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Department of the Treasury Internal Révenue Service

Return of Organization Exempt From Income Tax Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except black lung

benefit trust or private foundation)

Inspection

▶ The organization may have to use a copy of this return to satisfy state reporting requirements

Open to Public

	roi ili	e 2012 calendar year, or tax year beginning an	a enaing		
В	Check if applicab	C Name of organization		D Employer identific	cation number
_	□Addre	ss			
-	chang Name chang		·	27-0	924627
	Initial return		Room/suite	E Telephone number	
	Termi	·	Tiooniyouno		.880.9456
	Amen	ded C. A.		G Gross receipts \$	567,785.
	Applie	MONROE, CT 06468		H(a) Is this a group re	
	pendi	F Name and address of principal officer LORI O'DRISCOLL		for affiliates?	Yes X No
		SAME AS C ABOVE		H(b) Are all affiliates inc	luded? Yes No
		empt status X 501(c)(3) 501(c)() ◀ (insert no.) 4947(a)(1) or 527	~	list (see instructions)
		te: WWW.DRAVETFOUNDATION.ORG		H(c) Group exemption	
		f organization: X Corporation Trust Association Other ►	L Year	of formation: 2009 N	N State of legal domicile CT
	art I	Summary	MTCCTC		7.11EW
ခ်	1	Briefly describe the organization's mission or most significant activities THE SYNDROME FOUNDATION, (DSF) IS TO AGGRESS.			
ernance	2	Check this box If the organization discontinued its operations or disp			
ເນຣັ	1	Number of voting members of the governing body (Part VI, line 1a)	osea or more	3	4
Öő	4	Number of independent voting members of the governing body (Part VI, line 1b)	4	4
Ž		Total number of individuals employed in calendar year 2012 (Part V, line 2a)	,	5	0
Activities & Gov	1	Total number of volunteers (estimate if necessary)		6	0
	7 a	Total unrelated business revenue from Part VIII, column (C), line 12		7a	0.
<u>_`</u>	b	Net unrelated business taxable income from Form 990-T, line 34		7b	0.
Š			_	Prior Year	Current Year
2 1 2013	8	Contributions and grants (Part VIII, line 1h)	_	71,524.	132,679.
⊸ ē	9	Program service revenue (Part VIII, line 2g)	<u> </u>	0.	0.
E	10	Investment income (Part VIII, column (A), lines 3, 4, and 7d)	<u> </u>	0.	551.
ದ	11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	_	397,935. 469,459.	357,411. 490,641.
		Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12) Grants and similar amounts paid (Part IX, column (A), lines 1-3)		424,078.	427,230.
	1	Benefits paid to or for members (Part IX, column (A), line 4)	<u> </u>	0.	0.
S	1	Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10	, –	0.	45,252.
Expenses	16a	Professional fundraising fees (Part IX, column (A), line 11e)	′ <u> </u>	0.	0.
ē	b	Total fundraising experises (PartitX column (D), line 25) > 75, 2	239,		
ũ	17	Other expenses (Part IX, column (A), lines 1 a-11d, 11f-24e)		52,758.	57,862.
	18	Total expenses Add lines 13-17 (must equa Part IX, column (A), line 25)		476,836.	530,344.
	19	Revenue less expenses Subtractible 18 from line 12		<7,377.	<39,703.>
Sor		<u>x</u>	Be	ginning of Current Year	End of Year
t Assets or Balances	20	Total assets (Part X-line) 16) N 11T	_	206,892.	86,183.
let A		Total liabilities (Part X, Imé 26)	-	81,006.	0.
P	<u>22</u> art Ⅱ	Net assets or fund balances Subtract line 21 from line 20 Signature Block	1.	125,886.	86,183.
		alties of perjury, I declare that I have examined this return, including accompanying schedu	les and statem	ents, and to the best of m	v knowledge and helief it is
	-	ct, and complete. Declaration of preparer (other than officer) is based on all information of		· · · · · · · · · · · · · · · · · · ·	y Miowicago ana bollot, it is
	,	Lan Offiscol		2/3/	2.13
Sıg	n	Signature of officer		Date	
Her		LORI O'DRISCOLL, PRESIDENT			
		Type or print name and title			
		Print/Type preparer's name Preparer's signature		Date Check If self-employee	PTIN
Pai		BRIAN C. WHITE			
	parer		<u> </u>	Firm's EIN	06-0990132
Use	Only	Firm's address P.O. BOX 399		Db 2	N2 740 CE17
		DANBURY, CT 06813		Phone no. 2	03-748-6517 X Yes No
	y the I	RS discuss this return with the preparer shown above? (see instructions) 10-12 LHA For Paperwork Reduction Act Notice, see the separate instruc	tions		X Yes No Form 990 (2012)
2320		EEE SCHEDULE O FOR ORGANIZATION MISSION		NT CONTINUA	•
	_			7-7-7	

Pai	n 990 (2012) DRAVET SYNDROME FOUNDATION INC2	7-092 4 627 Page
	rt III Statement of Program Service Accomplishments	
	Check if Schedule O contains a response to any question in this Part III	
1	Briefly describe the organization's mission	
•	THE DSF FUNDS RESEARCH TOWARD BETTER TREATMENTS AND A CURI	E OF DRAVET
	SYNDROME AND RELATED EPILEPSIES BY AWARDING RESEARCH GRATI	
	QUALIFIED SCIENTISTS AND DOCTORS. THE DSF PRODUCES AN ANNU	
	ROUNDTABLE MEETING TO PROVIDE THE OPPORTUNITY FOR RESEARCH	
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 X
	\cdot	Tes Law i
_	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 X N
	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 mea	asured by expenses
	Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, t	the total expenses, and
	revenue, if any, for each program service reported	
4a	135 504	3,833
	THE DSF FUNDS RESEARCH TOWARD BETTER TREATMENTS AND A CURI	
	SYNDROME AND RELATED EPILEPSIES BY AWARDING RESEARCH GRAN	
	· · · · · · · · · · · · · · · · · · ·	15 10
	QUALIFIED SCIENTISTS AND DOCTORS	-
	<u> </u>	

41-		
4b	(Code) (Expenses \$	DDOUTDE
4b	THE DSF PRODUCES AN ANNUAL RESEARCH ROUNDTABLE MEETING TO	
4b	THE DSF PRODUCES AN ANNUAL RESEARCH ROUNDTABLE MEETING TO OPPORTUNITY FOR RESEARCHERS AND CLINICIANS TO COLLABORATE	AND DISCUSS
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_ <u>_</u>				
	In the exposuration described in section E01(s)(9) or 4047(s)(1) (should be a section for all 1)		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	,	x	ĺ
2	Is the organization required to complete Schedule B, Schedule of Contributors?	2	X	-
3	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for			
Ů	public office? If "Yes," complete Schedule C, Part I	3		Х
4	Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect			42
•	during the tax year? If "Yes," complete Schedule C, Part II	4		Х
5	Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or	 		
-	similar amounts as defined in Revenue Procedure 98-19? If "Yes," complete Schedule C, Part III	5		Х
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		X
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		X
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete			
	Schedule D, Part III	8		x
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		X
10	Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent			
	endowments, or quasi-endowments? If "Yes," complete Schedule D, Part V	10	X	
11	If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VIII, VIII, IX, or X			
	as applicable			
а	Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D,			
	Part VI	11a		Х
b	3			
	assets reported in Part X, line 169 If "Yes," complete Schedule D, Part VII	11b		X
С	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		X
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	X	
	Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X	11e		X
f	Service and the service and th	i		
10-	the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? If "Yes," complete Schedule D, Part X	11f		X
12a	Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete		77	
L	Schedule D, Parts XI and XII	12a	_X	
U	Was the organization included in consolidated, independent audited financial statements for the tax year?	40.		v
13	If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E	12b		X
14a	Did the organization maintain an office, employees, or agents outside of the United States?	13		
	Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business,	14a		X
~	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	14h		Х
15	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or assistance to any organization	14b		- 41
	or entity located outside the United States? If "Yes," complete Schedule F, Parts II and IV	15		Х
16	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or assistance to individuals			
	located outside the United States? If "Yes," complete Schedule F, Parts III and IV	16		Х
17	Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX,	<u></u>		
	column (A), lines 6 and 11e? If "Yes," complete Schedule G, Part I	17		Х
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	x	
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		X
20a	Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H	20a		X
	If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?	20h		

Form **990** (2012)

Part IV Checklist of Required Schedules (continued)

			Yes	No
21	Did the organization report more than \$5,000 of grants and other assistance to any government or organization in the			- 10
•	United States on Part IX, column (A), line 1? If "Yes," complete Schedule I, Parts I and II	21	X	
22	Did the organization report more than \$5,000 of grants and other assistance to individuals in the United States on Part IX,			
	column (A), line 2? If "Yes," complete Schedule I, Parts I and III	22	Х	
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			1
	Schedule J	23	ļ	X
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 25	24a		X
	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		
С	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	ļ	
d	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d	<u> </u>	
25a	Section 501(c)(3) and 501(c)(4) 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		X_
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	l		
	Schedule L, Part I	25b		X
26	Was a loan to or by a current or former officer, director, trustee, key employee, highest compensated employee, or disqualified	l		,,
07	person outstanding as of the end of the organization's tax year? If "Yes," complete Schedule L, Part II	26		X
27	Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial			
	contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity or family member			X
28	of any of these persons? If "Yes," complete Schedule L, Part III Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV	27		
20	instructions for applicable filing thresholds, conditions, and exceptions)			
а	A current or former officer, director, trustee, or key employee? If "Yes," complete Schedule L, Part IV	28a		х
b	A family member of a current or former officer, director, trustee, or key employee? If "Yes," complete Schedule L, Part IV	28b		X
	An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer,	200		- 22
-	director, trustee, or direct or indirect owner? If "Yes," complete Schedule L, Part IV	28c		x
29	Did the organization receive more than \$25,000 in non-cash contributions? If "Yes," complete Schedule M	29		X
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation			
	contributions? If "Yes," complete Schedule M	30		х
31	Did the organization liquidate, terminate, or dissolve and cease operations?			
	If "Yes," complete Schedule N, Part I	31		Х
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		X
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		X
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		X_
35a	,	35a		<u> </u>
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		X
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		<u> </u>
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? Note. All Form 990 filers are required to complete Schedule O		,,	
		38	X	

Page 5

-ţ-	Check if Schedule O contains a response to any question in this Part V			_
	Chock is estimated a contained a response to any question in this hart v		V	
1a	Enter the number reported in Box 3 of Form 1096 Enter -0- if not applicable	ı —	Yes	No
	Enter the number of Forms W-2G included in line 1a Enter -0- if not applicable	ī		
	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming	1		
	(gambling) winnings to prize winners?	1c	Х	1
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 (ار		
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	2b		
	Note. If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)			
За	Did the organization have unrelated business gross income of \$1,000 or more during the year?	3a		X
	If "Yes," has it filed a Form 990-T for this year? If "No," provide an explanation in 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		X
b	If "Yes," enter the name of the foreign country			
	See instructions for filing requirements for Form TD F 90-22 1, Report of Foreign Bank and Financial Accounts			
5а	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5a		X
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5b		X
	If "Yes," to line 5a or 5b, did the organization file Form 8886-T?	5c	<u> </u>	
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		X
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).	_		7.
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		X
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?	7b		1
C	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?	- -		v
ч	If "Yes," indicate the number of Forms 8282 filed during the year 7d	7c		X
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		
_	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 and section 509(a)(3) supporting organizations. Did the supporting			
	organization, or a donor advised fund maintained by a sponsoring organization, have excess business holdings at any time during the year?	8		
9	Sponsoring organizations maintaining donor advised funds.			
а	Did the organization make any taxable distributions under section 4966?	9a		
b	Did the organization make a distribution to a donor, donor advisor, or related person?	9b		
10	Section 501(c)(7) organizations. Enter:			
	Initiation fees and capital contributions included on Part VIII, line 12			
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities		,	İ
11	Section 501(c)(12) organizations. Enter			
	Gross income from members or shareholders	. !		
b	Gross income from other sources (Do not net amounts due or paid to other sources against		, ,	
	amounts due or received from them)		.	
	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?	12a		<u> </u>
	If "Yes," enter the amount of tax-exempt interest received or accrued during the year			1
13	Section 501(c)(29) qualified nonprofit health insurance issuers.	10.		<u> </u>
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		
h	Enter the amount of reserves the organization is required to maintain by the states in which the			
J	organization is licensed to issue qualified health plans			
c	Enter the amount of reserves on hand			
	Did the organization receive any payments for indoor tanning services during the tax year?	14a		х
	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O	14b	-	_
			990	(2012)
			,	. ,

232005 12-10-12

Form 990 (2012) 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 in Schedule O. See instructions

	Check if Schedule O contains a response to any question in this Part VI					X					
Sec	tion A. Governing Body and Management					بهد					
	don't dovorming body and management				Yes	No					
1a	Enter the number of voting members of the governing body at the end of the tax year	1a	4								
	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 in Schedule O.										
b	Enter the number of voting members included in line 1a, above, who are independent	1b	4								
2	Did any officer, director, trustee, or key employee have a family relationship or a business relationship										
	officer, director, trustee, or key employee?	,		2		Х					
3	Did the organization delegate control over management duties customarily performed by or under the	direct supervision									
	of officers, directors, or trustees, or key employees to a management company or other person?	·		3		X					
4	Did the organization make any significant changes to its governing documents since the prior Form 9	90 was filed?		4		X					
5	Did the organization become aware during the year of a significant diversion of the organization's ass	ets?		5		X					
6											
7a	Did the organization have members, stockholders, or other persons who had the power to elect or ap	point one or									
	more members of the governing body?			7a		X					
b	Are any governance decisions of the organization reserved to (or subject to approval by) members, st	ockholders, or	Ì								
	persons other than the governing body?			7b		X					
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year	r by the following:									
а	The governing body?			8a	Х						
b	Each committee with authority to act on behalf of the governing body?			8b	X						
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be read	ched at the									
	organization's mailing address? If "Yes," provide the names and addresses in Schedule O			9		Х					
Sec	tion B. Policies (This Section B requests information about policies not required by the Internal Re	venue Code)									
			ſ		Yes	No					
	Did the organization have local chapters, branches, or affiliates?		j	10a		<u> X</u>					
b	If "Yes," did the organization have written policies and procedures governing the activities of such ch	apters, affiliates,	l	10b							
	and branches to ensure their operations are consistent with the organization's exempt purposes?										
	Has the organization provided a complete copy of this Form 990 to all members of its governing body	before filing the for	m?	11a	X						
b	Describe in Schedule O the process, if any, used by the organization to review this Form 990.				٠.,						
12a	Did the organization have a written conflict of interest policy? If "No," go to line 13		-	12a	X						
b	, , , , , , , , , , , , , , , , , , , ,		-	12b	Х						
С	Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Ye in Schedule O how this was done	s," describe		40-	x						
13				12c	X						
14	Did the organization have a written whistleblower policy? Did the organization have a written document retention and destruction policy?		ł	13	X						
15	Did the process for determining compensation of the following persons include a review and approval	by independent	ŀ	14							
	persons, comparability data, and contemporaneous substantiation of the deliberation and decision?	by independent									
а	The organization's CEO, Executive Director, or top management official			15a		Х					
	Other officers or key employees of the organization			15b		X					
_	If "Yes" to line 15a or 15b, describe the process in Schedule O (see instructions)		1	100		- 					
16a	Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangem	ent with a									
_	taxable entity during the year?			16a		Х					
b	If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate	e its participation	Ì								
	in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organ	•									
	exempt status with respect to such arrangements?			16b							
Sec	tion C. Disclosure										
17	List the states with which a copy of this Form 990 is required to be filed ▶CT, IL			•							
18	Section 6104 requires an organization to make its Forms 1023 (or 1024 if applicable), 990, and 990-T	(Section 501(c)(3)s	only) a	vailab	le						
	for public inspection. Indicate how you made these available. Check all that apply										
	X Own website X Another's website X Upon request Other (explain i	n Schedule O)									
19	Describe in Schedule O whether (and if so, how), the organization made its governing documents, cor	flict of interest polic	y, and	l fınan	cıal						
	statements available to the public during the tax year										
20	State the name, physical address, and telephone number of the person who possesses the books an	d records of the org	anızatı	on 🕨	•						
	THE ORGANIZATION - 8203.880.9456	 -									
33300	11 NANCY DRIVE, MONROE, CT 06468										
232006 12-10-	12			Form	990	(2012)					

Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors

Check if Schedule O contains a response to any question 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 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 and/or Box 7 of Form 1099-MISC) 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

List persons in the following order individual trustees or directors, institutional trustees, officers; key employees, highest compensated employees, and former such persons

(A) Name and Title	(B) Average hours per week	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)					h an	(D) Reportable compensation from	(E) Reportable compensation from related	(F) Estimated amount of other
	(list any hours for related organizations below line)	Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former	the organization (W-2/1099-MISC)	organizations (W-2/1099-MISC)	compensation from the organization and related organizations
(1) LORI O'DRISCOLL PRESIDENT	40.00			x				0.	0.	0
(2) ABIGAIL HEMANI	40.00									
VICE PRESIDENT	10.00			X				0.	0.	0
(3) AMANDA RENZ SECRETARY	40.00			X				0.	0.	0
							:			
-11										
										<u></u>
·									<u>-</u>	
<u></u>										
										· · · · · · · · · · · · · · · · · · ·

Form 990 (2012)

Page 7

Par	t VII Section A. Officers, Directors, Trus	tees, Key Em	ploy	ees	, an	d Hi	ghe	st C	Compensated Employe	es (continued)				
-	(A)	(B)				C)			(D)	(E)			(F)	_
	Name and title	Average	(40		Pos				Reportable	Reportable		Es	timate	ed
•		hours per	box	, unle	ss pe	rson	than is bot	h an	compensation	compensation	.	an	nount	of
		week	\vdash	ceran	id a d	irecto	or/trus	itee)	from	from related			other	
		(list any hours for	recto						the	organizations			pensa	
		related	9 G	8			zated		organization	(W-2/1099-MIS	(ز		om th	
		organizations	Indiwdual trustee or director	Institutional trustee		8	npeu		(W-2/1099-MISC)				anızat d relat	
		below	dealt	utiona	_	Кеу етріоуее	st co	h					anızatı	
		line)	N P	Instit	Officer	Key e	Highest compensated employee	Former						
			1									ĺ		
			<u></u>											
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	-			<u> </u>			<u> </u>							
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1h	Sub-total		l	l	L	L	_		0.		0.		·	0.
	Total from continuation sheets to Part V	II Continu A							0.		0.			0.
	Total (add lines 1b and 1c)	ii, Section A							0.		0.			0.
u	Total number of individuals (including but r	not limited to th	088	liste	hd al	2016	2) W							<u> </u>
-	compensation from the organization	iot infinted to th	030	11310	,u ai	5040	<i>5,</i> **1	10 10	eceived more than wroc	,,000 of reportable				0
													Yes	No
3	Did the organization list any former officer,	director, or tru	ıste	e. ke	v en	olan	vee.	or I	highest compensated e	mplovee on	ſ			
	line 1a? If "Yes," complete Schedule J for s				,		,,					3		X
4	For any individual listed on line 1a, is the si		le co	mpe	ensa	ation	and	d oth	her compensation from	the organization	ŀ			
	and related organizations greater than \$15									3		4		Х
5	Did any person listed on line 1a receive or									dual for services	İ			
	rendered to the organization? If "Yes," com								_			_5		X
Sec	tion B. Independent Contractors													
1	Complete this table for your five highest co	mpensated inc	lepe	ende	nt c	ontr	acto	rs t	hat received more than	\$100,000 of comp	ens	ation f	rom	
	the organization Report compensation for	the calendar y	ear e	endı	ng w	/ith	or w	<u>ithir</u>	the organization's tax	year.				
	(A)								(B)			(C		
	Name and business	address	N	ONE	<u> </u>				Description of s	ervices		ompe	nsatio	n
								4						
								\dashv						
														
										1				
								\dashv						
2	Total number of independent contractors (i	ncluding but o	ot lir	niter	d to	thos	se lis	LL. Sted	above) who received m	ore than				
~	\$100,000 of compensation from the organi		J. 111		0)		. 22010, 11110 10001190 11					
	, , , , , , , , , , , , , , , , , , ,												200 //	

Form 990 (2012)

3,833.

490,641

e Total. Add lines 11a-11d

Total revenue See instructions.

3,833

0.

354,129. Form **990** (2012) Form 990 (2012) DRAVET SYNDROME FOUNDATION INC
Part IX Statement of Functional Expenses

Sect	ion 501(c)(3) and 501(c)(4) organizations must com	plete all columns All oth	er organizations must co	mplete column (A)	
	Check if Schedule O contains a respon	se to any question in th			
	not include amounts reported on lines 6b, 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 governments and				
	organizations in the United States. See Part IV, line 21	391,663.	391,663.		
2	Grants and other assistance to individuals in				
	the United States See Part IV, line 22	35,56 <u>7</u> .	35,567.		
3	Grants and other assistance to governments,				
	organizations, and individuals outside the				
	United States See Part IV, lines 15 and 16				-
4	Benefits paid to or for members				
5	Compensation of current officers, directors,				
	trustees, and key employees				
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	45,252.	2,649.	7,693.	34,910
8	Pension plan accruals and contributions (include				
	section 401(k) and 403(b) employer contributions)				
9	Other employee benefits				
10	Payroll taxes				
11	Fees for services (non-employees)				
а	Management				
b	Legal				
С	Accounting	3,000.	233.	678.	2,089
d	Lobbying				
е	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 Sch O.)	987.			987
12	Advertising and promotion	8,772.	513.	1,491.	6,768
13	Office expenses	4,482.	912.	1,876.	1,694
14	Information technology				
15	Royalties				
16	Occupancy				
17	Travel	3,095.	2,176.	526.	393
18	Payments of travel or entertainment expenses	,			
	for any federal, state, or local public officials				
19	Conferences, conventions, and meetings				
20	Interest				
21	Payments to affiliates				
22	Depreciation, depletion, and amortization				
23	Insurance	482.	339.	82.	61
24	Other expenses. Itemize expenses not covered above. (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
а	BANK CHARGES	16,826.	985.	2,860.	12,981
b	POSTAGE & PRINTING	7,740.	453.	1,316.	5,971
c	OTHER	7,463.	122	1,947.	5,516
d	DUES & SUBSCRIPTIONS	5,015.	294.	852.	3,869
	All other expenses	3,023.			
25	Total functional expenses. Add lines 1 through 24e	530,344.	435,784.	19,321.	75,239
<u>25</u> 26	Joint costs. Complete this line only if the organization	200/2440	200//020	10,001.	, 0, 20)
	reported in column (B) joint costs from a combined				
	educational campaign and fundraising solicitation.				
	Check here following SOP 98-2 (ASC 958-720)				
					Form 990 (2012)

Part X Balance Sheet Check if Schedule O contains a response to any question in this Part X (A) End of year Beginning of year 187,626 1 58,033. Cash - non-interest-bearing 2 2 Savings and temporary cash investments 3 Pledges and grants receivable, net 3 15,131. 1,645. 4 4 Accounts receivable, net Loans and other receivables from current and former officers, directors, trustees, key employees, and highest compensated employees Complete Part II of Schedule L 5 6 Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing employers and sponsoring organizations of section 501(c)(9) voluntary employees' beneficiary organizations (see instr) Complete Part II of Sch L 6 Assets 7 Notes and loans receivable, net Inventories for sale or use 8 6,703. 1,550. 9 Prepaid expenses and deferred charges 10a Land, buildings, and equipment cost or other basis Complete Part VI of Schedule D 10a 10b b Less accumulated depreciation 10c Investments - publicly traded securities 11 11 12 12 Investments - other securities See Part IV, line 11 13 Investments - program-related See Part IV, line 11 13 14 Intangible assets 14 10,918. 11,469 15 Other assets. See Part IV, line 11 15 206,892. 86,183 16 16 Total assets. Add lines 1 through 15 (must equal line 34) 81,006. 17 Accounts payable and accrued expenses 17 18 Grants payable 18 19 Deferred revenue 19 20 Tax-exempt bond liabilities 20 Escrow or custodial account liability Complete Part IV of Schedule D 21 21 Liabilities Loans and other payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons Complete Part II of Schedule L 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 81,006. 0. 26 Total liabilities. Add lines 17 through 25 26 Organizations that follow SFAS 117 (ASC 958), check here complete lines 27 through 29, and lines 33 and 34. Net Assets or Fund Balances 114,968. 74,714. 27 Unrestricted net assets 27 Temporarily restricted net assets 28 28 10,918. 11,469. 29 Permanently restricted net assets 29 Organizations that do not follow SFAS 117 (ASC 958), check here and complete lines 30 through 34. Capital stock or trust principal, or current funds 30 30 31 Paid-in or capital surplus, or land, building, or equipment fund 31 32 32 Retained earnings, endowment, accumulated income, or other funds 125,886. 86,183. 33 33 Total net assets or fund balances 206,892. 86,183. Total liabilities and net assets/fund balances

Form 990 (2012)

orn	1 990 (2012) DRAVET SYNDROME FOUNDATION INC	27-092	4627	Pa	ge 12				
Pa	rt XI Reconciliation of Net Assets								
	Check if Schedule O contains a response to any question in this Part XI								
1	Total revenue (must equal Part VIII, column (A), line 12)	1			<u>41.</u>				
2	Total expenses (must equal Part IX, column (A), line 25)	2			44.				
3	Revenue less expenses Subtract line 2 from line 1	3			03.3 86.				
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))								
5	Net unrealized gains (losses) on investments	5							
6	Donated services and use of facilities	6							
7	Investment expenses	7							
8	Prior period adjustments	8							
9	Other changes in net assets or fund balances (explain in Schedule O)	9			0.				
10	Net assets or fund balances at end of year Combine lines 3 through 9 (must equal Part X, line 33,								
	column (B))	10	8	6,1	<u>83.</u>				
Pa	rt XII Financial Statements and Reporting								
	Check if Schedule O contains a response to any question in this Part XII								
				Yes	No				
1	Accounting method used to prepare the Form 990 Cash Accrual Other			-					
	If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule	• O			ļ				
2 a	Were the organization's financial statements compiled or reviewed by an independent accountant?		2a		X				
	If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewe	d on a							
	separate basis, consolidated basis, or both								
	Separate basis Consolidated basis Both consolidated and separate basis				,				
b	Were the organization's financial statements audited by an independent accountant?		2b	X					
	If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separa	te basis,							
	consolidated basis, or both								
	X Separate basis Consolidated basis Both consolidated and separate basis								
С	If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the	ie audit,							
	review, or compilation of its financial statements and selection of an independent accountant?		2c	Х					
	If the organization changed either its oversight process or selection process during the tax year, explain in Sch	edule O							
За	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit								
	Act and OMB Circular A-133?		За		X				
b	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the requ	ired audit							
	or audits, explain why in Schedule O and describe any steps taken to undergo such audits		3b						
			Form	990	(2012)				

SCHEDULE A

(Form 990 or 990-EZ)

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. ▶ See separate instructions.

2012

Open to Public Inspection

Name of	the organizat	ion						E	mployer	identificati	ion nui	mber	
		DRAVET	SYNDROME FOU	NDATI	ON IN	C			27-0924627				
Part I	Reason	for Public Char	rity Status (All organiz	zations mu	st complet	te this par	t) See inst	tructions			,		
L	A church, co A school des A hospital or A medical re city, and sta An organizat section 170 A federal, sta An organizat section 170 A community An organizat activities rela	a private foundation invention of churche scribed in section 17 a cooperative hospi search organization te ion operated for the h(b)(1)(A)(iv). (Complete, or local government that normally received the function that normally received to its exempt further when the contraction of	because it is (For lines s, or association of chur (70(b)(1)(A)(ii). (Attach Soutal service organization operated in conjunction benefit of a college or unete Part II) itent or governmental uniterives a substantial part	1 through ches described with a hos niversity or it described of its supp (Complete 1/3% of its ain exception	11, check ribed in section spital descriving d in section or from a Part II) support fons, and (2	170(b)(1) ribed in section 170(b)(1) ribed in section 170(b)(1) government rom contri	pox) (A)(iii). ection 170 a governi (1)(A)(v). ental unit of	nental un r from the nembersh	e general p fees, a	public desc and gross rea t from gross	cribed ii	in from tment	
10	See section An organizat An organizat more publicly describes the a Type By checking foundation in If the organiz supporting of Since Augus (i) A perso the gove (ii) A family (iii) A 35% of	509(a)(2). (Complete ion organized and operation organized and operation organized and operation organized expe of supporting the box, I certify the managers and other the interest at 17, 2006, has the controlled entity of a controlled entity of a	e Part III) perated exclusively to te perated exclusively for the perated exclusively controls, either all perated exclusively controls, either all perated exclusively for the person described in (i) described in (i) described in (i) described in (i) described in (i) described in (ii) described in (iiii) described in (iiii) described in (iiiiiiiiiiiiiiiiiiiiiiiiiiiiiiiiii	est for public on 509(a)(1) ete lines 1 ype III - Fuit controlled y supporte the IRS that any gift or colone or tog	ic safety S of, to perfo 1) or section 1e through nctionally in directly o divectly o divectly o right ontribution ether with	See section or the function 509(a)(2 in 11h antegrated or indirectly attions described by the formany	on 509(a)(4) nctions of, 2) See sec to by one or cribed in s II, or Type	or to carrection 509(Typer more disection 509) High section 509	y out the (a)(3). Chose III - No qualified 9(a)(1) or soons?	e purposes of leck the box in-functional persons oth section 509	of one of that	or grated in	
	of supported	(ii) EIN	(iii) Type of organization (described on lines 1-9 above or IRC section	(iv) Is the oin col. (i) Is governing ((v) Did you organizat (i) of youi	u notify the ion in col.	(vi) ls organizati (i) organiz U.S	s the on in col. ed in the	(vii) Amount	t of mor	—— netary	
			(see instructions))	Yes	No	Yes	No	Yes	No				
_													
Total_ LHA For P	aperwork Re	duction Act Notice	, see the Instructions fo	or			<u> </u>	Schedul	e A (Fori	m 990 or 99	 0-EZ)	2012	

232021

Form 990 or 990-EZ.

27-0924627 Page 2

Schedule A (Form 990 or 990 EZ) 2012 DRAVET SYNDROME FOUNDATION INC 27-09240

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)

Sec	ction A. Public Support						
Cale	ndar year (or fiscal year beginning in)	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
1	Gifts, grants, contributions, and						
	membership fees received (Do not						
	ınclude any "unusual grants ")		15,912.	346,223.	459,959.	132,679.	954,7 <u>73.</u>
2	Tax revenues levied for the organ-						
	ızatıon'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		15,912.	346,223.	459,959.	132,679.	954,773.
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)						
	Public support. Subtract line 5 from line 4						954,773.
Sec	tion B. Total Support						
Cale	ndar year (or fiscal year beginning in) ► 🏻	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
7	Amounts from line 4		15,912.	346,223.	459,959.	132,679.	95 4 ,773.
8	Gross income from interest,						
	dividends, payments received on						
	securities loans, rents, royalties						
	and income from similar sources					551.	<u>551.</u>
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 IV)						
11	Total support. Add lines 7 through 10						955,324.
	Gross receipts from related activities,		·		Į	12	6,954.
13	First five years. If the Form 990 is for		first, second, third	d, fourth, or fifth ta	ix year as a section	n 501(c)(3)	
<u> </u>	organization, check this box and stop	here					▶ X
	tion C. Computation of Publi	14.50		-			
	Public support percentage for 2012 (li		•	olumn (f))	}	14	<u>%</u>
	Public support percentage from 2011	•	•			15	<u>%</u>
16a	33 1/3% support test - 2012. If the o	-			14 is 33 1/3% or m	ore, check this bo	x and
	stop here. The organization qualifies a		-				. ▶∟
	33 1/3% support test - 2011. If the o	•		•	line 15 is 33 1/3%	or more, check th	is box
	and stop here. The organization quali						
	10% -facts-and-circumstances test						
	and if the organization meets the "fact				· ·	t IV how the organ	ization
	meets the "facts-and-circumstances"	_			=		▶□
	10% -facts-and-circumstances test	-				=	
	more, and if the organization meets th				•		
	organization meets the "facts-and-circ			•	, ,,		
18	Private foundation. If the organization	n did not check a l	oox on line 13, 16a	i, 160, 1/a, or 17b		nd see instructions	

<u>-</u>

Schedule A (Form 990 or 990-EZ) 2012 Part III Support Schedule for Organizations Described in Section 509(a)(2)

(Complete only if you checked the box on line 9 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	siow, picuse com	piete i ait ii j				
Calendar year (or fiscal year beginning in) ▶	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
1 Gifts, grants, contributions, and						
membership fees received (Do not						
ınclude any "unusual grants ")						
2 Gross receipts from admissions,						
merchandise sold or services per-						
formed, 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 bus-			ļ			
iness under section 513						
4 Tax revenues levied for the organ-						
ization'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				İ		
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) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
9 Amounts from line 6						
10a Gross income from interest,						
dividends, payments received on securities loans, rents, royalties						·
and income from similar sources						
b Unrelated business taxable income						
(less section 511 taxes) from businesses						
acquired after June 30, 1975			_			
c Add lines 10a and 10b						
11 Net income from unrelated business						
activities not included in line 10b, whether or not the business is						
regularly carried on						
12 Other income. Do not include gain						
or loss from the sale of capital assets (Explain in Part IV)						
13 Total support. (Add lines 9, 10c, 11, and 12)						
14 First five years. If the Form 990 is for	the organization's	s first, second, thir	d, fourth, or fifth ta	ax year as a section	on 501(c)(3) organiz	ation,
check this box and stop here				_		
Section C. Computation of Publi	c Support Pe	rcentage				
15 Public support percentage for 2012 (In			olumn (f))	•	15	%
16 Public support percentage from 2011					16	%
Section D. Computation of Inves					 	
17 Investment income percentage for 20	12 (line 10c, colun	nn (f) divided by lir	e 13, column (f))		17	%
18 Investment income percentage from 2	011 Schedule A,	Part III, line 17			18	%
19a 33 1/3% support tests - 2012. If the	organization did n	ot check the box	on line 14, and line	e 15 is more than :	33 1/3%, and line 1	7 is not
more than 33 1/3%, check this box an	d stop here. The	organization qual	fies as a publicly s	supported organiz	ation	▶□
b 33 1/3% support tests - 2011. If the	organization did n	ot check a box on	line 14 or line 19a	a, and line 16 is mi	ore than 33 1/3%, a	and
line 18 is not more than 33 1/3%, chec	ck this box and st	t op here. The orga	ınızatıon qualıfıes a	as a publicly supp	orted organization	▶□
20 Private foundation. If the organization	did not check a	box on line 14, 19	a, or 19b, check th	nis box and see in	structions	> L_]

SCHEDULE D

(Form 990)

Department of the Treasury Internal Revenue Service

Supplemental Financial Statements

► Complete if the organization answered "Yes," to Form 990, Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b. ➤ Attach to Form 990. ➤ See separate instructions.

OMB No 1545-0047 Open to Public Inspection

Nam	e of the organization DRAVET SYNDROME FO	UNDATION INC	Employer identification number 27-0924627
Pa	rt I Organizations Maintaining Donor Advise	ed Funds or Other Similar Funds or	
	organization answered "Yes" to Form 990, Part IV, lin		2004
		(a) Donor advised funds	(b) Funds and other accounts
1	Total number at end of year		
2	Aggregate contributions to (during year)		
3	Aggregate 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 hold in donor advised t	fundo
3	are the organization's property, subject to the organization's		Yes No
6	Did the organization inform all grantees, donors, and donor a	J	 ::::
U	for charitable purposes and not for the benefit of the donor of		
	impermissible private benefit?	or deficit advisor, or for any other purpose con	Yes No
Pa		ganization answered "Ves" to Form 990. Part	
1	Purpose(s) of conservation easements held by the organization		iv, inte 7.
•	Preservation of land for public use (e.g., recreation or e		cally important land area
	Protection of natural habitat	· —	• •
	Preservation of open space	Preservation of a certified	Tristoric structure
2	Complete lines 2a through 2d if the organization held a quality	final annuariation annually the status of the status of	
2	day of the tax year	ned conservation contribution in the form of a	conservation easement on the last
	day of the tax year		Held at the End of the Tax Year
а	Total number of conservation easements		
b	Total acreage restricted by conservation easements		2a 2b
C	Number of conservation easements on a certified historic str	ructure included in (a)	2c 2c
d	Number of conservation easements included in (c) acquired	(,	20
ŭ	listed in the National Register	arter 0/17700, and not on a historic structure	2d
3	Number of conservation easements modified, transferred, re	leased extinguished or terminated by the ord	
•	year ▶	rodoca, extinguished, or terminated by the org	gainzation daring the tax
4	Number of states where property subject to conservation ea	sement is located	
5	Does the organization have a written policy regarding the per		
_	violations, and enforcement of the conservation easements in		Yes No
6	Staff and volunteer hours devoted to monitoring, inspecting,		
7	Amount of expenses incurred in monitoring, inspecting, and		
8	Does each conservation easement reported on line 2(d) above	-	
	and section 170(h)(4)(B)(ii)?	, , , ,	Yes No
9	In Part XIII, describe how the organization reports conservati	on easements in its revenue and expense sta	
	include, if applicable, the text of the footnote to the organization		
	conservation easements		
Pai	t III Organizations Maintaining Collections o	f Art, Historical Treasures, or Othe	er Similar Assets.
	Complete if the organization answered "Yes" to Form	990, Part IV, line 8.	
1a	If the organization elected, as permitted under SFAS 116 (AS	SC 958), not to report in its revenue statement	and balance sheet works of art,
	historical treasures, or other similar assets held for public exh	nibition, education, or research in furtherance	of public service, provide, in Part XIII,
	the text of the footnote to its financial statements that descri		
b	If the organization elected, as permitted under SFAS 116 (AS	SC 958), to report in its revenue statement and	d balance sheet works of art, historical
	treasures, or other similar assets held for public exhibition, ed		
	relating to these items		-
	(i) Revenues included in 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 trea	asures, or other similar assets for financial gai	
	the following amounts required to be reported under SFAS 1		
а	Revenues included in Form 990, Part VIII, line 1	· -	> \$
b	Assets included in Form 990, Part X		> \$

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Schedule D (Form 990) 2012

		SYNDROME F	OUNDATION	INC		27-0924627 Page 2
Pa	rt III Organizations Maintaining C	Collections of A	rt, Historical Tr	easures, or Oth	er Simil	ar Assets(continued)
3	Using the organization's acquisition, accessi	on, and other record	ls, check any of the	following that are a	significant	use of its collection items
	(check all that apply)					
а	Public exhibition	d		hange programs		
b	Scholarly research	е	· Other			
С	Preservation for future generations					
4	Provide a description of the organization's co	ollections and explai	n how they further t	he organization's ex	empt purpo	ose in Part XIII
5	During the year, did the organization solicit of				ar assets	
_	to be sold to raise funds rather than to be ma					Yes No
Pa	rt IV Escrow and Custodial Arran		ete if the organizatio	n answered "Yes" t	o Form 990), Part IV, line 9, or
	reported an amount on Form 990, Pa					<u> </u>
1a	Is the organization an agent, trustee, custod	an or other intermed	diary for contribution	is or other assets no	t included	
	on Form 990, Part X?					└─ Yes └─ No
b	If "Yes," explain the arrangement in Part XIII	and complete the fo	llowing table			:
						Amount
C	Beginning balance				1c	
d	Additions during the year				1d	
e	Distributions during the year				1e	
7-	Ending balance	000 David V Iva-	010		1f	
	Did the organization include an amount on Fe	• •				└─ Yes └─ No
$\overline{}$	If "Yes," explain the arrangement in Part XIII To V Endowment Funds. Complete in					
	Endownione Funds: Complete F	(a) Current year	(b) Prior year	(c) Two years back	(d) Three y	years back (e) Four years back
1a	Beginning of year balance			(C) I WO years back	(a) Three y	rears back (e) rour years back
h	Contributions	10,918.	10,000.			
	Net investment earnings, gains, and losses	551.				
q	Grants or scholarships	257.				
e	Other expenditures for facilities					
Ū	and programs					
f	Administrative expenses			-		· · · · · · · · · · · · · · · · · · ·
a	End of year balance	11 469.	10,000.			· ·····
2	Provide the estimated percentage of the curi			a)) held as:	1	<u></u>
а	Board designated or quasi-endowment	,	%	-,, · · · · · · · · · · · · · · · · · ·		
b	Permanent endowment	%	_			
С	Temporarily restricted endowment ▶					
	The percentages in lines 2a, 2b, and 2c should equal 100%.					
За	3a Are there endowment funds not in the possession of the organization that are held and administered for the organization					
	by					Yes No
	(i) unrelated organizations					3a(i) X
	(ii) related organizations					3a(ii) X
b	If "Yes" to 3a(ii), are the related organizations	s listed as required o	n Schedule R?			3b
4	Describe in Part XIII the intended uses of the					
Par	t VI Land, Buildings, and Equipm	ent. See Form 990	, Part X, line 10			
	Description of property	(a) Cost or o basis (investin			Accumulate epreciation	
1a	Land					
b	Buildings					
С	Leasehold improvements					
d	Equipment					
e	Other					
<u>Total</u>	. Add lines 1a through 1e (Column (d) must e	qual Form 990, Part	X, column (B), line 1	0(c))		▶ 0.

Schedule D (Form 990) 2012

	dule D (Form 990) 2012 DRAVET SYNDROME FOUNDATION INC	27-	0924627 Page 4
Par	t XI Reconciliation of Revenue per Audited Financial Statements With Revenue per F	Returr	
1	Total revenue, gains, and other support per audited financial statements	1	506,628.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12		
a	Net unrealized gains on investments 2a		
b	Donated services and use of facilities 2b 15,987	.]	
С	Recoveries of prior year grants 2c		
d	Other (Describe in Part XIII)	1	
е	Add lines 2a through 2d	2e	_15,987.
3	Subtract line 2e from line 1	3	490,641.
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1		
а	Investment expenses not included on Form 990, Part VIII, line 7b		
b	Other (Describe in Part XIII)	1 I	
-	Add lines 4a and 4b	4c	0.
5	Total revenue Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)	5	490,641.
Par	t XII Reconciliation of Expenses per Audited Financial Statements With Expenses per		
1	Total expenses and losses per audited financial statements	1	546,331.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25		310,3311
a	Donated services and use of facilities 2a 15,987		
h	Prior year adjustments 2b	1	
Č	Other losses 2c	1	
d	Other (Describe in Part XIII)	┤ │	
	Add lines 2a through 2d	2e	15 987
3	Subtract line 2e from line 1	3	<u>15,987.</u> 530,344.
	Amounts included on Form 990, Part IX, line 25, but not on line 1	3	330,344.
		-	
	Other (Describe in Part XIII) Add lines 4a and 4b	┥╻ ┃	0
		4c	530,344.
	Total expenses Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.) t XIII Supplemental Information	5	530,344.
	plete this part to provide the descriptions required for Part II, lines 3, 5, and 9, Part III, lines 1a and 4, Part IV, lines 1		2b, Paπ V, line 4, Paπ
	e 2, Part XI, lines 2d and 4b, and Part XII, lines 2d and 4b Also complete this part to provide any additional informa TTV, LINE 4: THE INTEREST INCOME WILL BE USED TO PROVIDE		UTOEC
FAN	RT V, LINE 4: THE INTEREST INCOME WILL BE USED TO PROVIDE	SEK	AICES
то	INDIVUDUAL SUFFERING FROM DRAVET SYNDROME IN THE STATE OF	i IO	ΔW
	INDIVODOME BUILDRING I KOM DRAVBI DINDROME IN THE DIATE OF	10	nr.

SCHEDULE G

Department of the Treasury

Internal Revenue Service

Part I

С

(Form 990 or 990-EZ)

Supplemental Information Regarding Fundraising or Gaming Activities

Complete if the organization answered "Yes" to Form 990, Part IV, lines 17, 18, or 19, or if the organization entered more than \$15,000 on Form 990-EZ, line 6a.

OMB No 1545-0047

Open To Public

Inspection

Name of the organization

➤ Attach to Form 990 or Form 990-EZ. ➤ See separate instructions.

Employer identification number 27-0924627 DRAVET SYNDROME_FOUNDATION INC Fundraising Activities. Complete if the organization answered "Yes" to Form 990, Part IV, line 17 Form 990-EZ filers are not required to complete this part Indicate whether the organization raised funds through any of the following activities. Check all that apply Mail solicitations ∃ Solicitation of non-government grants Internet and email solicitations Solicitation of government grants Phone solicitations Special fundraising events In-person solicitations 2 a 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? No Yes b If "Yes," list the ten highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization (v) Amount paid (iii) Did (vi) Amount paid (i) Name and address of individual (iv) Gross receipts to (or retained by) (ii) Activity have custody or control of contributions? to (or retained by) fundraiser or entity (fundraiser) from activity organization listed in col (i) Yes No

Oτ	P
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
-	

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Schedule G (Form 990 or 990-EZ) 2012

Pa	art		e organization answered	d "Yes" to Form 990, Part	IV, line 18, or reported	
	_	of fundraising event contributions and gr				ts greater than \$5,000
	-		(a) Event #1	(b) Event #2	(c) Other events	(d) Total events
			CIARA'S		_	(add col (a) through
			BUTTERFLY BA	PIPERS SONG	4_	col. (c))
ne			(event type)	(event type)	(total number)	
Revenue	1	Gross receipts	129,187.	71,843.	229,692.	430,722.
	2	Less Contributions				
	3	Gross income (line 1 minus line 2)	129,187.	71,843.	229,692.	430,722.
	4	Cash prizes	<u> </u>			
es	5	Noncash prizes				
xbens	6	Rent/facility costs				
Direct Expenses	7	Food and beverages				
	_	Entartainment				
	8	Entertainment	48,237.	7 015	21 002	77 1 4 4
	9	Other direct expenses		7,815.	21,092.	77,144.
		Direct expense summary Add lines 4 through			.	(77,144)
Dr	ırt	Net income summary Combine line 3, colum		. 000 Dart IV Iva 40 ava		353,578.
ГС	11 (answered Yes to Form	1990, Part IV, line 19, or r	eported more than	
		\$15,000 on Form 990-EZ, line 6a		A > Dull to be for store		(N T-A-1 /- d-1
Revenue			(a) Bingo	(b) Pull tabs/instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col (a) through col (c))
æ		Gross revenue				
	1	Gloss revenue			· · · · · · · · · · · · · · · · · · ·	
ses	2	Cash prizes			· · · · · · · · · · · · · · · · · · ·	
Direct Expenses	3	Noncash prizes				
Direct	4	Rent/facility costs				
	_	Other direct expenses				
	6	Volunteer labor	Yes% No	Yes %	Yes% No	
	7	Direct expense summary Add lines 2 through	n 5 ın column (d)		•	()
	8	Net gaming income summary. Combine line 1	, column d, and line 7		>	
9	En	ter the state(s) in which the organization opera	tes gaming activities _		· · · · · · · · · · · · · · · · · · ·	-
а	ls t	the organization licensed to operate gaming ac	tivities in each of these	states?		Yes No
b	lf "	No," explain				<u>-</u>
	_					
		ere any of the organization's gaming licenses re Yes," explain			ear?	Yes No
	_					
2220	32 0	1-07-13			Schedule G /For	m 990 or 990-EZ) 2012
					- 3 1. 0.	12

Schedule G (Form 990 or 990-EZ) 2012 DRAVET SYNDROME FOUNDATION INC 27	-0924627 Page 3
11. Does the organization operate gaming activities with nonmembers?	Yes No
12 Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity formed	
to administer charitable gaming?	Yes No
13 Indicate the percentage of gaming activity operated 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	<u> </u>
Address ▶	
15a Does the organization have a contract with a third party from whom the organization receives gaming revenue?	Yes No
b If "Yes," enter the amount of gaming revenue received by the organization ▶ \$ and the amount	
of gaming revenue retained by the third party > \$	
c If "Yes," enter name and address of the third party	
,	
Name	
Address >	
16 Gaming manager information	
Name	
Gaming manager compensation > \$	
Description of services provided	
Director/officer Employee Independent contractor	
17 Mandatory distributions	
a Is the organization required under state law to make charitable distributions from the gaming proceeds to	
retain the state gaming license?	Yes No
b Enter the amount of distributions required under state law to be distributed to other exempt organizations or spent in the	
organization's own exempt activities during the tax year > \$	
Part IV Supplemental Information. Complete this part to 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 complete this part to provide any additional information	ition (see instructions)
-	

SCHEDULE (Form 990)

Complete if the organization answered "Yes" to Form 990, Part IV, line 21 or 22. Governments, and Individuals in the United States Grants and Other Assistance to Organizations,

OMB No 1545-0047	2012	Open to Public

≗

Employer identification number 27-0924627 Inspection X Yes 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 ▶ Attach to Form 990. DRAVET SYNDROME FOUNDATION INC General Information on Grants and Assistance criteria used to award the grants or assistance? Name of the organization Department of the Treasury Internal Revenue Service

Part

Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States

Part II	Fart III Grants and Other Assistance to Governments and Organizations in the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 21, for any	Governments and	d Organizations in the	• United States. C	omplete if the org	lanization answered "Y	es" to Form 990, Part	IV, line 21, for any
1 (a)	1 (a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
REGENTS UNIVE 1855 FOLSOM ST SAN FRANCISCO	UNIVERSITY OF CALIFORNIA LSOM ST NCISCO, CA 94143	36-3357006	501 (C) 3	0	0	EMV		RESEARCH
CURE CI: IN EPILA	CURE CITIZENS UNITED FOR RESEARCH IN EPILELPSY - 223 WEST ERIE - CHICAGO, IL 60614	36-4253176	501 (C) 3	0	0	PMV		RESEARCH
REGENTS MICHIGAN	REGENTS OF THE UNIVERSITY OF MICHIGAN - 3003 S STATE STREET - ANN ARBOR, MI 48109	38-6006309	501 (C) 3	0	0	VMT		RESEARCH
3 Ente	Enter total number of section 501(c)(3) and government organizations Enter total number of other organizations listed in the line 1 table	nd government or slisted in the line	l suoi:	isted in the line 1 table			to the second se	A A
LHA Fo	For Paperwork Reduction Act Notice, see the Instructions for Form 990.	see the Instructi	ions for Form 990.					Schedule I (Form 990) (2012)

Schedule I (Form 990) (2012)

30

232102 12-18-12

Page 2

27-0924627

Grants and Other Assistance to Individuals in the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 22 Part III can be duplicated if additional space is needed

DRAVET SYNDROME FOUNDATION INC

Schedule I (Form 990) (2012)

Part III

SCHEDULE O

(Farm 990 or 990-EZ)

Supplemental Information to Form 990 or 990-EZ Complete to provide information for responses to specific questions on

OMB No 1545-0047

Open to Public Inspection

Department of the Treasury Internal Revenue Service Name of the organization Form 990 or 990-EZ or to provide any additional information. ► Attach to Form 990 or 990-EZ.

> Employer identification number 27-0924627

DRAVET SYNDROME FOUNDATION INC	27-0924627		
FORM 990, PART I, LINE 1, DESCRIPTION OF ORGANIZATION MIS	SION:		
FOR DRAVET SYNDROME AND RELATED EPILEPSIES, WHILE PROVIDE	NG_SUPORT TO		
AFFECTED INDIVIDUALS AND FAMILIES. THE DSF SEEKS BETTER T	REATMENT		
OPTIONS AND A CURE FOR THESE DEVASTATING SEIZURE DISORDER	s.		
FORM 990, PART III, LINE 1, DESCRIPTION OF ORGANIZATION M	ISSION:		
CLINICIANS TO COLLABORATE AND DISCUSS BETTER TREATMENT OP	TIONS AND A		
ROADMAP TOWARD A CURE AND HOW TO BEST FACILITATE BOTH. WE	UNDERSTAND		
THAT MEDICAL EXPENSES ARE HIGH WHEN CARING FOR A CHILD WI	TH CHRONIC		
HEALTH ISSUES. UNFORTUNATLEY, SOME OF TE ITEMS THAT MIGHT	IMPROVE THE		
QUALITY OF LIFE FOR THE CHILD AND/OR FAMILY ARE NOT ALWAY	S COVERED BY		
MEDICAL INSURANCE. THROUGH OUT INTERNATIONAL PATIENT ASSI	STANCE PROGRAM		
GRANT PROGRAM(IPAG), WE PROVIDE GRANTS TO COVER THESE ITEMS.			
FORM 990, PART VI, SECTION B, LINE 11: THE EXECUTIVE COMM	ITTEE OF THE		
BOARD OF DIRECTORS MEETS WITH THE CERTIFIED PUBLIC ACCOUNT	TANT TO REVIEW AND		
APPROVE THE AUDITED FINANCIAL STATEMENTS AND FORM 990			
FORM 990, PART VI, SECTION B, LINE 12C: MONITORING AND EN	FORCING THE		
ORGANIZATIONS CONFLICT OF INTEREST POLICY			
FORM 990, PART VI, SECTION C, LINE 18: THE DRAVET SYNDROM	E FOUNDATION FORM		
990 IS AVAILABLE FOR PUBLIC INSPECTION ON THE ORGANIZATON	S WEBSITE. THE		
ORGANIZATIONS ORGANIZING DOCUMENTS ARE AVAILABLE FOR INSP.	ECTION UPON		

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ. 232211 01-04-13

WRITTEN REQUEST TO THE PRESIDENT

Schedule O (Form 990 or 990-EZ) (2012)

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Natine of the organization DRAVET SYNDROME FOUNDATION INC	Employer identification number 27-0924627
FORM 990, PART VI, SECTION C, LINE 19: THE DRAVET SYNDROM	E FOUNDATION
MAKES ITS GOVERNING DOCUMENTS, CONFLICT OF INTERST POLICY	AND FINANCIAL
STATEMENTS AVAIABLE TO THE PUBLIC UPON PRIOR WRITTEN REQU	EST TO THE
PESIDENT.	
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