Form **990**

Department of the Treasury Internal Revenue Service **Return of Organization Exempt From Income Tax**

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

► Do not enter social security numbers on this form as it may be made public. ► Information about Form 990 and its instructions is at www.irs.gov/form990. OMB No. 1545-0047

Open to Public Inspection

2016, and ending For the 2016 calendar year, or tax year beginning D Employer identification number Check if applicable: BATTEN DISEASE SUPPORT & RESEARCH ASSOC 91-1397792 Address change 1175 DUBLIN ROAD Name change COLUMBUS, OH 43215 Initial return 800-448-4570 Final return/terminated **G** Gross receipts \$ 812,976. Amended return Application pending | F Name and address of principal officer: H(a) Is this a group return for subordinates Yes **H(b)** Are all subordinates included? If 'No,' attach a list. (see instructions) Yes SAME AS C ABOVE Tax-exempt status X 501(c)(3) 501(c) () ◀ (insert no.) 4947(a)(1) or 527 Website: ► N/A H(c) Group exemption number ► X Corporation Other ► Form of organization: Trust Association L Year of formation: 1987 M State of legal domicile: OH Summary Part I Briefly describe the organization's mission or most significant activities: BATTEN DISEASE SUPPORT & RESEARCH ASSOCIATION'S MISSION IS TO BE AN INTERNATIONAL SUPPORT AND RESEARCH NETWORKING Governance ORGANIZATION FOR FAMILIES OF CHILDREN AND YOUNG ADULTS WITH AN INHERITED NEUROLOGICAL DEGENERATIVE DISORDER KNOWN AS BATTEN DISEASE. Check this box Fig. 1 if the organization discontinued its operations or disposed of more than 25% of its net assets. Number of voting members of the governing body (Part VI, line 1a)..... 3 ∘ઇ Number of independent voting members of the governing body (Part VI, line 1b). 0 Total number of individuals employed in calendar year 2016 (Part V, line 2a) 5 4 Total number of volunteers (estimate if necessary)..... 6 0 7a Total unrelated business revenue from Part VIII, column (C), line 12 7a **b** Net unrelated business taxable income from Form 990-T. line 34...... 0. **Prior Year Current Year** Contributions and grants (Part VIII, line 1h). . 977,295. 803,869. Program service revenue (Part VIII, line 2g) . . . 10 Investment income (Part VIII, column (A), lines 3, 4, and 7d 16,908 9,107. Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, 11 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12).... 994,203 812,976. Grants and similar amounts paid (Part IX, column (A), lines 1-3). 13 Benefits paid to or for members (Part IX, column (A), line 4)...... 14 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10) 15 273,748 273,117 **16a** Professional fundraising fees (Part IX, column (A), line 11e).... **b** Total fundraising expenses (Part IX, column (D), line 25) ► Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)..... 17 606,389 781,199. Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)...... 1,054,316. 880,137. Revenue less expenses. Subtract line 18 from line 12..... 114,066. -241,340.**Beginning of Current Year** End of Year 20 Total assets (Part X, line 16)..... 657,635 664,508. Total liabilities (Part X. line 26)..... 21 90,954 324,716. 22 Net assets or fund balances. Subtract line 21 from line 20..... 566,681 339,792 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. Signature of officer Date Sign Here MARGIE FRAZIER EXECUTIVE DIRECTOR Type or print name and title Print/Type preparer's name Preparer's signature Date FRED W. LAUBIE FRED W. LAUBIE self-employed P00454836 **Paid** Preparer ► LAUBIE, KARLING & ASSOCIATES, Use Only Firm's address 1041 DUBLIN RD. Firm's EIN ► 20-5890880 COLUMBUS, OH 43215 (614) 481-0700 May the IRS discuss this return with the preparer shown above? (see instructions)..... X Yes Nο

Check if Schedule O contains	a response or note to any line in this Part III		П
Briefly describe the organization's mis			_
-		CCTOM TO TO BE AM TMTEDMATTOMAT	
		SSION IS TO BE AN INTERNATIONAL	
		AMILIES OF CHILDREN AND YOUNG	
ADULTS WITH AN INHERITE	D_NEUROLOGICAL_DEGENERATIVE	DISORDER KNOWN AS BATTEN DISEASE.	
• D: III	c		
-	ficant program services during the year which w	· — — —	
		Yes 💢 No)
If 'Yes,' describe these new services	on Schedule O.		
3 Did the organization cease conducting	g, or make significant changes in how it cond	ducts, any program services? Yes X No)
If 'Yes,' describe these changes on S	chedule O.		
4 Describe the organization's program s	service accomplishments for each of its three	e largest program services, as measured by expenses	
Section 501(c)(3) and 501(c)(4) organ	nizations are required to report the amount of	f grants and allocations to others, the total expenses,	
and revenue, if any, for each program	service reported.		
4a (Code:) (Expenses \$	454,043. including grants of \$) (Revenue \$	_)
GRANTS WERE GIVEN FOR R	ESEARCH FOR A CURE FOR BATTE	EN DISEASE	
4b (Code:) (Expenses \$	270,475. including grants of \$) (Revenue \$)
		RS AND THE GENERAL BEREAVEMENT	_′
		SHIP ON FAMILIES WHOSE LOVED ONES	
ARE VICTIMS OF BATTEN D	ISEASE		
	4.4		
	Y		
	440.000		_
	140,232. including grants of \$) (Revenue \$	_)
	NS HELD FOR RESEARCH, DISCUS	SSIONS AND SUPPORT FOR A CURE FOR	
BATTEN DISEASE			
		_	_
		===	
			
4 d Other program services (Describe in S	Schedule O.)		
4d Other program services (Describe in S (Expenses \$	Schedule O.) including grants of \$) (Revenue \$	

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	Х	
2	Is the organization required to complete Schedule B, Schedule of Contributors (see instructions)?	2	X	
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		Х
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? <i>If 'Yes,' complete Schedule C, Part II</i>	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		Х
7	Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? <i>If 'Yes,' complete Schedule D, Part II</i>	7		Х
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? If 'Yes,' complete Schedule D, Part III.	8		Х
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		Х
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		Х
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	11 a	Х	
	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? <i>If 'Yes,' complete Schedule D, Part VII</i>	11 b		Х
	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 VII).	11 c		Х
	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.	11 d		Х
	e Did the organization report an amount for other liabilities in Part X, line 25? If 'Yes,' complete Schedule D, Part X	11 e	X	
	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	11 f		Х
12	a Did the organization obtain separate, independent audited financial statements for the tax year? If 'Yes,' complete Schedule D, Parts XI and XII	12a	Х	
	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		Х
	Is the organization a school described in section 170(b)(1)(A)(ii)? If 'Yes,' complete Schedule E	13		Х
14	a Did the organization maintain an office, employees, or agents outside of the United States?	14a		Х
	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? <i>If 'Yes,' complete Schedule F, Parts I and IV</i>	14b		Х
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		Х
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		Х
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		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		Х
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		Х

Form 990 (2016) BATTEN DISEASE SUPPORT & RESEARCH ASSOC Part IV Checklist of Required Schedules (continued)

			Yes	No
20a	Did the organization operate one or more hospital facilities? If 'Yes,' complete Schedule H	20a		X
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		Х
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		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? <i>If 'Yes,' complete Schedule J.</i>	23		Х
24 a	a 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		Х
t	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		
	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		
C	1 Did the organization act as an 'on behalf of' issuer for bonds outstanding at any time during the year?	24d		
25 a	a 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		X
k	s 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		Х
26	Did the organization report any amount on Part X, line 5, 6, or 22 for receivables from or payables to any current or former officers, directors, trustees, key employees, highest compensated employees, or disqualified persons? If 'Yes,' complete Schedule L, Part II.	26		Х
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 of any of these persons? If 'Yes,' complete Schedule L, Part III.	27		Х
28	Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions):			
	A current or former officer, director, trustee, or key employee? If Yes, complete Schedule L, Part IV	28a		Х
t	A family member of a current or former officer, director, trustee, or key employee? If 'Yes,' complete Schedule L, Part IV	28b		Х
c	An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer, director, trustee, or direct or indirect owner? If 'Yes,' complete Schedule L, Part IV	28c		Х
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? <i>If 'Yes,' complete Schedule M</i>	30		Х
31	Did the organization liquidate, terminate, or dissolve and cease operations? If 'Yes,' complete Schedule N, Part I	31		X
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		Х
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		Х
	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		Х
	a Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a		Χ
t	olf '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		Х
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		Х
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	Х	

Part V | Statements Regarding Other IRS Filings and Tax Compliance

	Check if Schedule O contains a response or note to any line in this Part V								
				Yes	No				
1 a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable	1 a	1						
b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable	1 b	5						
С	Did the organization comply with backup withholding rules for reportable payments to vendors and r	eportable gaming			17				
	(gambling) winnings to prize winners?	 I	1 c		Х				
2 a	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	1						
b	If at least one is reported on line 2a, did the organization file all required federal employmen		2 b	Х					
-	Note. If the sum of lines 1a and 2a is greater than 250, you may be required to <i>e-file</i> (see in:		~						
3a Did the organization have unrelated business gross income of \$1,000 or more during the year?									
	If 'Yes,' has it filed a Form 990-T for this year? If 'No' to line 3b, provide an explanation in Schedule O		3 b						
4 a 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)?									
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).									
5 a	Was the organization a party to a prohibited tax shelter transaction at any time during the ta	·	5 a		Х				
	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelt	•	5 b		Х				
С	If 'Yes,' to line 5a or 5b, did the organization file Form 8886-T?		5 c						
-									
6 a 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?									
b If 'Yes,' did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?									
7 Organizations that may receive deductible contributions under section 170(c).									
а	Did the organization receive a payment in excess of \$75 made partly as a contribution and p services provided to the payor?	partly for goods and	7 a		Х				
b If 'Yes,' did the organization notify the donor of the value of the goods or services provided?									
c Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file									
	Form 8282?	- J	7 c		Х				
	If 'Yes,' indicate the number of Forms 8282 filed during the year	7 d	7 e		Х				
e Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?									
	If the organization received a contribution of qualified intellectual property, did the organization file I		7 f		Х				
_	as required?		7 g						
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the Form 1098-C?	organization file a	7 h						
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						
	Sponsoring organizations maintaining donor advised funds.								
	Did the sponsoring organization make any taxable distributions under section 4966?		9 a						
	Did the sponsoring organization make a distribution to a donor, donor advisor, or related per	son?	9 b						
	Section 501(c)(7) organizations. Enter:	10 -							
	Initiation fees and capital contributions included on Part VIII, line 12	10 a 10 b							
	Section 501(c)(12) organizations. Enter:	100							
	Gross income from members or shareholders.	11 a							
	Gross income from other sources (Do not net amounts due or paid to other sources	114							
	against amounts due or received from them.).	11 b							
	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu o	i i	12a						
	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?									
d	Note. See the instructions for additional information the organization must report on Schedul		13a						
h	· ·								
	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							
	Enter the amount of reserves on hand	13 c							
	Did the organization receive any payments for indoor tanning services during the tax year?		14a		X				
b AA	If 'Yes,' has it filed a Form 720 to report these payments? If 'No,' provide an explanation in	Schedule O	14b	000	(2016)				

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 or note to any line in this Part VI. Section A. Governing Body and Management No Yes 1 a Enter the number of voting members of the governing body at the end of the tax year. 12 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 ... 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 Χ 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 Χ Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?.... Χ 4 X Did the organization become aware during the year of a significant diversion of the organization's assets?.... 5 Did the organization have members or stockholders?..... Χ 6 7 a 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?..... 7 a Χ **b** Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?..... Χ 7 b Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following: a The governing body?..... Χ 8 a X **b** Each committee with authority to act on behalf of the governing body?..... 8 b 9 Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If 'Yes,' provide the names and addresses in Schedule O. 9 Section B. Policies (This Section B requests information about policies not required by the Internal Revenue Code. Yes No 10 a Did the organization have local chapters, branches, or affiliates? 10 a Χ 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 Χ 11 a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?...... X b Describe in Schedule O the process, if any, used by the organization to review this Form 990. SEE SCHEDULE O 12a Did the organization have a written conflict of interest policy? If 'No,' go to line 13...... Χ 12a b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise 12b Χ to conflicts?..... Χ 12c 13 Did the organization have a written whistleblower policy?..... 13 Χ Χ **14** Did the organization have a written document retention and destruction policy?..... 14 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? Χ a The organization's CEO, Executive Director, or top management official...... 15 a **b** Other officers or key employees of the organization..... 15 b X If 'Yes' to line 15a or 15b, describe the process in Schedule O (see instructions). 16a Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year?..... Χ 16 a 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?. 16 b Section C. Disclosure List the states with which a copy of this Form 990 is required to be filed NONE Section 6104 requires an organization to make its Forms 1023 (or 1024 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 X Upon request Other (explain in Schedule O) Describe in Schedule 0 whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to 19 the public during the tax year. SEE SCHEDULE O State the name, address, and telephone number of the person who possesses the organization's books and records:

COLUMBUS OH 43215 800-448-4570

MARGIE FRAZIER 1175 DUBLIN ROAD

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

Check 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

- 1 a 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

employees; and former such persons.										
Check this box if neither the organization nor any relat	ed organiz	ation	com	npen	sate	d any	y cu	ırrent officer, direct	or, or trustee.	
				(C)						
(A) Name and Title	(B) Average hours per	Pos thar is	dire	(do not check more box, unless person n an officer and a rector/trustee)				(D) Reportable compensation from	(E) Reportable compensation from	(F) Estimated amount of other compensation
	wook	Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former	the organization (W-2/1099-MISC)	relatéd organizations (W-2/1099-MISC)	from the organization and related organizations
	$-\frac{0}{0}$	Х						10	0.	0.
(2) KATE HALLER	0	Λ					. 1		<u> </u>	<u> </u>
DIRECTOR	0	Х						0.	0.	0.
	0 0	X						0.	0.	0
(4) DONNA FOGLE	0	Λ						0.	0.	0.
DIRECTOR		Х						0.	0.	0.
(5) BOB JENSEN	0									
DIRECTOR	0	Х						0.	0.	0.
(6) DAVE PEARCE	0									
DIRECTOR	0	Χ						0.	0.	0.
(7) MIKE COLLINS	0									
SECRETARY	0	X						0.	0.	0.
(8) DARLENE ROYALTY	0									
DIRECTOR	0	X						0.	0.	0.
(9) BARBARA WUEBBELS	0									
DIRECTOR	0	Х						0.	0.	0.
(10) TRACY VANHOUTAN	0									_
VICE PRESIDENT	0	X						0.	0.	0.
(11) ROB GEER	0									•
PRESIDENT	0	Х						0.	0.	0.
(12) TONY FERRANDINO	0	37							0	0
DIRECTOR	0	Х						0.	0.	0.
(13) MARJORIE FRAZIER EXECUTIVE DIR.	$-\frac{40}{0}$			Х				98,289.	0.	0.
(14)	U U			Λ				30,209.	0.	0.
		1								

BAA TEEA0107L 11/16/16 Form **990** (2016)

Part VII Section A. Officers, Directors, I		ney	⊏II	•		es, a	anc	a riignest Corr	ipensated Emp	loyees	(cont	inuea)
	(B)			(C	•			(D)	(E)		(F)	
(A) Name and title	Average hours	box	, unle	ess pe	erson	than o	n an	(D) Reportable	(E) Reportable	E	(F) stimated	d
Name and the	per week (list any					or/trust		compensation from the organization (W-2/1099-MISC)	compensation from related organizations (W-2/1099-MISC)	amo	unt of o pensati	ther ion
	hours	Individual trustee or director	Institutional trustee	Officer	Key employee	lighe: mplo	Former	(W-2/1099-MISC)	(W-2/1099-MISC)	org	rom the	on
	related organiza	ector	lion	댗	mplc	st co yee	ď				d relate anizatio	
	- tions below	trust	T T)yee	mper						
	dotted line)	ee	stee			Highest compensated employee						
(15)						- 0						
_(15)		-										
(16)												
(17)												
(18)												
(19)												
(00)												
(20)		•										
(21)												
(22)		-										
(23)								- 11				
10.00									•			
(24)					1	1	N	11.				
(25)	1	1)	-							
1 b Sub-total.							>	98,289.	0.			0.
c Total from continuation sheets to Part VII, Set d Total (add lines 1b and 1c)							-	98,289.	0.			0.
Total number of individuals (including but not limit							/ed			ensatio	n	0.
from the organization • 0				,				,				
											Yes	No
3 Did the organization list any former officer, dir on line 1a? <i>If 'Yes,' complete Schedule J for s</i>	ector, or tru	istee, <i>ial</i>	, key	err err	ploy	/ee, (or h	ighest compensati	ted employee	. 3		Х
4 For any individual listed on line 1a, is the sum												21
the organization and related organizations greated individual	ater than \$1	50,00	00?	If '	∕es,'	com	plei	te Schedule J for		. 4		Х
5 Did any person listed on line 1a receive or acc for services rendered to the organization? If 'Y	rue comper 'es.' comple	nsatio	n fro	om Iule	any <i>J fo</i>	unre r suc	late h p	ed organization or erson	individual	. 5		Х
Section B. Independent Contractors	•											
Complete this table for your five highest components compensation from the organization. Report comp	ensated ind ensation for	epen the c	dent alen	t coi dar	ntrad year	ctors endir	tha ng w	t received more th vith or within the or	nan \$100,000 of ganization's tax year			
(A) Name and business a								(B)		(C)	
Name and business ad	aaress							Description of	of services	Compè	ensatio	on
	1 1 12											
2 Total number of independent contractors (including \$100,000 of compensation from the organization)	-	ited to	o tho	se I	ıstec	abov	ve) v	wno received more	tnan			
Troo, ooo or compensation from the organization	U III											

Part VIII Statement of Revenue Check if Schedule O contains a response or note to any line in this Part VIII..... (A) Total revenue (B) (D) Related or Unrelated Revenue business excluded from tax exempt under sections 512-514 function revenue revenue Contributions, Gifts, Grants and Other Similar Amounts 1 a Federated campaigns 1 a **b** Membership dues..... 1 b 4,755 c Fundraising events..... 1 c **d** Related organizations..... 1 d e Government grants (contributions) 1 e **f** All other contributions, gifts, grants, and similar amounts not included above . . . 799,114 g Noncash contributions included in lines 1a-1f: \$ h Total. Add lines 1a-1f..... 803,869 **Business Code** Program Service Revenue b **f** All other program service revenue. . . g Total. Add lines 2a-2f Investment income (including dividends, interest and 9,107. 9,107 Income from investment of tax-exempt bond proceeds.. ▶ Royalties.... TMAII (i) Real (ii) Personal 6a Gross rents..... **b** Less: rental expenses c Rental income or (loss) . . . d Net rental income or (loss) (i) Securities 7 a Gross amount from sales of assets other than inventory **b** Less: cost or other basis and sales expenses c Gain or (loss)..... **d** Net gain or (loss)..... 8 a Gross income from fundraising events Other Revenue (not including.. \$ of contributions reported on line 1c). See Part IV, line 18..... **b** Less: direct expenses **b** c Net income or (loss) from fundraising events 9 a Gross income from gaming activities. See Part IV, line 19..... a **b** Less: direct expenses b c Net income or (loss) from gaming activities..... 10a Gross sales of inventory, less returns and allowances a **b** Less: cost of goods sold..... **b** c Net income or (loss) from sales of inventory..... Miscellaneous Revenue **Business Code** c **d** All other revenue e Total. Add lines 11a-11d **Total revenue.** See instructions.....

812

,976

0

0

9,107

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 r	<u>'</u>			
Do i 6b,	not include amounts reported on lines 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		·	<u> </u>	
2	Grants and other assistance to domestic individuals. See Part IV, line 22				
3	Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16				
4	Benefits paid to or for members				
5	Compensation of current officers, directors, trustees, and key employees	98,289.	68,802.	29,487.	0.
6	Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)	0.	0.	0.	0.
7	Other salaries and wages	152,613.	79,218.	18,180.	55,215.
8	Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	132,013.	79,210.	10,100.	33,213.
9	Other employee benefits				
10	Payroll taxes	22,215.	12,160.	4,623.	5,432.
11	Fees for services (non-employees):		·		
a	Management				
ŀ) Legal				
(Accounting	7,600.	5,016.	2,584.	
C	1 Lobbying				
6	Professional fundraising services. See Part IV, line 17				
f	Investment management fees				
_	Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule 0.) Advertising and promotion	9,242.	6,100.	3,142.	
13	Office expenses	1,798.	1,187.	611.	
14	Information technology	1,050.	1,107.	011.	
15	Royalties	, –			
16	Occupancy	32,399.	21,383.	11,016.	
17	Travel	40,503.	26,732.	13,771.	
18	Payments of travel or entertainment expenses for any federal, state, or local public officials	10,000.	20,702.	10,7711	
	Conferences, conventions, and meetings	140,232.	136,595.	3,637.	
20	Interest				
21	Payments to affiliates			1 221	
22	Depreciation, depletion, and amortization	4,091.	44 004	4,091.	
23 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.).	19,729.	11,031.	4,376.	4,322.
a	RESEARCH AWARDS	454,043.	454,043.		
_	P PROGRAM EXPENSES	17,373.	17,373.		
	FEES/DUES	15,978.	10,545.	5,433.	
	FUNDRAISING EXPENSE	10,086.	10,040.	5, 155.	10,086.
	All other expenses	28,125.	14,565.	13,560.	10,000.
25	Total functional expenses. Add lines 1 through 24e	1,054,316.	864,750.	114,511.	75,055.
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 ► ☐ if following SOP 98-2 (ASC 958-720)	. ,	,	, .	,

		Check if Schedule O contains a response or note to	any	line in this Part X	· · · · · · · · · · · · · · · · · · ·	<u>.</u>	
					(A) Beginning of year		(B) End of year
	1	Cash — non-interest-bearing			230,287.	1	331,678.
	2	Savings and temporary cash investments			,	2	,
	3	Pledges and grants receivable, net				3	
	4	Accounts receivable, net				4	
	5	Loans and other receivables from current and former trustees, key employees, and highest compensated el Part II of Schedule L	office mploy	rs, directors, ees. Complete		5	
	6	Loans and other receivables from other disqualified posection 4958(f)(1)), persons described in section 4958(c)(c) employers and sponsoring organizations of section 501(c) beneficiary organizations (see instructions). Complete	erson	s (as defined under		6	
ts	7	Notes and loans receivable, net				7	
Assets	8	Inventories for sale or use				8	
As	9	Prepaid expenses and deferred charges			8,482.	9	
	10 a	Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a	20,435.			
	b	Less: accumulated depreciation		- /	5,716.	10 c	4,083.
	11	Investments – publicly traded securities		.,	410,441.	11	326,039.
	12	Investments – other securities. See Part IV, line 11				12	5_5/555
	13	Investments – program-related. See Part IV, line 11.				13	
	14	Intangible assets				14	
	15	Other assets. See Part IV, line 11		<u> </u>	2,709.	15	2,708.
	16	Total assets. Add lines 1 through 15 (must equal line	34)		657,635.	16	664,508.
	17	Accounts payable and accrued expenses				17	
	18	Grants payable				18	
	19	Deferred revenue				19	
	20	Tax-exempt bond liabilities				20	
es	21	Escrow of custodial account hability. Complete Part 1	A OI S	chedule D		21	
Liabilities	22	Loans and other payables to current and former office key employees, highest compensated employees, and Complete Part II of Schedule L	ers, di d disq	rectors, trustees, palified persons.		22	
ij	23	Secured mortgages and notes payable to unrelated th				23	
	24	Unsecured notes and loans payable to unrelated third		<u></u>		24	
	25	Other liabilities (including federal income tax, payable and other liabilities not included on lines 17-24). Com	•	<u>L</u>			
	26	and other liabilities not included on lines 17-24). Com Total liabilities. Add lines 17 through 25			90,954. 90,954.	25 26	324,716. 324,716.
		Organizations that follow SFAS 117 (ASC 958), check he			70,754.		324,710.
es		lines 27 through 29, and lines 33 and 34.	16	A and complete			
anc	27	Unrestricted net assets			324,819.	27	263,484.
Sala	28	Temporarily restricted net assets			107,513.	28	-58,041.
d E	29	Permanently restricted net assets			134,349.	29	134,349.
Net Assets or Fund Balances		Organizations that do not follow SFAS 117 (ASC 958), chand complete lines 30 through 34.	eck h	ere ►	·		·
0	30	Capital stock or trust principal, or current funds				30	
že į	31	Paid-in or capital surplus, or land, building, or equipm				31	
488	32	Retained earnings, endowment, accumulated income,				32	
et/	33	Total net assets or fund balances			566,681.	33	339,792.
Ž	34	Total liabilities and net assets/fund balances			657,635	34	664,508

Form **990** (2016) BAA

BAA

Form **990** (2016)

Par	t XI	Reconciliation of Net Assets				
		Check if Schedule O contains a response or note to any line in this Part XI				. X
1	Total	revenue (must equal Part VIII, column (A), line 12)	1	8	12,9	76.
2	Total	expenses (must equal Part IX, column (A), line 25)	2		54,3	
3	Rever	nue less expenses. Subtract line 2 from line 1	3		41,3	
4	Net as	ssets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4		66,6	
5	Net u	nrealized gains (losses) on investments	5		17,1	
6	Donat	ted services and use of facilities	6			
7	Invest	tment expenses	7			
8	Prior	period adjustments	8			
9	Other	changes in net assets or fund balances (explain in Schedule O). SEE SCHEDULE O	9		-2,7	28.
10	Net as	ssets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 33,				
		ın (B))	10	3	39,7	92.
Par	t XII	Financial Statements and Reporting				
		Check if Schedule O contains a response or note to any line in this Part XII				
					Yes	No
1	Accou	unting method used to prepare the Form 990: Cash X Accrual Other				
	If the	organization changed its method of accounting from a prior year or checked 'Other,' explain				
	in Sch	hedule 0.				
2 a	Were	the organization's financial statements compiled or reviewed by an independent accountant?		2a		Χ
	If 'Yes	s,' check a box below to indicate whether the financial statements for the year were compiled or reviewe	d on a			
		ate basis, consolidat <u>ed</u> basis, or both:	u 011 u			
		Separate basis Consolidated basis Both consolidated and separate basis				
ŀ	Were	the organization's financial statements audited by an independent accountant?		2 b	Χ	
	If 'Yes	s,' check a box below to indicate whether the financial statements for the year were audited on a separa	te			
		, consolidated basis, or both:				
	لتت	Separate basis Consolidated basis Both consolidated and separate basis				
(If 'Yes	s' to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, v, or compilation of its financial statements and selection of an independent accountant?		2 c		Х
				20		Λ
	in Sch	organization changed either its oversight process or selection process during the tax year, explain hedule O.				
3 a	Asar	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?		3 a		X
ŀ		s,' did the organization undergo the required audit or audits? If the organization did not undergo the required audi				
	or aud	dits, explain why in Schedule O and describe any steps taken to undergo such audits		3 b		

TEEA0112L 11/16/16

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.

► Information about Schedule A (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.

OMB No. 1545-0047

2016

Open to Public Inspection

Name of the organization Employer identification number BATTEN DISEASE SUPPORT & RESEARCH ASSOC 91-1397792 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.) A church, convention of churches, or association of churches described in section 170(b)(1)(A)(i). 1 2 A school described in section 170(b)(1)(A)(ii). (Attach Schedule E (Form 990 or 990-EZ).) 3 A hospital or a cooperative hospital service organization described in section 170(b)(1)(A)(iii). 4 A medical research organization operated in conjunction with a hospital described in section 170(b)(1)(A)(iii). Enter the hospital's name, city, and state: 5 An organization operated for the benefit of a college or university owned or operated by a governmental unit described in section 170(b)(1)(A)(iv). (Complete Part II.) 6 A federal, state, or local government or governmental unit described in section 170(b)(1)(A)(v). 7 An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in section 170(b)(1)(A)(vi). (Complete Part II.) 8 A community trust described in section 170(b)(1)(A)(vi). (Complete Part II.) 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 An organization that normally receives: (1) more than 33-1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions—subject to certain exceptions, and (2) no more than 33-1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after 10 June 30, 1975. See section 509(a)(2). (Complete Part III.) An organization organized and operated exclusively to test for public safety. See section 509(a)(4). 11 An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2). See section 509(a)(3). Check the box in lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g.

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. 12 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. 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. С **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.** 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. Enter the number of supported organizations **q** Provide the following information about the supported organization(s). (i) Name of supported organization (iii) Type of organization (described on lines 1-10 above (see instructions)) (v) Amount of monetary (iv) Is the organization listed (vi) Amount of other support (see instructions) support (see instructions) in your governing document? 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.)

Sec	tion A. Public Support						
Cale begi	ndar year (or fiscal year nning in) ►	(a) 2012	(b) 2013	(c) 2014	(d) 2015	(e) 2016	(f) Total
1	Gifts, grants, contributions, and membership fees received. (Do not include any 'unusual grants.')						
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						
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						
Sec	tion B. Total Support						
Cale begi	ndar year (or fiscal year nning in) ►	(a) 2012	(b) 2013	(c) 2014	(d) 2015	(e) 2016	(f) Total
7	Amounts from line 4						
8	Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources			- M	AIL		
9	Net income from unrelated business activities, whether or not the business is regularly carried on		JNG), ,			
10	Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)	N.					
11	Total support. Add lines 7 through 10						
12	Gross receipts from related activ	rities, etc. (see ins	structions)				2
13	First five years. If the Form 990 is organization, check this box and	for the organization stop here	n's first, second, th	ird, fourth, or fifth t	ax year as a sectio	n 501(c)(3)	>
Sec	tion C. Computation of Pul	blic Support P	ercentage				
	Public support percentage for 20						4 %
	Public support percentage from 2						
16a	33-1/3% support test—2016. If the and stop here. The organization						
b	33-1/3% support test—2015. If the and stop here. The organization	e organization did qualifies as a pu	d not check a box blicly supported o	on line 13 or 16a organization	, and line 15 is 33	3-1/3% or more	e, check this box
17a	10%-facts-and-circumstances te or more, and if the organization the organization meets the 'facts'	meets the 'facts-a	and-circumstance	s' test, check this	box and stop her	e. Explain in F	Part VI how
b	10%-facts-and-circumstances te or more, and if the organization organization meets the 'facts-and	meets the 'facts-a	and-circumstance	s' test, check this	box and stop her	e. Explain in F	Part VI how the
18	Private foundation. If the organiz	zation did not che	eck a box on line	13, 16a, 16b, 17a	or 17b, check thi	s box and see	instructions ►

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

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

Sec	tion A. Public Support			·			
	lar year (or fiscal year beginning in)	(a) 2012	(b) 2013	(c) 2014	(d) 2015	(e) 2016	(f) Total
I	Gifts, grants, contributions, and membership fees received. (Do not include any 'unusual grants.')	528,777.	621,576.	676,263.	977,295.	835,676.	3,639,587.
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.	320,777.	021,370.	070,200.	311,233.	033,070.	0.
3	Gross receipts from activities that are not an unrelated trade or business under section 513.						0.
	Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						0.
	The value of services or facilities furnished by a governmental unit to the organization without charge						0.
	Total. Add lines 1 through 5	528,777.	621,576.	676,263.	977,295.	835,676.	3,639,587.
/a	Amounts included on lines 1, 2, and 3 received from disqualified persons	0.	0.	0.	0.	0.	0.
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.	0	0	0.	0.	0	0
_	Add lines 7a and 7b	0.	0.	0.	0.	0.	0.
	Public support. (Subtract line	0.	0.	0.	0.	0.	0.
	7c from line 6.)tion B. Total Support			- N			3,639,587.
	dar year (or fiscal year beginning in)	(a) 2012	(b) 2013	(c) 2014	(d) 2015	(e) 2016	(f) Total
	Amounts from line 6	528,777	621,576.	676,263.	977,295.	835,676.	3,639,587.
	Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from	D	J , ,	,	·	,	
b	similar sources. Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975.	3,880.	9,182.	13,210.	16,908.	9,107.	52,287.
	Add lines 10a and 10b	3,880.	9,182.	13,210.	16,908.	9,107.	52,287.
11	Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						0.
12	Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.).						0.
	Total support. (Add lines 9, 10c, 11, and 12.)	532,657.	630,758.	689,473.	994,203.	844,783.	3,691,874.
	First five years. If the Form 990 organization, check this box and	stop here		d, third, fourth, o	r fifth tax year as	a section 501(c)(3) ▶
	tion C. Computation of Pul	• • • • • • • • • • • • • • • • • • • •					
	Public support percentage for 20	•	• •				98.58 %
	Public support percentage from 2					16	98.51 %
	tion D. Computation of Inv				(6)	1 1	0
	Investment income percentage for	•		-			1.42 %
	Investment income percentage fr						1.49 %
	33-1/3% support tests—2016. If t is not more than 33-1/3%, check 33-1/3% support tests— 2015. If t	this box and stop	here. The organ	ization qualifies a	s a publicly suppo	orted organization	ı ► <u>X</u>
D	33-1/3% support tests—2015. If t line 18 is not more than 33-1/3%						
20	Private foundation. If the organiz	zation did not che	ck a box on line 1		heck this box and	see instructions.	

Part IV Supporting Organizations

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

Section A. All Supporting Organizations

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

Par	t IV	Supporting Organizations (continued)			
11	∐ac t	the organization accepted a gift or contribution from any of the following persons?		Yes	No
		rson who directly or indirectly controls, either alone or together with persons described in (b) and (c) below, the			
		rning body of a supported organization?	11a		
b	A fan	nily member of a person described in (a) above?	11b		
		% controlled entity of a person described in (a) or (b) above? If 'Yes' to a, b, or c, provide detail in Part VI.	11c		
Sec	tion I	B. Type I Supporting Organizations			
1	Did th	ne directors, trustees, or membership of one or more supported organizations have the power to regularly appoint		Yes	No
•	or ele	ext at least a majority of the organization's directors or trustees at all times during the tax year? If 'l\0,' describe in VI how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. The organization had more than one supported organization, describe how the powers to appoint and/or remove			
	direct	tors or trustees were allocated among the supported organizations and what conditions or restrictions, if any, ied to such powers during the tax year.	1		
2	Did th	he organization operate for the benefit of any supported organization other than the supported organization(s)			
	bene	operated, supervised, or controlled the supporting organization? If 'Yes,' explain in Part VI how providing such fit carried out the purposes of the supported organization(s) that operated, supervised, or controlled the orting organization.	2		
Sec	tion (C. Type II Supporting Organizations			
				Yes	No
1	of ea	a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees ich of the organization's supported organization(s)? If 'No,' describe in Part VI how control or management of the orting organization was vested in the same persons that controlled or managed the supported organization(s).	1		
Sac		D. All Type III Supporting Organizations	-		
<u> </u>		D. All Type III Supporting Organizations		Yes	No
1	Did the	he organization provide to each of its supported organizations, by the last day of the fifth month of the nization'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 nization's governing documents in effect on the date of notification, to the extent not previously provided?	1		
	orgai	ilization's governing documents in election the date of notification, to the extent not breviously provided:			
2	Were	any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported nization(s) or (ii) serving on the governing body of a supported organization? If 'No.' explain in Part VI how			
	the o	nization(s) or (ii) serving on the governing body of a supported organization? If 'No,' explain in Part VI how organization maintained a close and continuous working relationship with the supported organization(s).	2		
3	voice	eason of the relationship described in (2), did the organization's supported organizations have a significant in the organization's investment policies and in directing the use of the organization's income or assets at			
		mes during the tax year? If 'Yes,' describe in Part VI the role the organization's supported organizations played is regard.	3		
Sec		E. Type III Functionally Integrated Supporting Organizations			
1	Check	k the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).			
a		The organization satisfied the Activities Test. Complete line 2 below.			
b		The organization satisfied the Activities rest. Complete line 2 below. The organization is the parent of each of its supported organizations. Complete line 3 below.			
	H	The organization is the parent of each of its supported organizations. <i>Complete line's below.</i> The organization supported a governmental entity. <i>Describe in Part VI how you supported a government entity (see in Part VI how you supported entity (see in Par</i>	actruo	tions)	
C	' Ш'	The organization supported a governmental entity. Describe in Fait VI now you supported a government entity (see in	istiuc	110115).	•
2	Activi	ities Test. Answer (a) and (b) below.		Yes	No
а	suppo organ	substantially all of the organization's activities during the tax year directly further the exempt purposes of the orted organization(s) to which the organization was responsive? If 'Yes,' then in Part VI identify those supported nizations and explain how these activities directly furthered their exempt purposes, how the organization was			
		onsive to those supported organizations, and how the organization determined that these activities constituted tantially all of its activities.	2a		
b		he activities described in (a) constitute activities that, but for the organization's involvement, one or more of organization's supported organization(s) would have been engaged in? If 'Yes,' explain in Part VI the reasons for			
	the o	organization's position that its supported organization(s) would have engaged in these activities but for the Dization's involvement.	2b		
,		nt of Supported Organizations. <i>Answer (a) and (b) below.</i>			
		the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of			
a	each	of the supported organizations? Provide details in Part VI.	За		
b		ne organization exercise a substantial degree of direction over the policies, programs, and activities of each of its orted organizations? If 'Yes,' describe in Part VI the role played by the organization in this regard.	3b		

Pa	Type III Non-Functionally Integrated 509(a)(3) Supporting Organic			JJ11JZ Tuge
1	Check here if the organization satisfied the Integral Part Test as a qualifying trus instructions. All other Type III non-functionally integrated supporting organization	t on N	lov. 20, 1970 (explain in	n Part VI). See through E.
Sec	tion 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		
Sec	tion 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):			
- 7	Average monthly value of securities	1a		
ŀ	Average monthly cash balances	1b		
(Fair market value of other non-exempt-use assets	1c		
(Total (add lines 1a, 1b, and 1c)	1d		
•	Discount claimed for blockage or other factors (explain in detail in Part VI):			
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 1-1/2% 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 .035.	6		
7	Recoveries of prior-year distributions	7		
8	Minimum Asset Amount (add line 7 to line 6)	8		
Sec	tion C — Distributable Amount			Current Year
1	Adjusted net income for prior year (from Section A, line 8, Column A)	1		
2	Enter 85% of line 1.	2		
3	Minimum asset amount for prior year (from Section B, line 8, Column A)	3		
4	Enter greater of line 2 or line 3.	4		
5	Income tax imposed in prior year	5		
6	Distributable Amount. Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions).	6		1

Schedule A (Form 990 or 990-EZ) 2016

BAA

Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see instructions).

Pa	Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations (continued)				
Sec	tion D - Distributions Current Year				
1	Amounts paid to supported organizations to accomplish exempt purposes				
2	Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity				
3	Administrative expenses paid to accomplish exempt purposes of supported organizations				
4	Amounts paid to acquire exempt-use assets				
5	Qualified set-aside amounts (prior IRS approval required)				
6	Other distributions (describe in Part VI). See instructions.				
7	Total annual distributions. Add lines 1 through 6.				
8	Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI). See instructions.				
9	Distributable amount for 2016 from Section C, line 6				
10	Line 8 amount divided by Line 9 amount				
	(i) (ii) (iii)				

Section E — Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2016	(iii) Distributable Amount for 2016
1 Distributable amount for 2016 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2016 (reasonable cause required — explain in Part VI). See instructions.			
3 Excess distributions carryover, if any, to 2016:			
a			
b			
c From 2013			
d From 2014			
e From 2015			
f Total of lines 3a through e			
g Applied to underdistributions of prior years			
h Applied to 2016 distributable amount			
i Carryover from 2011 not applied (see instructions)	7 111		
j Remainder. Subtract lines 3g, 3h, and 3i from 3f.	111		
4 Distributions for 2016 from Section D, line 7:			
a Applied to underdistributions of prior years			
b Applied to 2016 distributable amount			
c Remainder. Subtract lines 4a and 4b from 4.			
5 Remaining underdistributions for years prior to 2016, 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 2016. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in Part VI. See instructions.			
7 Excess distributions carryover to 2017. Add lines 3j and 4c.			
8 Breakdown of line 7:			
a			
b Excess from 2013			
c Excess from 2014			
d Excess from 2015			
e Excess from 2016			

BAA

Schedule A (Form 990 or 990-EZ) 2016

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 B (Form 990, 990-EZ, or 990-PF)

Department of the Treasury Internal Revenue Service Name of the organization

Schedule of Contributors

► Attach to Form 990, Form 990-EZ, or Form 990-PF.
Information about Schedule B (Form 990, 990-EZ, 990-PF) and its instructions is at www.irs.gov/form990.

OMB No. 1545-0047

2016

Employer identification number

BATTEN DISEASE SUPPORT & RESI	EARCH ASSOC	91-1397792
Organization type (check one):		
Filers of:	Section:	
Form 990 or 990-EZ	X 501(c)(3) (enter number) organization
	4947(a)(1) no	onexempt charitable trust not treated as a private foundation
	527 political of	organization
		• •
Form 990-PF	501(c)(3) exe	empt private foundation
	4947(a)(1) no	onexempt charitable trust treated as a private foundation
	501(c)(3) tax	able private foundation
Check if your organization is covered by the Gener	al Rule or a Special F	Rule.
Note. Only a section 501(c)(7), (8), or (10) or	ganization can chec	ck boxes for both the General Rule and a Special Rule. See instructions.
General Rule		
For an organization filing Form 990, 990-E property) from any one contributor. Compl	Z, or 990-PF that rete Parts I and II. S	received, during the year, contributions totaling \$5,000 or more (in money or See instructions for determining a contributor's total contributions.
Special Rules		
For an organization described in section 5	01(c)(3) filing Form	n 990 or 990-EZ that met the 33-1/3% support test of the regulations
under sections 509(a)(1) and 1/0(b)(1)(A)(vi) received from any one contributor, during	, that checked Sched the year, total cont	dule A (Form 990 or 990-EZ), Part II, line 13, 16a, or 16b, and that tributions of the greater of (1) \$5,000 or (2) 2% of the amount on (i) plete Parts I and II.
Form 990, Part VIII, line 1h, or (ii) Form 9	90-EZ, line 1. Com	plete Parts I and II.
Ear an organization described in section 5	01(a)(7) (8) or (1(D) filing Form 990 or 990-EZ that received from any one contributor,
during the year, total contributions of more	e than \$1.000 <i>exclu</i>	usively for religious, charitable, scientific, literary, or educational
purposes, or for the prevention of cruelty t	o children or anima:	als. Complete Parts I, II, and III.
		filing Form 990 or 990-EZ that received from any one contributor, able, etc., purposes, but no such contributions totaled more than
		ons that were received during the year for an <i>exclusively</i> religious,
		ess the General Rule applies to this organization because
it received <i>nonexclusively</i> religious, charita	able, etc., contributi	ions totaling \$5,000 or more during the year ▶ \$
Caution An organization that isn't covered by	the General Rule :	and/or the Special Rules doesn't file Schedule B (Form 990, 990-EZ, or
990-PF), but it must answer 'No' on Part IV. I	ine 2. of its Form 99	90; or check the box on line H of its Form 990-EZ or on its Form 990-PF, as of Schedule B (Form 990, 990-EZ, or 990-PF).
i are i, into 2, to continy that it doesn't inteet the	, ming requirement	3 of Goldand D (1 offi 330, 330-LZ, of 330-F1).

BAA For Paperwork Reduction Act Notice, see the Instructions for Form 990, 990-EZ, or 990-PF.

Schedule B (Form 990, 990-EZ, or 990-PF) (2016)

Page

1 of

2 of Part I

Name of organization

Employer identification number

BATTEN DISEASE SUPPORT & RESEARCH ASSOC 91-1397792

Part I Contributors (see instructions). Use duplicate copies of Part I if additional space is needed.

(a) Number	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
1	EASTER FOUNDATION PO BOX 5501	\$20,000.	Person X Payroll Noncash
	DE PERE, WI 54115		(Complete Part II for noncash contributions.)
(a) Number	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
2	PHILIP C & KATHERINE W SPROGER 5002 CAMP MEETING ROAD	\$ <u>5,050.</u>	Person X Payroll Noncash
	CENTER VALLEY, PA 18034		(Complete Part II for noncash contributions.)
(a) Number	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
3	OUR PROMISE TO NICHOLAS FOUNDATION PO BOX 10106 BEDFORD, NH 03110	\$	Person X Payroll Noncash (Complete Part II for noncash contributions.)
(a) Number	Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
4	DREW'S HOPE RESEARCH FOUNDATION 36 ATKINSON LANE NEWTOWN, PA 18940	\$20,000.	Person X Payroll Noncash (Complete Part II for noncash contributions.)
(a) Number	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
5 1	GREGG & PAULA FROIO 25 ABERDEEN DRIVE SICKLERVILLE, NJ 08081	\$9,000.	Person X Payroll Noncash (Complete Part II for noncash contributions.)
(a) Number	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
6	MAKEUP GEEK LLC PO BOX 6413 JACKSON, MI 49204	\$35,500.	Person X Payroll Noncash (Complete Part II for noncash contributions.)

Page

2 of

2 of Part I

BATTEN DISEASE SUPPORT & RESEARCH ASSOC

Employer identification number

91-1397792

Part I	Contributors	(see instructions).	Use duplicate of	copies of Part I	if additional space is needed.
--------	--------------	---------------------	------------------	------------------	--------------------------------

(a) Number	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
7	BIOMARIN PHARACEUTICAL INC 105 DIGITAL DRIVE	\$45,000.	Person X Payroll Noncash
	NOVATO, CA 94949		(Complete Part II for noncash contributions.)
(a) Number	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
	NOAH'S HOPE - HOPE 4 BRIDGET FOUND 4930 NORTHCOTT AVENUE DOWNERS GROVE, IL 60515	\$108,500.	Person X Payroll Noncash (Complete Part II for noncash contributions.)
(a) Number	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
9	ARTHUR BLUM 9 FAIRVIEW DRIVE CORTE MADERA, CA 94925	\$ <u>10,000.</u>	Person X Payroll Noncash (Complete Part II for noncash contributions.)
(a) Number	Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
10_	COMM FOUND OF MIDDLE TN 3833 CLEGHORN AVE STE 400 NASHVILLE, TN 37215	\$30,000.	Person X Payroll Noncash (Complete Part II for noncash contributions.)
(a) Number	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
<u>11</u> _	RACEPENGUIN TIMING 163 ROSWELL PLACE POWELL, OH 43065	\$5,801.	Person X Payroll Noncash (Complete Part II for noncash contributions.)
(a) Number	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		\$	Person Payroll Complete Part II for noncash contributions.)

Schedule B (Form 990, 990-EZ, or 990-PF) (2016)

Name of organization

Page

1 to

of Part II

BATTEN DISEASE SUPPORT & RESEARCH ASSOC

91-1397792

Employer identification number

Noncash Property (see instructions). Use duplicate copies of Part II if additional space is needed. (b)
Description of noncash property given (a) No. from Part I (c) FMV (or estimate) (see instructions) (d) Date received N/A (a) No. from (c) FMV (or estimate) (see instructions) (b) (d) Description of noncash property given Date received Part I (a) No. from (b) Description of noncash property given (d) Date received (c) FMV (or estimate) (see instructions) Part I (b)
Description of noncash property given (a) No. from Part I (c) FMV (or estimate) (d) Date received (see instructions) (a) No. from (d) Date received (b) Description of noncash property given (c) FMV (or estimate) Part I (see instructions) (b) Description of noncash property given (c) FMV (or estimate) (d) (a) No. Date received from (see instructions) Part I

BAA

Schedule B (Form 990, 990-EZ, or 990-PF) (2016)

of Part III

Name of organization

Employer identification number

BATTEN DISEASE SUPPORT & RESEARCH ASSOC 91-1397792 Exclusively religious, charitable, etc., contributions to organizations described in section 501(c)(7), (8), or (10) that total more than \$1,000 for the year from any one contributor. Complete columns (a) through (e) and the following line entry. For organizations completing Part III, enter the total of exclusively religious, charitable, etc., contributions of \$1,000 or less for the year. (Enter this information once. See instructions.)..... Use duplicate copies of Part III if additional space is needed. (b) Purpose of gift (d) Description of how gift is held (c) Use of gift (a) No. from Part I (e) Transfer of gift Transferee's name, address, and ZIP + 4 Relationship of transferor to transferee (d) Description of how gift is held (b) Purpose of gift (a) No. from (c) Use of gift Part I (e) Transfer of gift Transferee's name, address, and ZIP + 4 Relationship of transferor to transferee (d) Description of how gift is held (a) No. from (b) (c) Use of gift Purpose of gift Part I (e) Transfer of gift Transferee's name, address, and ZIP + 4 Relationship of transferor to transferee (c) Use of gift (b) Purpose of gift (d) Description of how gift is held (a) No. from Part I (e) Transfer of gift

Schedule B (Form 990, 990-EZ, or 990-PF) (2016)

Relationship of transferor to transferee

Transferee's name, address, and ZIP + 4

SCHEDULE D (Form 990)

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.

► Information about Schedule D (Form 990) and its instructions is at www.irs.gov/form990.

OMB No. 1545-0047

Department of the Treasury Internal Revenue Service Name of the organization

m990. Open to Public Inspection
Employer identification number

	BATTEN DISEASE SUPPORT & RESEARCH ASSOC		91-13977	792	
Par	Organizations Maintaining Donor Advised Funds or Other Similar Funds	nds or Acc			
	Organizations Maintaining Donor Advised Funds or Other Similar Fur Complete if the organization answered 'Yes' on Form 990, Part IV, line	6.			
	(a) Donor advised funds	(b) F	unds and oth	er 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 do are the organization's property, subject to the organization's exclusive legal control?	onor advised	funds	′es No	
6	Did the organization inform all grantees, donors, and donor advisors in writing that grant fund	ds can be us	ed only		
_	Did the organization inform all grantees, donors, and donor advisors in writing that grant function charitable purposes and not for the benefit of the donor or donor advisor, or for any other impermissible private benefit?	purpose coi	nferring Y	'es No	
Par					
	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).				
	Preservation of land for public use (e.g., recreation or education)				
	Protection of natural habitat	of a certified	historic struct	ture	
_	Preservation of open space				
2	Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form last day of the tax year.	m of a conser	vation easeme	ent on the	
	last day of the tax year.		Held at the Er	nd of the Tax Yea	ar
á	Total number of conservation easements	2a			
	Total acreage restricted by conservation easements	2 b			
(Number of conservation easements on a certified historic structure included in (a)	2c			
(Number of conservation easements included in (c) acquired after 8/17/06, and not on a history	ric			
	structure listed in the National Register	2 d			
3	Number of conservation easements modified, transferred, released, extinguished, or terminated by the tax year ▶	he organization	on during the		
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, har			/aa □Na	
c	and enforcement of the conservation easements it holds?			'es No	
6	Start and volunteer flours devoted to monitoring, inspecting, flandling of violations, and emorcing co	i isei valioi i ea	isements dunin	y the year	
7	Amount of expenses incurred in monitoring, inspecting, handling of violations, and enforcing conserv ► \$	vation easem	ents during the	e year	
8	Does each conservation easement reported on line 2(d) above satisfy the requirements of se and section 170(h)(4)(B)(ii)?			′es No	
9	In Part XIII, describe how the organization reports conservation easements in its revenue and expeninclude, if applicable, the text of the footnote to the organization's financial statements that describes the control of the control of the control of the organization of the control of the c	se statement lescribes the	, and balance organization	sheet, and 's accounting for	
D	conservation easements. † III Organizations Maintaining Collections of Art, Historical Treasures, or	Othor Sin	nilar Accat	<u> </u>	
Par	Organizations Maintaining Collections of Art, Historical Treasures, or Complete if the organization answered 'Yes' on Form 990, Part IV, line	8.	illiar Asset	5.	
1 a	If the organization elected, as permitted under SFAS 116 (ASC 958), not to report in its reversart, historical treasures, or other similar assets held for public exhibition, education, or research in full Part XIII, the text of the footnote to its financial statements that describes these items.	nue stateme urtherance of	nt and baland public service,	ce sheet works o , provide,	f
I	If the organization elected, as permitted under SFAS 116 (ASC 958), to report in its revenue historical treasures, or other similar assets held for public exhibition, education, or research in further following amounts relating to these items:	erance of pub	lic service, pro	vide the	.,
	(i) Revenue included on Form 990, Part VIII, line 1.		▶\$_		
	(ii) Assets included in Form 990, Part X		▶\$		
	If the organization received or held works of art, historical treasures, or other similar assets for finan amounts required to be reported under SFAS 116 (ASC 958) relating to these items:	-		ring	
	Revenue included on Form 990, Part VIII, line 1		. —		
- 1	Assets included in Form 990, Part X		►\$		

• · · · · · · · · · · · · · · · · · · ·	
3 Using the organization's acquisition, accession, and other records, check any of the following that are a significant use of its collection items (check all that apply):	
a Public exhibition d Loan or exchange programs	
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.	
	No
Part IV Escrow and Custodial Arrangements. Complete if the organization answered 'Yes' on Form 990, Part line 9, or reported an amount on Form 990, Part X, line 21.	IV,
1 a Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X?	No
b If 'Yes,' explain the arrangement in Part XIII and complete the following table:	
Amount	
c Beginning balance	
d Additions during the year. 1d	
e Distributions during the year.	
f Ending balance	
	No
b If 'Yes,' explain the arrangement in Part XIII. Check here if the explanation has been provided on Part XIII.	NO
bili res, explain the arrangement in Part Alli. Check here if the explanation has been provided on Part Alli	
Doubly Fundament Funda Complete if the agreementing appropriate or Fundament (Verlag Forms 000 Doubly) line 10	
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	ack
1 a Beginning of year balance	
b Contributions	
c Net investment earnings, gains, and losses	
d Grants or scholarships	
e Other expenditures for facilities and programs	
f Administrative expenses	
g End of year balance	
2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:	
a Board designated or guasi-endowment ► %	
b Permanent endowment ► %	
c Temporarily restricted endowment ► %	
The percentages on lines 2a, 2b, and 2c should equal 100%.	
3 a 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	110
(ii) related organizations.	
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	ie
1 a Land	
b Buildings	
c Leasehold improvements	
'	083.
e Other	,,,,,
	083.
BAA Schedule D (Form 990) 2	

Schedule **D** (Form 990) 2016

LAMBIELE II DE AMADIZADA ARGUARAN Y DE AN FARM SUN PARTIX	N/A line 11h See Form 990 Part X line 12
Complete if the organization answered 'Yes' on Form 990, Part IV, (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	modified of valuation, cook of one of your market value
(2) Closely-held equity interests.	
(3) Other	
(A)	
(B)	
(C)	
(D)	
(E)	
(F)	
(G)	
(H)	
(l)	
Total. (Column (b) must equal Form 990, Part X, column (B) line 12.)	
Part VIII Investments — Program Related.	N/A
Complete if the organization answered 'Yes' on Form 990, Part IV,	
(a) Description of investment (b) Book value (c) Method	d of valuation: Cost or end-of-year market value
(1)	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
(10)	
Total. (Column (b) must equal Form 990, Part X, column (B) line 13.) ▶	
Part IX Other Assets. Complete if the organization answered 'Yes' on Form 990, Part IV.	line 11d See Form 990 Part V line 15
(a) Description	(b) Book value
(1)	(2) Book value
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9) (10)	
	>
Total. (Column (b) must equal Form 990, Part X, column (B) line 15.).	
Other Liabilities. Complete if the organization answered 'Ves' on Form 990 Part IV line 11e or 11f Se	e Form 990 Part X line 25
Complete if the organization answered 'Yes' on Form 990, Part IV, line 11e or 11f. Se	ee Form 990, Part X, line 25
Complete if the organization answered 'Yes' on Form 990, Part IV, line 11e or 11f. Se (a) Description of liability (b) Book value (1) Federal income taxes	ee Form 990, Part X, line 25
Complete if the organization answered 'Yes' on Form 990, Part IV, line 11e or 11f. Se (a) Description of liability (b) Book value (1) Federal income taxes	ee Form 990, Part X, line 25
Complete if the organization answered 'Yes' on Form 990, Part IV, line 11e or 11f. Se (a) Description of liability (b) Book value (1) Federal income taxes (2) CREDIT CARD PAYABLE (3) DEFERRED REVENUE 214,248.	ee Form 990, Part X, line 25
Complete if the organization answered 'Yes' on Form 990, Part IV, line 11e or 11f. Se (a) Description of liability (b) Book value (1) Federal income taxes (2) CREDIT CARD PAYABLE 4, 278. (3) DEFERRED REVENUE 214, 248. (4) PAYROLL W/H 3, 690.	ee Form 990, Part X, line 25
Complete if the organization answered 'Yes' on Form 990, Part IV, line 11e or 11f. Se (a) Description of liability (b) Book value (1) Federal income taxes (2) CREDIT CARD PAYABLE 4,278. (3) DEFERRED REVENUE 214,248. (4) PAYROLL W/H 3,690. (5) RESEARCH AWARDS PAYABLE 102,500.	ee Form 990, Part X, line 25
Complete if the organization answered 'Yes' on Form 990, Part IV, line 11e or 11f. Se (a) Description of liability (b) Book value (1) Federal income taxes (2) CREDIT CARD PAYABLE 4, 278. (3) DEFERRED REVENUE 214, 248. (4) PAYROLL W/H 3, 690. (5) RESEARCH AWARDS PAYABLE 102, 500. (6)	ee Form 990, Part X, line 25
Complete if the organization answered 'Yes' on Form 990, Part IV, line 11e or 11f. Se (a) Description of liability (b) Book value (1) Federal income taxes (2) CREDIT CARD PAYABLE 4, 278. (3) DEFERRED REVENUE 214, 248. (4) PAYROLL W/H 3, 690. (5) RESEARCH AWARDS PAYABLE 102, 500. (6) (7)	ee Form 990, Part X, line 25
Complete if the organization answered 'Yes' on Form 990, Part IV, line 11e or 11f. Se (a) Description of liability (b) Book value (1) Federal income taxes (2) CREDIT CARD PAYABLE 4, 278. (3) DEFERRED REVENUE 214, 248. (4) PAYROLL W/H 3, 690. (5) RESEARCH AWARDS PAYABLE 102, 500. (6) (7) (8)	ee Form 990, Part X, line 25
Complete if the organization answered 'Yes' on Form 990, Part IV, line 11e or 11f. Se (a) Description of liability (b) Book value (1) Federal income taxes (2) CREDIT CARD PAYABLE 4, 278. (3) DEFERRED REVENUE 214, 248. (4) PAYROLL W/H 3, 690. (5) RESEARCH AWARDS PAYABLE 102, 500. (6) (7) (8) (9)	ee Form 990, Part X, line 25
Complete if the organization answered 'Yes' on Form 990, Part IV, line 11e or 11f. Se (a) Description of liability (b) Book value (1) Federal income taxes (2) CREDIT CARD PAYABLE 4, 278. (3) DEFERRED REVENUE 214, 248. (4) PAYROLL W/H 3, 690. (5) RESEARCH AWARDS PAYABLE 102, 500. (6) (7) (8) (9) (10)	ee Form 990, Part X, line 25
Complete if the organization answered 'Yes' on Form 990, Part IV, line 11e or 11f. Se (a) Description of liability (b) Book value (1) Federal income taxes (2) CREDIT CARD PAYABLE 4,278. (3) DEFERRED REVENUE 214,248. (4) PAYROLL W/H 3,690. (5) RESEARCH AWARDS PAYABLE 102,500. (6) (7) (8) (9) (10) (11)	ee Form 990, Part X, line 25
Complete if the organization answered 'Yes' on Form 990, Part IV, line 11e or 11f. Se (a) Description of liability (b) Book value (1) Federal income taxes (2) CREDIT CARD PAYABLE 4, 278. (3) DEFERRED REVENUE 214, 248. (4) PAYROLL W/H 3, 690. (5) RESEARCH AWARDS PAYABLE 102, 500. (6) (7) (8) (9) (10)	

Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per	r 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	828,317.
2 Amounts included on line 1 but not on Form 990, Part VIII, line 12:	70	
a Net unrealized gains (losses) on investments. 2a 17, 1	79.	
b Donated services and use of facilities 2b		
c Recoveries of prior year grants		
e Add lines 2a through 2d.	20	17 170
3 Subtract line 2e from line 1.	2e	17,179. 811,138.
4 Amounts included on Form 990, Part VIII, line 12, but not on line 1:		011,130.
a Investment expenses not included on Form 990, Part VIII, line 7b		
b Other (Describe in Part XIII.) SEE PART XIII 4b 1,8	30	
c Add lines 4a and 4b.		1,838.
5 Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)		812,976.
Part XII Reconciliation of Expenses per Audited Financial Statements With Expenses		
Complete if the organization answered 'Yes' on Form 990, Part IV, line 12a.	per recui	
1 Total expenses and losses per audited financial statements	1	1,056,611.
2 Amounts included on line 1 but not on Form 990, Part IX, line 25:		
a Donated services and use of facilities		
b Prior year adjustments		
c Other losses		
d Other (Describe in Part XIII.) SEE PART XIII 2d 2,7	28.	
e Add lines 2a through 2d	2e	2,728.
3 Subtract line 2e from line 1	3	1,053,883.
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 b Other (Describe in Part XIII.) SEE PART XIII 4b 4b	-	
b Other (Describe in Part XIII.) SEE FART ATTI 4b 4 c Add lines 4a and 4b	33.	422
5 Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.)	4 c	433. 1,054,316.
Part XIII Supplemental Information.	3	1,034,310.
	. David \/	
Provide the descriptions required for Part II, lines 3, 5, and 9; Part III, lines 1a and 4; Part IV, lines 1b and 2b line 4; Part X, line 2; Part XI, lines 2d and 4b; and Part XII, lines 2d and 4b. Also complete this part to provid	e any addition	onal information.
SCHEDULE D, PART XI, LINE 4B OTHER REVENUE INCLUDED ON FORM 990 BUT NOT INCLUDED IN F/S		
TAX RETURN ADJUSTMENT	\$	1,838.
	OTAL \$	1,838.
SCHEDULE D, PART XII, LINE 2D OTHER EXPENSES AND LOSSES PER AUDITED F/S		
EO& MENIC C ENTEDTATNMENT	ć	2 720
50% MEALS & ENTERTAINMENT	<u>\$</u> 'OTAL \$	<u>2,128.</u> 2.728
·	<u>7</u>	2,120.

BAA Schedule **D** (Form 990) 2016

Part XIII | Supplemental Information (continued)

SCHEDULE D, PART XII, LINE 4B OTHER EXPENSES INCLUDED ON FORM 990 BUT NOT INCLUDED IN F/S

 TAX RETURN ADJUSTMENT
 \$ 433

 TOTAL \$ 433



BAA TEEA3305L 08/15/16 Schedule **D** (Form 990) 2016

SCHEDULE O (Form 990 or 990-EZ)

Supplemental Information to Form 990 or 990-EZ

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

Attach to Form 990 or 990-EZ.

► Information about Schedule O (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.

OMB No. 1545-0047

Open to Public Inspection

Department of the Treasury Internal Revenue Service

Name of the organization

BATTEN DISEASE SUPPORT & RESEARCH ASSOC

Employer identification number

91-1397792

FORM 990, PART VI, LINE 11B - FORM 990 REVIEW PROCESS

THE GOVERNING BODY WILL RECEIVE AND REVIEW RETURN PRIOR TO FILING

FORM 990, PART VI, LINE 12C - EXPLANATION OF MONITORING AND ENFORCEMENT OF CONFLICTS

OFFICERS, DIRECTORS AND KEY EMPLOYEES ARE REQUIRED TO ANNUALLY SIGN A LETTER OF AGREEMENT WITH CONFLICT OF INTEREST POLICIES AND GUIDELINES.

FORM 990, PART VI, LINE 19 - OTHER ORGANIZATION DOCUMENTS PUBLICLY AVAILABLE

RECORD REQUESTS ARE INDIVIDUALLY REVIEWED AND APPROVED BY THE BOARD.

FORM 990, PART XI, LINE 9 OTHER CHANGES IN NET ASSETS OR FUND BALANCES

50% MEALS & ENTERTAINMENT. \$ -2,728 TOTAL \$ -2,728



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11/15/17

FEDERAL WORKSHEETS

PAGE 1

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BATTEN DISEASE SUPPORT & RESEARCH ASSOC

91-1397792 03:16PM

FORM 990, PART III, LINE 4E
PROGRAM SERVICES TOTALS

PROGRAM
SERVICES

	SERVICES TOTAL	FORM 990	FORM 990 SOURCE		
TOTAL EXPENSES	864,750.	0.	PART IX, LINE 25, COL. B		
GRANTS	0.		PART IX, LINES 1-3, COL. B		
REVENUE	0.		PART VIII, LINE 2, COL. A		

FORM 990, PART IX, LINE 11G OTHER FEES FOR SERVICES

		(A)	(B) PROGRAM	(C) MANAGEMENT	(D) FUND-
		TOTAL	SERVICES	& GENERAL	RAISING
PROFESSIONAL FEES	TOTAL \$	9,242. 9,242.	6,100. \$ 6,100.	3,142. \$ 3,142.	<u>\$</u> 0.
		- 7	1 0, = 0 0 1	1 7	

FORM 990, PART IX, LINE 24E OTHER EXPENSES

FORM 990, PART IX, LINE 24E OTHER EXPENSES	~~~~	MA	L	
	(A)	(B)	(C)	(D)
		PROGRAM	MANAGEMENT	
	TOTAL _	SERVICES	<u>& GENERAL</u>	<u>FUNDRAISING</u>
EQUIPMENT RENTAL/MAINT	3,559.		3,559.	
FLOWERS/CARDS/GIFTS	784.	518.	266.	
INTERNET	3,862.	2,549.	1,313.	
MEALS & ENTERTAINMENT	2,729.	1,801.	928.	
OUTSIDE SERVICES	2,500.	•	2,500.	
POSTAGE AND SHIPPING	10,017.	6,611.	3,406.	
PRINTING AND PUBLICATIONS	142.	95.	47.	
STAFF TRAINING & DEVELOPMENT	982.	648.	334.	
SUPPLIES	886.	585.	301.	
TELEPHONE	2,664.	1,758.	906.	
TOTAL	\$ 28,125.	14,565.	\$ 13,560.	\$ 0.