
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 SheetCheck if Schedule O contains a response or note to any line in this Part X ☐

		(A) Beginning of year		(B) End of year
Assets	1 Cash—non-interest-bearing	369,253	1	383,617
	2 Savings and temporary cash investments	571,462	2	1,696,246
	3 Pledges and grants receivable, net		3	
	4 Accounts receivable, net	36,608	4	36,352
	5 Loans and other receivables from 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	5,418	8	19,025
	9 Prepaid expenses and deferred charges	83,285	9	56,059
	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	6,443,876	11	6,345,617
	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)	7,509,902	16	8,536,916	
Liabilities	17 Accounts payable and accrued expenses	68,571	17	50,233
	18 Grants payable	462,833	18	1,493,749
	19 Deferred revenue	63,762	19	16,881
	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	
	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	0	25	0
	26 Total liabilities. Add lines 17 through 25	595,166	26	1,560,863
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	6,887,248	27	6,937,386
	28 Net assets with donor restrictions	27,488	28	38,667
	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	6,914,736	32	6,976,053
33 Total liabilities and net assets/fund balances	7,509,902	33	8,536,916	

Part XI Reconciliation of Net AssetsCheck 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	4,221,622
2	Total expenses (must equal Part IX, column (A), line 25)	2	4,259,172
3	Revenue less expenses. Subtract line 2 from line 1	3	-37,550
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	6,914,736
5	Net unrealized gains (losses) on investments	5	98,867
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 on 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	6,976,053

Part XII Financial Statements and ReportingCheck if Schedule O contains a response or note to any line in this Part XII ☐

	Yes	No
1 Accounting method used to prepare the Form 990: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other _____ If the organization changed its method of accounting from a prior year or checked "Other," explain on 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. <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> 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. <input checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> 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 on 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 Uniform Guidance, 2 C.F.R. Part 200, Subpart F?		✓
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 on Schedule O and describe any steps taken to undergo such audits		

SCHEDULE A
(Form 990)

Department of the Treasury
Internal Revenue Service

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

2024

Open to Public
Inspection

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).)
- 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 **section 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 33¹/₃% 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 33¹/₃% 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 on 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		
(A)						
(B)						
(C)						
(D)						
(E)						
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 fails to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	1,228,571	1,437,446	1,713,227	2,530,132	3,106,930	10,016,306
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	1,228,571	1,437,446	1,713,227	2,530,132	3,106,930	10,016,306
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						10,016,306

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(f) Total
7 Amounts from line 4	1,228,571	1,437,446	1,713,227	2,530,132	3,106,930	10,016,306
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources	16,250	5,151	88,364	218,415	304,376	632,556
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						10,648,862
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						<input type="checkbox"/>

Section C. Computation of Public Support Percentage

14 Public support percentage for 2024 (line 6, column (f), divided by line 11, column (f))	14	94.06 %
15 Public support percentage from 2023 Schedule A, Part II, line 14	15	95.83 %
16a 33¹/₃% support test—2024. 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	<input checked="" type="checkbox"/>	
b 33¹/₃% support test—2023. 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	<input type="checkbox"/>	
17a 10%-facts-and-circumstances test—2024. 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	<input type="checkbox"/>	
b 10%-facts-and-circumstances test—2023. 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	<input type="checkbox"/>	
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	<input type="checkbox"/>	

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) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(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) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(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 on 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 <input type="checkbox"/>						

Section C. Computation of Public Support Percentage

15 Public support percentage for 2024 (line 8, column (f), divided by line 13, column (f))	15	%
16 Public support percentage from 2023 Schedule A, Part III, line 15	16	%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2024 (line 10c, column (f), divided by line 13, column (f)) . . .	17	%
18 Investment income percentage from 2023 Schedule A, Part III, line 17	18	%
19a 33¹/₃% support tests—2024. 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 . . . <input type="checkbox"/>		
b 33¹/₃% support tests—2023. 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 . . . <input type="checkbox"/>		
20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions . . . <input type="checkbox"/>		

Part IV Supporting Organizations

(Complete only if you checked a box on line 12 of Part I. If you checked box 12a, Part I, complete Sections A and B. If you checked box 12b, Part I, complete Sections A and C. If you checked box 12c, Part I, complete Sections A, D, and E. If you checked box 12d, 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? <i>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.</i>		
2 Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? <i>If "Yes," explain in Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).</i>		
3a Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? <i>If "Yes," answer lines 3b and 3c below.</i>		
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)? <i>If "Yes," describe in Part VI when and how the organization made the determination.</i>		
c Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? <i>If "Yes," explain in Part VI what controls the organization put in place to ensure such use.</i>		
4a Was any supported organization not organized in the United States ("foreign supported organization")? <i>If "Yes," and if you checked box 12a or 12b in Part I, answer lines 4b and 4c below.</i>		
b Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? <i>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.</i>		
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)? <i>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.</i>		
5a Did the organization add, substitute, or remove any supported organizations during the tax year? <i>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).</i>		
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? <i>If "Yes," provide detail in Part VI.</i>		
7 Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (as 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? <i>If "Yes," complete Part I of Schedule L (Form 990).</i>		
8 Did the organization make a loan to a disqualified person (as defined in section 4958) not described on line 7? <i>If "Yes," complete Part I of Schedule L (Form 990).</i>		
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))? <i>If "Yes," provide detail in Part VI.</i>		
b Did one or more disqualified persons (as defined on line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? <i>If "Yes," provide detail in Part VI.</i>		
c Did a disqualified person (as defined on line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? <i>If "Yes," provide detail in Part VI.</i>		
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)? <i>If "Yes," answer line 10b below.</i>		
b Did the organization have any excess business holdings in the tax year? <i>(Use Schedule C, Form 4720, to determine whether the organization had excess business holdings.)</i>		

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 on lines 11b and 11c below, the governing body of a supported organization?		
11a		
b A family member of a person described on line 11a above?		
11b		
c A 35% controlled entity of a person described on line 11a or 11b above? If "Yes" to line 11a, 11b, or 11c, provide detail in Part VI .		
11c		

Section B. Type I Supporting Organizations

	Yes	No
1 Did the governing body, members of the governing body, officers acting in their official capacity, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's officers, directors, or trustees at all times during the tax year? 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 officers, directors, or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.		
1		
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? 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.		
2		

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)? 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).		
1		

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?		
1		
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? If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).		
2		
3 By reason of the relationship described on 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? If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.		
3		

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 governmental 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? 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.			
2a			
b Did the activities described on line 2a, above, constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? 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.			
2b			
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? If "Yes" or "No," provide details in Part VI .			
3a			
b Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? If "Yes," describe in Part VI the role played by the organization in this regard.			
3b			

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):		
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 0.85 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 (prior IRS approval required—provide details in Part VI)	5
6	Other distributions (describe in Part VI). 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 (provide details in Part VI). See instructions.	8
9	Distributable amount for 2024 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-2024	(iii) Distributable Amount for 2024
1 Distributable amount for 2024 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2024 (reasonable cause required—explain in Part VI). See instructions.			
3 Excess distributions carryover, if any, to 2024			
a From 2019			
b From 2020			
c From 2021			
d From 2022			
e From 2023			
f Total of lines 3a through 3e			
g Applied to underdistributions of prior years			
h Applied to 2024 distributable amount			
i Carryover from 2019 not applied (see instructions)			
j Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
4 Distributions for 2024 from Section D, line 7: \$			
a Applied to underdistributions of prior years			
b Applied to 2024 distributable amount			
c Remainder. Subtract lines 4a and 4b from line 4.			
5 Remaining underdistributions for years prior to 2024, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, explain in Part VI . See instructions.			
6 Remaining underdistributions for 2024. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in Part VI . See instructions.			
7 Excess distributions carryover to 2025. Add lines 3j and 4c.			
8 Breakdown of line 7:			
a Excess from 2020 . . .			
b Excess from 2021 . . .			
c Excess from 2022 . . .			
d Excess from 2023 . . .			
e Excess from 2024 . . .			

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.)

SCHEDULE C
(Form 990)

Department of the Treasury
Internal Revenue Service

Political Campaign and Lobbying Activities

For Organizations Exempt From Income Tax Under Section 501(c) and Section 527

Complete if the organization is described below. Attach to Form 990 or Form 990-EZ.
Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

2024

**Open to Public
Inspection**

If the organization answered "Yes" on Form 990, Part IV, line 3, or Form 990-EZ, Part V, line 46 (Political Campaign Activities), then:

- Section 501(c)(3) organizations: Complete Parts I-A and I-B. Do not complete Part I-C.
- Section 501(c) (other than section 501(c)(3)) organizations: Complete Parts I-A and I-C below. Do not complete Part I-B.
- Section 527 organizations: Complete Part I-A only.

If the organization answered "Yes" on Form 990, Part IV, line 4, or Form 990-EZ, Part VI, line 47 (Lobbying Activities), then:

- Section 501(c)(3) organizations that have filed Form 5768 (election under section 501(h)): Complete Part II-A. Do not complete Part II-B.
- Section 501(c)(3) organizations that have NOT filed Form 5768 (election under section 501(h)): Complete Part II-B. Do not complete Part II-A.

If the organization answered "Yes" on Form 990, Part IV, line 5 (Proxy Tax) (see separate instructions), or Form 990-EZ, Part V, line 35c (Proxy Tax) (see separate instructions), then:

- Section 501(c)(4), (5), or (6) organizations: Complete Part III.

Name of organization DRAVET SYNDROME FOUNDATION INC	Employer identification number (EIN) 27-0924627
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Part I-A Complete if the organization is exempt under section 501(c) or is a section 527 organization.

- 1 Provide a description of the organization's direct and indirect political campaign activities in Part IV. See instructions for definition of "political campaign activities."
- 2 Political campaign activity expenditures. See instructions \$
- 3 Volunteer hours for political campaign activities. See instructions

Part I-B Complete if the organization is exempt under section 501(c)(3).

- 1 Enter the amount of any excise tax incurred by the organization under section 4955 \$
- 2 Enter the amount of any excise tax incurred by organization managers under section 4955 \$
- 3 If the organization incurred a section 4955 tax, did it file Form 4720 for this year? ☐ Yes ☐ No
- 4a Was a correction made? ☐ Yes ☐ No
- b If "Yes," describe in Part IV.

Part I-C Complete if the organization is exempt under section 501(c), except section 501(c)(3).

- 1 Enter the amount directly expended by the filing organization for section 527 exempt function activities \$
- 2 Enter the amount of the filing organization's funds contributed to other organizations for section 527 exempt function activities \$
- 3 Total exempt function expenditures. Add lines 1 and 2. Enter here and on Form 1120-POL, line 17b \$
- 4 Did the filing organization file **Form 1120-POL** for this year? ☐ Yes ☐ No
- 5 Enter the names, addresses, and EINs of all section 527 political organizations to which the filing organization made payments. For each organization listed, enter the amount paid from the filing organization's funds. Also enter the amount of political contributions received that were promptly and directly delivered to a separate political organization, such as a separate segregated fund or a political action committee (PAC). If additional space is needed, provide information in Part IV.

(a) Name	(b) Address	(c) EIN	(d) Amount paid from filing organization's funds. If none, enter -0-.	(e) Amount of political contributions received and promptly and directly delivered to a separate political organization. If none, enter -0-.
(1)				
(2)				
(3)				
(4)				
(5)				
(6)				

Part II-A Complete if the organization is exempt under section 501(c)(3) and filed Form 5768 (election under section 501(h)).**A** Check ☐ if the filing organization belongs to an affiliated group (and list in Part IV each affiliated group member's name, address, EIN, expenses, and share of excess lobbying expenditures).**B** Check ☐ if the filing organization checked box A and "limited control" provisions apply.

Limits on Lobbying Expenditures (The term "expenditures" means amounts paid or incurred.)		(a) Filing organization's totals	(b) Affiliated group totals												
1a	Total lobbying expenditures to influence public opinion (grassroots lobbying)	2,984													
b	Total lobbying expenditures to influence a legislative body (direct lobbying)	6,298													
c	Total lobbying expenditures (add lines 1a and 1b)	9,282													
d	Other exempt purpose expenditures	4,249,889													
e	Total exempt purpose expenditures (add lines 1c and 1d)	4,259,171													
f	Lobbying nontaxable amount. Enter the amount from the following table in both columns.	362,959													
<table border="1"> <thead> <tr> <th>IF the amount on line 1e, column (a) or (b), is:</th> <th>THEN the lobbying nontaxable amount is:</th> </tr> </thead> <tbody> <tr> <td>not over \$500,000</td> <td>20% of the amount on line 1e.</td> </tr> <tr> <td>over \$500,000 but not over \$1,000,000</td> <td>\$100,000 plus 15% of the excess over \$500,000.</td> </tr> <tr> <td>over \$1,000,000 but not over \$1,500,000</td> <td>\$175,000 plus 10% of the excess over \$1,000,000.</td> </tr> <tr> <td>over \$1,500,000 but not over \$17,000,000</td> <td>\$225,000 plus 5% of the excess over \$1,500,000.</td> </tr> <tr> <td>over \$17,000,000</td> <td>\$1,000,000.</td> </tr> </tbody> </table>		IF the amount on line 1e, column (a) or (b), is:	THEN the lobbying nontaxable amount is:	not over \$500,000	20% of the amount on line 1e.	over \$500,000 but not over \$1,000,000	\$100,000 plus 15% of the excess over \$500,000.	over \$1,000,000 but not over \$1,500,000	\$175,000 plus 10% of the excess over \$1,000,000.	over \$1,500,000 but not over \$17,000,000	\$225,000 plus 5% of the excess over \$1,500,000.	over \$17,000,000	\$1,000,000.		
IF the amount on line 1e, column (a) or (b), is:	THEN the lobbying nontaxable amount is:														
not over \$500,000	20% of the amount on line 1e.														
over \$500,000 but not over \$1,000,000	\$100,000 plus 15% of the excess over \$500,000.														
over \$1,000,000 but not over \$1,500,000	\$175,000 plus 10% of the excess over \$1,000,000.														
over \$1,500,000 but not over \$17,000,000	\$225,000 plus 5% of the excess over \$1,500,000.														
over \$17,000,000	\$1,000,000.														
g	Grassroots nontaxable amount (enter 25% of line 1f)	90,740													
h	Subtract line 1g from line 1a. If zero or less, enter -0-	0													
i	Subtract line 1f from line 1c. If zero or less, enter -0-	0													
j	If there is an amount other than zero on either line 1h or line 1i, did the organization file Form 4720 reporting section 4911 tax for this year?	<input type="checkbox"/> Yes <input type="checkbox"/> No													

4-Year Averaging Period Under Section 501(h)

(Some organizations that made a section 501(h) election do not have to complete all of the five columns below. See the separate instructions for lines 2a through 2f.)

Lobbying Expenditures During 4-Year Averaging Period					
Calendar year (or fiscal year beginning in)	(a) 2021	(b) 2022	(c) 2023	(d) 2024	(e) Total
2a Lobbying nontaxable amount	0	0	0	362,959	362,959
b Lobbying ceiling amount (150% of line 2a, column (e))					544,439
c Total lobbying expenditures	0	0	0	9,282	9,282
d Grassroots nontaxable amount	0	0	0	90,740	90,740
e Grassroots ceiling amount (150% of line 2d, column (e))					136,110
f Grassroots lobbying expenditures	0	0	0	2,984	2,984

Part II-B Complete if the organization is exempt under section 501(c)(3) and has NOT filed Form 5768 (election under section 501(h)).

For each "Yes" response on lines 1a through 1i below, provide in Part IV a detailed description of the lobbying activity.

		(a)		(b)
		Yes	No	Amount
<i>For each "Yes" response on lines 1a through 1i below, provide in Part IV a detailed description of the lobbying activity.</i>				
1	During the year, did the filing organization attempt to influence foreign, national, state, or local legislation, including any attempt to influence public opinion on a legislative matter or referendum, through the use of:			
a	Volunteers?			
b	Paid staff or management (include compensation in expenses reported on lines 1c through 1i)?			
c	Media advertisements?			
d	Mailings to members, legislators, or the public?			
e	Publications, or published or broadcast statements?			
f	Grants to other organizations for lobbying purposes?			
g	Direct contact with legislators, their staffs, government officials, or a legislative body? . . .			
h	Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means? . .			
i	Other activities?			
j	Total. Add lines 1c through 1i			
2a	Did the activities in line 1 cause the organization to not be described in section 501(c)(3)? . .			
b	If "Yes," enter the amount of any tax incurred under section 4912			
c	If "Yes," enter the amount of any tax incurred by organization managers under section 4912 .			
d	If the filing organization incurred a section 4912 tax, did it file Form 4720 for this year? . . .			

Part III-A Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6).

		Yes	No
1	Were substantially all (90% or more) dues received nondeductible by members?	1	
2	Did the organization make only in-house lobbying expenditures of \$2,000 or less?	2	
3	Did the organization agree to carry over lobbying and political campaign activity expenditures from the prior year?	3	

Part III-B Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered "No," OR (b) Part III-A, line 3, is answered "Yes."

1	Dues, assessments, and similar amounts from members	1	
2	Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid):		
a	Current year	2a	
b	Carryover from last year	2b	
c	Total	2c	
3	Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues . .	3	
4	If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditures next year?	4	
5	Taxable amount of lobbying and political expenditures. See instructions	5	

Part IV Supplemental Information

Provide the descriptions required for Part I-A, line 1; Part I-B, line 4; Part I-C, line 5; Part II-A (affiliated group list); Part II-A, lines 1 and 2 (see instructions); and Part II-B, line 1. Also, complete this part for any additional information.

[illegible]

SCHEDULE D
(Form 990)

(Rev. December 2024)

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

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.

	(a) Donor advised funds	(b) Funds and other accounts
1 Total number at end of year		
2 Aggregate value of contributions to (during year)		
3 Aggregate value of grants from (during year) .		
4 Aggregate value at end of year		
5 Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control?		<input type="checkbox"/> Yes <input type="checkbox"/> No
6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit?		<input type="checkbox"/> Yes <input type="checkbox"/> No

Part II Conservation Easements

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

1 Purpose(s) of conservation easements held by the organization (check all that apply). <input type="checkbox"/> Preservation of land for public use (for example, recreation or education) <input type="checkbox"/> Preservation of a historically important land area <input type="checkbox"/> Protection of natural habitat <input type="checkbox"/> Preservation of a certified historic structure <input type="checkbox"/> Preservation of open space	
2 Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year.	
a Total number of conservation easements	2a
b Total acreage restricted by conservation easements	2b
c Number of conservation easements on a certified historic structure included on line 2a	2c
d Number of conservation easements included on line 2c acquired after July 25, 2006, and not on a historic structure listed in the National Register	2d
3 Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year	
4 Number of states where property subject to conservation easement is located	
5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds?	<input type="checkbox"/> Yes <input type="checkbox"/> No
6 Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing conservation easements during the year	
7 Amount of expenses incurred in monitoring, inspecting, handling of violations, and enforcing conservation easements during the year	\$
8 Does each conservation easement reported on line 2d above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)?	<input type="checkbox"/> Yes <input type="checkbox"/> No
9 In Part XIII, describe how the organization reports conservation easements in its revenue and expense statement and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements.	

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.

1a If the organization elected, as permitted under FASB ASC 958, not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide in Part XIII the text of the footnote to its financial statements that describes these items.	
b If the organization elected, as permitted under FASB ASC 958, to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items.	
(i) Revenue included on Form 990, Part VIII, line 1	\$
(ii) Assets included in Form 990, Part X	\$
2 If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under FASB ASC 958 relating to these items.	
a Revenue included on Form 990, Part VIII, line 1	\$
b Assets included in Form 990, Part X	\$

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 make significant use of its collection items (check all that apply).

a ☐ Public exhibition

d ☐ Loan or exchange program

b ☐ Scholarly research

e ☐ Other

c ☐ Preservation for future generations

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.

	Amount
c Beginning balance	1c
d Additions during the year	1d
e Distributions during the year	1e
f Ending balance	1f

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.

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1a Beginning of year balance	549,579	228,680	275,171	101,887	0
b Contributions	271,071	250,000	0	150,000	100,000
c Net investment earnings, gains, and losses	117,023	70,899	-46,491	23,285	1,887
d Grants or scholarships	0	0	0	0	0
e Other expenditures for facilities and programs	0	0	0	0	0
f Administrative expenses	0	0	0	0	0
g End of year balance	937,673	549,579	228,680	275,172	101,887

2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:

a Board designated or quasi-endowment 99.89 %

b Permanent endowment 0.11 %

c Term endowment 0 %

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?

	Yes	No
3a(i)		✓
3a(ii)		✓
3b		

b If "Yes" on line 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.

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
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, line 10c, column (B))

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 _____		
(A) _____		
(B) _____		
(C) _____		
(D) _____		
(E) _____		
(F) _____		
(G) _____		
(H) _____		
Total. (Column (b) must equal Form 990, Part X, line 12, col. (B))		

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) _____		
Total. (Column (b) must equal Form 990, Part X, line 13, col. (B))		

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) _____	
Total. (Column (b) must equal Form 990, Part X, line 15, col. (B))	

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	0
(2) _____	
(3) _____	
(4) _____	
(5) _____	
(6) _____	
(7) _____	
(8) _____	
(9) _____	
Total. (Column (b) must equal Form 990, Part X, line 25, col. (B))	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 FASB 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	4,309,310
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:		
a	Net unrealized gains (losses) on investments	2a	98,867
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	98,867
3	Subtract line 2e from line 1	3	4,210,443
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	11,179
c	Add lines 4a and 4b	4c	11,179
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)	5	4,221,622

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	4,214,080
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	4,214,080
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	45,092
c	Add lines 4a and 4b	4c	45,092
5	Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.)	5	4,259,172

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.

Schedule D, Part V, Line 4 - The purpose of the Endowment is to support the mission of the Foundation by providing an alternative source of funds for current and future use. The endowment has two primary goals. First, the principal of the endowment's assets which are not self-funded, must be preserved in perpetuity; second, the endowment should strive to achieve investment returns sufficient to supplement ongoing Foundation operations. To the extent these first two goals are achieved, the Foundation endeavors to grow the endowment so that it represents an even larger source of funding for future generations.

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 DSF had no uncertain tax positions that qualify for either recognition or disclosure in the financial statements. In the normal course of business DSF's tax filings are subjected to examination by federal and state authorities. The tax returns for the years ended December 31, 2021 and forward are subject to examination by taxing authorities.

Schedule D, Part XI, Line 4b - Change in net assets with donor restrictions

Schedule D, Part XII, Line 4b - Present value discount on grant payable not recognized on Form 990.

SCHEDULE F
(Form 990)

(Rev. December 2024)
Department of the Treasury
Internal Revenue Service

Statement of Activities Outside the United States

Complete if the organization answered "Yes" on 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

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? [X] 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 the 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
(1) Sch F, Stmt 1					
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					
(8)					
(9)					
(10)					
(11)					
(12)					
(13)					
(14)					
(15)					
(16)					
(17)					
3a Subtotal					
b Total from continuation sheets to Part I					
c Totals (add lines 3a and 3b)	0	0			498,963

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)
(1)			Sch F, Stmt 2						
(2)									
(3)									
(4)									
(5)									
(6)									
(7)									
(8)									
(9)									
(10)									
(11)									
(12)									
(13)									
(14)									
(15)									
(16)									

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

3 Enter total number of other organizations or entities . . . 0

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)
(1)							
(2)							
(3)							
(4)							
(5)							
(6)							
(7)							
(8)							
(9)							
(10)							
(11)							
(12)							
(13)							
(14)							
(15)							
(16)							
(17)							
(18)							

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 the 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 the 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 the 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 the 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 the 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 the 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.

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 written 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 healthcare provider explaining the medical necessity of the request and when possible, a letter of denial from the insurance provider.

Accounts and Activities Outside the United States

		Offices	Employees	Total
Region	Europe (including Iceland and Greenland)	0	0	250,000
Activities	Grantmaking			
Services	Research grants.			
Region	North America (including Canada and Mexico, but not the United States)	0	0	248,963
Activities	Grantmaking			
Services	Research grants.			
Total:		0	0	498,963

Grants To Organization Outside US

		Cash Grant	Non-Cash Assistance
Region	Europe (including Iceland and Greenland)	250,000	0
Grant	RCSI University of Medicine and Health Sciences. Most caregivers report concerns about sleep problems and highlight the urgent need for a better diagnosis and management of severe sleep disorders in Dravet syndrome (DS). The circadian system determines the 24-hour cycles in body changes, which include the regulation of sleep patterns, hormones, body temperature, and brain waves. The precise molecular mechanisms of sleep disturbances in DS children are poorly understood and there are no tools to predict the risk of developing severe sleep problems. This project will focus on characterizing sleep and circadian patterns in DS children and their families, using multiple clinical and molecular assessments involving questionnaires, a long-term actigraph device, and saliva collections.		
Cash Disbursement	Wire Transfer		
Desc. of Non-Cash Asst.			
Valuation	FMV		
Region	North America (including Canada and Mexico, but not the United States)	247,498	
Grant	The University of British Columbia - Individuals with Dravet syndrome (DS) have a higher chance of dying compared to those with other forms of seizures, and one common cause of this is sudden unexpected death in epilepsy (SUDEP). It is not understood how SUDEP occurs in DS, but seizures can cause rapid or very slow heart rates. In a mouse model of DS, seizures affected the part of the brain that controls the heart and breathing and this suggests that abnormal heart rhythms triggered by seizures could be a major factor in SUDEP. This study will use a heart monitor placed under the skin in 20 individuals with DS to measure their heart rhythms during seizures over a period of two years or longer. Information obtained from these monitors and seizure diaries will be analyzed to identify any serious abnormal heart rhythms that occur during seizures. This study aims to help us better understand how seizures affect the heart and if they can lead to life threatening heart rhythms.		
Cash Disbursement	Wire Transfer		
Desc. of Non-Cash Asst.			
Valuation	FMV		

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 Mail solicitations
b Internet and email solicitations
c Phone solicitations
d In-person solicitations
e Solicitation of nongovernment grants
f Solicitation of government grants
g Special fundraising events
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?
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.

Table with 6 columns: (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. Includes rows 1-10 and a Total row.

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.

		(a) Event #1 Dance for Dravet	(b) Event #2 A Night Under the Stars 22	(c) Other events	(d) Total events (add col. (a) through col. (c))
		(event type)	(event type)	(total number)	
Revenue	1 Gross receipts	563,601	341,118	885,158	1,789,877
	2 Less: Contributions	430,926	256,785	724,935	1,412,646
	3 Gross income (line 1 minus line 2)	132,675	84,333	160,223	377,231
Direct Expenses	4 Cash prizes	0	0	0	0
	5 Noncash prizes	0	0	0	0
	6 Rent/facility costs	5,381	0	11,533	16,914
	7 Food and beverages	62,339	41,207	45,553	149,099
	8 Entertainment	6,716	4,350	10,925	21,991
	9 Other direct expenses	21,366	22,600	69,735	113,701
	10 Direct expense summary. Add lines 4 through 9 in column (d)				301,705
	11 Net income summary. Subtract line 10 from line 3, column (d)				75,526

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.

		(a) Bingo	(b) Pull tabs/instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col. (a) through col. (c))
Revenue	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? | <input type="checkbox"/> Yes | <input type="checkbox"/> 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? | <input type="checkbox"/> Yes | <input type="checkbox"/> 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 the name and address of the third party: _____

Name _____

Address _____

16 Gaming manager information:

Name _____

Gaming manager compensation \$ _____

Description of services provided	Date	Time	Location	Remarks

☐ 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 to be 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.

SCHEDULE I
(Form 990)

(Rev. December 2024)
Department of the Treasury
Internal Revenue Service

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 instructions and the latest information.

OMB No. 1545-0047

Open to Public
Inspection

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.

1 (a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of noncash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
(1) Sch I, Stmt 1							
(2)							
(3)							
(4)							
(5)							
(6)							
(7)							
(8)							
(9)							
(10)							
(11)							
(12)							

2

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

5

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 See Schedule I, Part IV, Statement 2					
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.

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 written 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 healthcare provider explaining the medical necessity of the request and when possible, a letter of denial from the insurance provider.

Description of Grants and Other Assistance to Governments and Organizations in the United States

		Recipient EIN	Amt. of cash grant	Amt. of non- cash asst.
Name and address	Children's Hospital of Philadelphia 2716 South Street Philadelphia, PA 19146-2305	23-1352166	1,000,000	
IRC code section	501(c)(3)			
Method of valuation	FMV			
Desc. of Non-Cash Asst.				
Purpose of grant	Individuals with Dravet syndrome (DS) can have different disease courses, and there are important differences in how seizure and development affect them over time. Identifying the causes of variation within the patient population may be helpful in providing accurate prognosis and developing new treatments. This project will generate broad genetic data with whole genome sequencing on 500 individuals with DS. These genetic analyses will be paired with clinical data using pioneered novel methods to transform clinical information to a format that can be used for computational analysis. Finally, this project is built for data sharing - all biosample data, genomic data, and clinical data will be shared within the DS Community.			
Name and address	Regents Of The University Of Michigan 3003 South State Street Ann Arbor, MI 48109	38-6006309	500,000	
IRC code section	501(c)(3)			
Method of valuation	FMV			
Desc. of Non-Cash Asst.				
Purpose of grant	Despite recent advances in small molecule drug discovery, the majority of Dravet syndrome (DS) patients remain intractable and non-seizure symptoms are not addressed. This project aims to exploit an alternative therapeutic strategy that has been successful in mouse models: Medial Ganglionic Eminence (MGE) progenitor cell transplantation to restore healthy fast-spiking interneurons in DS patient brains. While transgenic mice have provided invaluable insights into seizures and some comorbidities associated with DS, mice have critical differences in physiology and neuroanatomy compared to humans and thus are not the most appropriate model to test a cell transplantation-based therapy. In contrast, this study will use rabbits, which are larger vertebrates, more similar to humans. The results of this large animal work will strengthen the preclinical foundation for future cell transplantation therapeutic strategies in DS patients.			
Name and address	Brown University Box 1929 Providence, RI 02912-9002	05-0258809	250,000	
IRC code section	501(c)(3)			
Method of valuation	FMV			
Desc. of Non-Cash Asst.				
Purpose of grant	The scientific understanding of how the SCN1A gene changes brain activity is rapidly evolving. This work will explore whether a brain cell that is integrally important in Dravet syndrome symptomatology has disruptions that lead to specific malfunctions. This work aims to determine how mutations in the SCN1A gene impact these cells' normally powerful ability to "put the brakes on" the brain when it is too active. We believe that the loss of this "brake" may lead to seizures, and our experiments may yield			

	important clues about how to get it working again.		
Name and address	Children's Hospital of Philadelphia 2716 South Street Philadelphia, PA 19145-2305	23-1352166	75,000
IRC code section	501(c)(3)		
Method of valuation	FMV		
Desc. of Non-Cash Asst.			
Purpose of grant	Mutations in the SCN1A gene most commonly cause reduced functioning of the Nav1.1 protein and lead to Dravet syndrome, a debilitating epilepsy disorder. However, a new class of SCN1A mutations causes excessive activity of Nav1.1. Individuals with these mutations exhibit an even more severe form of epilepsy as well as developmental delay and intellectual disability. This research group has generated the first mouse expressing a patient-derived mutation associated with this severe early-onset condition. In this fellowship, they will evaluate the novel mouse for neurological abnormalities, including seizures and movement disorders. Additionally, they will investigate the electrical properties of neurons. The overall goal is to understand the mechanism by which both reduced and excessive activity of Nav1.1 can cause epilepsy and to identify treatments for both disorders.		
Name and address	University of Colorado Denver 13001 E 17th Place Aurora, CO 80045	84-6000555	75,000
IRC code section	501(c)(3)		
Method of valuation	FMV		
Desc. of Non-Cash Asst.			
Purpose of grant	Current precision therapeutic clinical trials for Dravet syndrome (DS) utilize seizure frequency as the primary outcome measure, but using this alone to assess outcome does not capture the full array of challenges associated with DS. This project will focus on refining a set of clinician and caregiver-reported outcome measures previously created for CDKL5-deficiency disorder and piloting them in patients with DS. The overarching objective is to design valid and feasible outcome measures specifically for DS that represent the full range of the phenotype. The creation of the DS clinical severity assessment-clinician and caregiver (DS-CSA) will be a crucial step towards disease modifying clinical trial readiness in DS.		
Name and address	Regents Of The University Of Michigan 3003 South State Street Ann Arbor, MI 48109	38-6006309	75,000
IRC code section			
Method of valuation	FMV		
Desc. of Non-Cash Asst.			
Purpose of grant	Individuals with Dravet syndrome (DS) suffer from severe seizures that cannot be completely controlled by medications. While most epilepsy research has focused on the more superficial brain regions that we know are prone to seizures, an improved understanding of the role of deeper brain regions in epilepsy may open the door to new therapies. The focus of this proposal is a deep brain region called the locus coeruleus, which sends noradrenergic projections throughout seizure-prone brain regions. The locus coeruleus is known as a "master regulator" that coordinates brain-wide states, such as reward and attention; this project will test the hypothesis that it also plays a critical role in seizures in DS using a mouse model of DS, to (1) determine the activity of noradrenergic neurons during seizures and (2) test whether their activation curtails seizures.		
Name and address	Coriell Institute for Medical Research	21-0672684	12,617

403 Haddon Ave
Camden, NJ 08103

IRC code section 501(c)(3)

Method of valuation FMV

Desc. of Non-Cash Asst.

Purpose of grant This project aims to establish a biobank of five unique lines of commercially-available induced pluripotent stem cells (iPSCs) from patient blood samples. The cellular reprogramming will be conducted by the Coriell Institute for Medical Research and samples will be housed and distributed through an additional partnership with the Orphan Disease Center at The University of Pennsylvania. Cell lines will be available to researchers in academic and for-profit research settings at a low cost, set to cover the long-term maintenance of the biobank effort.

Description of Grants and Other Assistance to Individuals in the United States

		Number of recipients	Amt. of cash grant	Amt. of non-cash asst.
Type of grant	Patient Assistance Grants. The DSF Patient Assistant Grant program offers 29 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.		7,274	11,316
Method of valuation	FMV			
Desc. of Non-Cash Asst.	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 the situation.			
Type of grant	Caregiver Connect Grants. Caregiver Connect Grants are available from \$100-\$400 and can partially or fully fund a local Dravet family gathering or an ongoing Dravet support group in your area. The goal of the grants is to allow our community members to connect and receive support from one another. At this time, Caregiver Connect grants are only available for events within the United States that are members of the DSF Family Network. Funds are not available for parties for an individual child or family, awareness events, or for the benefit of individuals outside of the Dravet community. Epilepsy Awareness Day at Disneyland Family Scholarship. This grant is designed to cover most of the expenses for a family of four to attend EADDL, and is provided through an unrestricted educational grant from an industry partner.	5	3,950	
Method of valuation	FMV			
Desc. of Non-Cash Asst.				

**SCHEDULE J
(Form 990)**

(Rev. December 2024)

Department of the Treasury
Internal Revenue Service

Compensation Information

For certain Officers, Directors, Trustees, Key Employees, and Highest
Compensated Employees
Complete if the organization answered "Yes" on Form 990, Part IV, line 23.
Attach to Form 990.
Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

**Open to Public
Inspection**

Name of the organization

DRAVET SYNDROME FOUNDATION INC

Employer identification number

27-0924627

Part I Questions Regarding Compensation

	Yes	No
1a Check the appropriate box(es) if the organization provided any of the following to or for a person listed on Form 990, Part VII, Section A, line 1a. Complete Part III to provide any relevant information regarding these items. <div><input type="checkbox"/> First-class or charter travel <input type="checkbox"/> Travel for companions <input type="checkbox"/> Tax indemnification and gross-up payments <input type="checkbox"/> Discretionary spending account</div> <div><input type="checkbox"/> Housing allowance or residence for personal use <input type="checkbox"/> Payments for business use of personal residence <input type="checkbox"/> Health or social club dues or initiation fees <input type="checkbox"/> Personal services (such as maid, chauffeur, chef)</div>		
b If any of the boxes on line 1a are checked, did the organization follow a written policy regarding payment or reimbursement or provision of all of the expenses described above? If "No," complete Part III to explain	1b	
2 Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all directors, trustees, and officers, including the CEO/Executive Director, regarding the items checked on line 1a?	2	
3 Indicate which, if any, of the following the organization used to establish the compensation of the organization's CEO/Executive Director. Check all that apply. Do not check any boxes for methods used by a related organization to establish compensation of the CEO/Executive Director, but explain in Part III. <div><input type="checkbox"/> Compensation committee <input type="checkbox"/> Independent compensation consultant <input checked="" type="checkbox"/> Form 990 of other organizations</div> <div><input type="checkbox"/> Written employment contract <input checked="" type="checkbox"/> Compensation survey or study <input checked="" type="checkbox"/> Approval by the board or compensation committee</div>		
4 During the year, did any person listed on Form 990, Part VII, Section A, line 1a, with respect to the filing organization or a related organization: a Receive a severance payment or change-of-control payment? b Participate in or receive payment from a supplemental nonqualified retirement plan? c Participate in or receive payment from an equity-based compensation arrangement? If "Yes" to any of lines 4a–c, list the persons and provide the applicable amounts for each item in Part III.	4a 4b 4c	 <input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/>
Only section 501(c)(3), 501(c)(4), and 501(c)(29) organizations must complete lines 5–9.		
5 For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the revenues of: a The organization? b Any related organization? If "Yes" on line 5a or 5b, describe in Part III.	5a 5b	 <input checked="" type="checkbox"/> <input checked="" type="checkbox"/>
6 For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the net earnings of: a The organization? b Any related organization? If "Yes" on line 6a or 6b, describe in Part III.	6a 6b	 <input checked="" type="checkbox"/> <input checked="" type="checkbox"/>
7 For persons listed on Form 990, Part VII, Section A, line 1a, did the organization provide any nonfixed payments not described on lines 5 and 6? If "Yes," describe in Part III	7	<input checked="" type="checkbox"/>
8 Were any amounts reported on Form 990, Part VII, paid or accrued pursuant to a contract that was subject to the initial contract exception described in Regulations section 53.4958-4(a)(3)? If "Yes," describe in Part III	8	<input checked="" type="checkbox"/>
9 If "Yes" on line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53.4958-6(c)?	9	

Part II

Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees. Use duplicate copies if additional space is needed.

For each individual whose compensation must be reported on Schedule J, report compensation from the organization on row (i) and from related organizations, described in the instructions, on row (ii). Do not list any individuals that aren't listed on Form 990, Part VII.

Note: The sum of columns (B)(i)–(iii) for each listed individual must equal the total amount of Form 990, Part VII, Section A, line 1a, applicable column (D) and (E) amounts for that individual.

(A) Name and Title		(B) Breakdown of W-2 and/or 1099-MISC and/or 1099-NEC compensation			(C) Retirement and other deferred compensation	(D) Nontaxable benefits	(E) Total of columns (B)(i)–(D)	(F) Compensation in column (B) reported as deferred on prior Form 990
		(i) Base compensation	(ii) Bonus & incentive compensation	(iii) Other reportable compensation				
1	Mary Anne Meskis, Executive Director	(i) 169,586	(ii) 3,000	(iii) 0	6,903	0	179,489	0
		(i) 0	(ii) 0	(iii) 0	0	0	0	0
2	Veronica Hood, Scientific Director	(i) 164,959	(ii) 500	(iii) 0	6,619	0	172,078	0
		(i) 0	(ii) 0	(iii) 0	0	0	0	0
3		(i)	(ii)	(iii)				
		(i)	(ii)	(iii)				
4		(i)	(ii)	(iii)				
		(i)	(ii)	(iii)				
5		(i)	(ii)	(iii)				
		(i)	(ii)	(iii)				
6		(i)	(ii)	(iii)				
		(i)	(ii)	(iii)				
7		(i)	(ii)	(iii)				
		(i)	(ii)	(iii)				
8		(i)	(ii)	(iii)				
		(i)	(ii)	(iii)				
9		(i)	(ii)	(iii)				
		(i)	(ii)	(iii)				
10		(i)	(ii)	(iii)				
		(i)	(ii)	(iii)				
11		(i)	(ii)	(iii)				
		(i)	(ii)	(iii)				
12		(i)	(ii)	(iii)				
		(i)	(ii)	(iii)				
13		(i)	(ii)	(iii)				
		(i)	(ii)	(iii)				
14		(i)	(ii)	(iii)				
		(i)	(ii)	(iii)				
15		(i)	(ii)	(iii)				
		(i)	(ii)	(iii)				
16		(i)	(ii)	(iii)				
		(i)	(ii)	(iii)				

Part III Supplemental Information

Provide the information, explanation, or descriptions required for Part I, lines 1a, 1b, 3, 4a, 4b, 4c, 5a, 5b, 6a, 6b, 7, and 8, and for Part II. Also complete this part for any additional information.

[illegible]

SCHEDULE L
(Form 990)

(Rev. December 2024)

Department of the Treasury
Internal Revenue Service

Transactions With Interested Persons

Complete if the organization answered "Yes" on Form 990, Part IV, line 25a, 25b, 26, 27, 28a, 28b, or 28c; or Form 990-EZ, Part V, line 38a or 40b.

Attach to Form 990 or Form 990-EZ.

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

OMB No. 1545-0047

Open to Public Inspection

Name of the organization: DRAVET SYNDROME FOUNDATION INC
Employer identification number: 27-0924627

Part I Excess Benefit Transactions (section 501(c)(3), section 501(c)(4), and section 501(c)(29) organizations only)
Complete if the organization answered "Yes" on Form 990, Part IV, line 25a or 25b; or Form 990-EZ, Part V, line 40b.

Table with 5 columns: (a) Name of disqualified person, (b) Relationship between disqualified person and organization, (c) Description of transaction, (d) Corrected? (Yes/No), and a summary section for lines 2 and 3 regarding tax amounts.

Part II Loans to and/or From Interested Persons
Complete if the organization answered "Yes" on Form 990-EZ, Part V, line 38a, or Form 990, Part IV, line 26; or if the organization reported an amount on Form 990, Part X, line 5, 6, or 22.

Table with 9 columns: (a) Name of interested person, (b) Relationship with organization, (c) Purpose of loan, (d) Loan to or from the organization? (To/From), (e) Original principal amount, (f) Balance due, (g) In default? (Yes/No), (h) Approved by board or committee? (Yes/No), and (i) Written agreement? (Yes/No).

Part III Grants or Assistance Benefiting Interested Persons
Complete if the organization answered "Yes" on Form 990, Part IV, line 27.

Table with 5 columns: (a) Name of interested person, (b) Relationship between interested person and the organization, (c) Amount of assistance, (d) Type of assistance, and (e) Purpose of assistance.

Part IV

Business Transactions Involving Interested Persons

Complete if the organization answered "Yes" on Form 990, Part IV, line 28a, 28b, or 28c.

(a) Name of interested person	(b) Relationship between interested person and the organization	(c) Amount of transaction	(d) Description of transaction	(e) Sharing of organization's revenues?	
				Yes	No
(1) Substantial Contributor	Board Trustee of Organiz	384,131	Contribution		✓
(2) Substantial Contributor	Board Trustee of Organiz	250,000	Contribution		✓
(3)					
(4)					
(5)					
(6)					
(7)					
(8)					
(9)					
(10)					

Part V

Supplemental Information

Provide additional information for responses to questions on Schedule L. See instructions.

Schedule L, Part IV - Two current board members also serve on two other 501(c)(3) organizations dedicated to advancing research for Dravet syndrome. Rather than reviewing grant applications through their organizations, they prefer to support grants that our Scientific and Medical Advisory Boards have vetted and approved each year, ensuring that these projects receive the necessary resources to make a meaningful impact in the field.

Name of the organization	Employer identification number
DRAVET SYNDROME FOUNDATION INC	27-0924627

[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.](#)

[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.](#)

[Form 990, Part VI, Section C, Line 19 - DSF makes its governing documents and conflict of interest policy available to the public upon written request from the president. Financial statements are available for public view on the organization's website.](#)

[Form 990, Part IX, Line 11g - Other fees for services include Media Relations \(\\$150,000\), Payroll & Human Resources \(\\$5,620\), and Video Production \(\\$2,450\).](#)

Mission Description

Description

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.

Second Program Service Accomplishments Description

Description

educational aids not covered by private insurance or other programs. This program is available to all patients worldwide who are members of the DSF Family Network. Since 2009, DSF has awarded \$279,000 to 249 families. Birthday Buddies: Families can register their loved one with Dravet syndrome to receive a birthday card and small gift from DSF's mascot, Aurora, around their birthday. In 2024, DSF sent 640 gifts. Super Siblings Club: DSF provides a day camp at our biennial conference and annual Day of Dravet workshops for siblings of individuals with Dravet syndrome. These events offer a fun and supportive environment for siblings to connect, express their feelings, and bond with others facing similar challenges. Bereavement Support: Losing a loved one, especially a child, is profoundly painful. DSF offers resources for coping with grief, including a Bereavement Support Group and Remembrance Wall. Legislative Advocacy Program: We are committed to keeping our patient community informed about legislative actions affecting Medicaid and rare disease research, which are essential for maintaining access to care and driving advancements in treatment for Dravet syndrome. By ensuring our constituents have accurate and nonpartisan information, they can advocate for their loved one and family effectively. Biennial Conference: This 3-day event brings together families, caregivers, clinicians, researchers, and pharmaceutical professionals to collaborate on improving the lives of those with Dravet syndrome. The conference features presentations on the latest research and patient care, fostering new relationships and collaborations. Over 500 people attended the 2024 conference. Day of Dravet Workshops: Held in alternating years from the biennial conference, these workshops offer families the opportunity to learn about research, treatment options, and connect with others. Sessions are led by community experts, including fellow parents. The workshops also include our VIP Sib Camp and activities for patients. In 2023, over 500 attendees participated at workshops in Colorado (Denver), Florida (Sanford), Connecticut (Stamford), California (Anaheim), and Kentucky (Newport).

States Where Copy Of Return Is Filed

States
AL
AR
FL
IL
KS
KY
MA
MD
MI
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MO
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NH
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NM
NY
RI