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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 black lung benefit trust or private foundation)	OMB No 1545-0047 2009
	The organization may have to use a copy of this return to satisfy state reporting requirements	Open to Public Inspection

A For the 2009 calendar year, or tax year beginning 07-01-2009 and ending 06-30-2010		B Check if applicable ☐ Address change ☐ Name change ☐ Initial return ☐ Terminated ☐ Amended return ☐ Application pending		C Name of organization BEYOND BATTEN DISEASE FOUNDATION Doing Business As Number and street (or P O box if mail is not delivered to street address) Room/suite 3300 DUVAL RD SUITE 110 City or town, state or country, and ZIP + 4 AUSTIN, TX 78759		D Employer identification number 26-3223661 E Telephone number (512) 275-2600 G Gross receipts \$ 686,135	
		F Name and address of principal officer SUZANNE KHO 3300 DUVALSTE 110 AUSTIN,TX 78759		H(a) Is this a group return for affiliates? ☐ Yes ☒ No H(b) Are all affiliates included? ☐ Yes ☐ No If "No," attach a list (see instructions) H(c) Group exemption number			
I Tax-exempt status ☒ 501(c) (3) (insert no) ☐ 4947(a)(1) or ☐ 527							
J Website: www.beyondbatten.org							
K Form of organization ☒ Corporation ☐ Trust ☐ Association ☐ Other		L Year of formation 2008		M State of legal domicile TX			

Part I		Summary		
Activities & Governance	1	Briefly describe the organization's mission or most significant activities Beyond Batten Disease Foundation was established to eradicate Batten disease by funding research to find a cure, and by developing a simple carrier screening test to detect the gene mutations for Batten disease, and hundreds of other devastating genetic diseases that affect children		
	2	Check this box ☐ if the organization discontinued its operations or disposed of more than 25% of its net assets		
	3	Number of voting members of the governing body (Part VI, line 1a)	3	
	4	Number of independent voting members of the governing body (Part VI, line 1b)	4	
	5	Total number of employees (Part V, line 2a)	5	
	6	Total number of volunteers (estimate if necessary)	6	
	7a	Total gross unrelated business revenue from Part VIII, column (C), line 12	7a	
	b	Net unrelated business taxable income from Form 990-T, line 34	7b	
Revenue	8	Contributions and grants (Part VIII, line 1h)	Prior Year	Current Year
	9	Program service revenue (Part VIII, line 2g)	1,290,974	514,210
	10	Investment income (Part VIII, column (A), lines 3, 4, and 7d)	5,159	54
	11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)		99,007
	12	Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)	1,296,133	613,271
	Expenses	13	Grants and similar amounts paid (Part IX, column (A), lines 1–3)	266,691
14		Benefits paid to or for members (Part IX, column (A), line 4)		0
15		Salaries, other compensation, employee benefits (Part IX, column (A), lines 5–10)	70,629	130,128
16a		Professional fundraising fees (Part IX, column (A), line 11e)	6,000	0
b		Total fundraising expenses (Part IX, column (D), line 25)		
17		Other expenses (Part IX, column (A), lines 11a–11d, 11f–24f)	183,977	141,984
18		Total expenses Add lines 13–17 (must equal Part IX, column (A), line 25)	527,297	1,794,131
19		Revenue less expenses Subtract line 18 from line 12	768,836	-1,180,860
Net Assets or Fund Balances				Beginning of Current Year
	20	Total assets (Part X, line 16)	853,093	424,513
	21	Total liabilities (Part X, line 26)	29,257	782,791
	22	Net assets or fund balances Subtract line 21 from line 20	823,836	-358,278

Part II Signature Block	
Sign Here	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 2011-02-14 Date
	SUZANNE KHO EXECUTIVE DIRECTOR Type or print name and title
Paid Preparer's Use Only	Preparer's signature BRITT LEISSNER CPA Date Check if self-employed ☐ Preparer's identifying number (see instructions)
	Firm's name (or yours if self-employed), address, and ZIP + 4 BRITT LEISSNER CPA PLLC 7211 MESA DR AUSTIN, TX 78731 EIN
	Phone no (512) 659-3368

1 Briefly describe the organization's mission

Beyond Batten Disease Foundation was

2	Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ?	☐ Yes ☒ No
	If "Yes," describe these new services on Schedule O	
3	Did the organization cease conducting, or make significant changes in how it conducts, any program services?	☐ Yes ☒ No
	If "Yes," describe these changes on Schedule O	
4	Describe the exempt purpose achievements for each of the organization's three largest program services by expenses. Section 501(c)(3) and 501(c)(4) organizations and section 4947(a)(1) trusts are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.	

4a	(Code) (Expenses \$ 1,425,155 including grants of \$ 1,266,814) (Revenue \$ 683,182)
	THE BEYOND BATTEN DISEASE FOUNDATION AWARDED A GRANT TO THE NATIONAL CENTER FOR GENOME RESOURCES TO DEVELOP A LOW-COST CARRIER SCREENING TEST FOR HUNDREDS OF DEVASTATING, RECESSIVE GENETIC DISEASES THAT AFFECT CHILDREN, INCLUDING BATTEN DISEASE THE FOUNDATION'S GOAL IS TO PREVENT BATTEN DISEASE AND OTHER GENETIC DISEASES BY SCREENING YOUNG MEN AND WOMEN BEFORE THEY DECIDE TO HAVE CHILDREN THIS APPROACH HAS PROVEN EFFECTIVE IN PREVENTING OTHER DISEASES, SUCH AS TAY-SACHS DISEASE, WHICH HAS BEEN VIRTUALLY ELIMINATED FROM THE NORTH AMERICAN ASHKENAZI JEWISH POPULATION THROUGH VOLUNTARY CARRIER SCREENING AND GENETIC COUNSELING THE FOUNDATION PLANS TO MAKE THE TEST AVAILABLE TO THE PUBLIC IN 2011

4b	(Code	) (Expenses \$	250,000	including grants of \$	250,000) (Revenue \$	)
	THE BEYOND BATTEN DISEASE FOUNDATION AWARDED A GRANT TO TEXAS CHILDREN'S HOSPITAL FOR REASEARCH RELATED TO JUVENILE BATTEN DISEASE					

[illegible]

4d Other program services (Describe in Schedule O)
(Expenses \$ 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	Yes
2	Is the organization required to complete Schedule B, Schedule of Contributors?	2	Yes
3	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I	3	No
4	Section 501(c)(3) organizations. Did the organization engage in lobbying activities? If "Yes," complete Schedule C, Part II	4	No
5	Section 501(c)(4), 501(c)(5), and 501(c)(6) organizations. Is the organization subject to the section 6033(e) notice and reporting requirement and proxy tax? If "Yes," complete Schedule C, Part III	5	
6	Did the organization maintain any donor advised funds or any similar funds or accounts where 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	Yes
7	Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas or historic structures? If "Yes," complete Schedule D, Part II	7	No
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III	8	No
9	Did the organization report an amount in Part X, line 21, 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	No
10	Did the organization, directly or through a related organization, hold assets in term, permanent, or quasi-endowments? If "Yes," complete Schedule D, Part V	10	No
11	Is the organization's answer to any of the following questions "Yes"? If so, complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable.	11	Yes
	• Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D, Part VI.		
	• Did the organization report an amount for investments—other securities in Part X, line 12 that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VII.		
	• Did the organization report an amount for investments—program related in Part X, line 13 that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VIII.		
	• 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.		
	• Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X.		
	• 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? If "Yes," complete Schedule D, Part X.		
12	Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI, XII, and XIII	12	No
12A	Was the organization included in consolidated, independent audited financial statements for the tax year?	Yes	No
	If "Yes," completing Schedule D, Parts XI, XII, and XIII is optional	12A	No
13	Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E	13	No
14a	Did the organization maintain an office, employees, or agents outside of the United States?	14a	No
b	Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, and program service activities outside the United States? If "Yes," complete Schedule F, Part I	14b	No
15	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or assistance to any organization or entity located outside the U S ? If "Yes," complete Schedule F, Part II	15	No
16	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or assistance to individuals located outside the U S ? If "Yes," complete Schedule F, Part III	16	No
17	Did the organization report a total of more than \$15,000, of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? If "Yes," complete Schedule G, Part I	17	No
18	Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? If "Yes," complete Schedule G, Part II	18	Yes
19	Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? If "Yes," complete Schedule G, Part III	19	No
20	Did the organization operate one or more hospitals? If "Yes," complete Schedule H	20	No

Part IV

Checklist of Required Schedules (continued)

21	Did the organization report more than \$5,000 of grants and other assistance to governments and organizations in the United States on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>	21	Yes	
22	Did the organization report more than \$5,000 of grants and other assistance to individuals in the United States on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>	22	Yes	
23	Did the organization answer "Yes" to Part VII, Section A, questions 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		No
24a	Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer questions 24b–24d and complete Schedule K. If "No," go to line 25</i>	24a		No
b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		
c	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?	24c		
d	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d		
25a	Section 501(c)(3) and 501(c)(4) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i>	25a		No
b	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I</i>	25b		No
26	Was a loan to or by a current or former officer, director, trustee, key employee, highly compensated employee, or disqualified person outstanding as of the end of the organization's tax year? <i>If "Yes," complete Schedule L, Part II</i>	26	Yes	
27	Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor, or a grant selection committee member, or to a person related to such an individual? <i>If "Yes," complete Schedule L, Part III</i>	27		No
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	A current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>	28a		No
b	A family member of a current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>	28b		No
c	An entity of which a current or former officer, director, trustee, or key employee of the organization (or a family member) was an officer, director, trustee, or owner? <i>If "Yes," complete Schedule L, Part IV</i>	28c		No
29	Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i>	29		No
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		No
31	Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>	31		No
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II</i>	32		No
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? <i>If "Yes," complete Schedule R, Part I</i>	33		No
34	Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Parts II, III, IV, and V, line 1</i>	34		No
35	Is any related organization a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i>	35		No
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i>	36		No
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? <i>If "Yes," complete Schedule R, Part VI</i>	37		No
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11 and 19? Note. All Form 990 filers are required to complete Schedule O	38	Yes	

Part V

Statements Regarding Other IRS Filings and Tax Compliance

			Yes	No
1a	Enter the number reported in Box 3 of Form 1096, <i>Annual Summary and Transmittal of U.S. Information Returns</i> . Enter -0- if not applicable	1a8	1cYes	
	b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable		
c Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?				
2a	Enter the number of employees reported on Form W-3, <i>Transmittal of Wage and Tax Statements</i> filed for the calendar year ending with or within the year covered by this return	2a3	2bYes	
	b If at least one is reported on line 2a, did the organization file all required federal employment tax returns? Note: If the sum of lines 1a and 2a is greater than 250, you may be required to e-file this return (see instructions)			
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year covered by this return?	3a		No
b If "Yes," has it filed a Form 990-T for this year? If "No," provide an explanation in Schedule O			3b	
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?	4a		No
	b If "Yes," enter the name of the foreign country: See the instructions for exceptions and filing requirements for Form TD F 90-22.1, Report of Foreign Bank and Financial Accounts			
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5a		No
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5b		No
c If "Yes" to line 5a or 5b, did the organization file Form 8886-T, Disclosure by Tax-Exempt Entity Regarding Prohibited Tax Shelter Transaction?			5c	
6a	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible?	6a		No
b If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?			6b	
7 Organizations that may receive deductible contributions under section 170(c).				
a	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?	7a	Yes	
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?	7b	Yes	
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?	7c		No
d	If "Yes," indicate the number of Forms 8282 filed during the year	7d		
e Did the organization, during the year, receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?			7e	No
f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?			7f	No
g For all contributions of qualified intellectual property, did the organization file Form 8899 as required?			7g	
h For contributions of cars, boats, airplanes, and other vehicles, did the organization file a Form 1098-C as required?			7h	
8 Sponsoring organizations maintaining donor advised funds and section 509(a)(3) supporting organizations. Did the supporting organization, or a donor advised fund maintained by a sponsoring organization, have excess business holdings at any time during the year?			8	
9 Sponsoring organizations maintaining donor advised funds.				
a Did the organization make any taxable distributions under section 4966?			9a	
b Did the organization make a distribution to a donor, donor advisor, or related person?			9b	
10 Section 501(c)(7) organizations. Enter				
a Initiation fees and capital contributions included on Part VIII, line 12		10a		
b Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities		10b		
11 Section 501(c)(12) organizations. Enter				
a Gross income from members or shareholders		11a		
b Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them)		11b		
12a Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?			12a	
b If "Yes," enter the amount of tax-exempt interest received or accrued during the year		12b		

Part VI

Governance, Management, and Disclosure

For each "Yes" response to lines 2 through 7b below, and for a "No" response to lines 8a, 8b, or 10b below, describe the circumstances, processes, or changes in Schedule O. See instructions.

Section A. Governing Body and Management

			Yes	No
1a	Enter the number of voting members of the governing body	1a	3	
b	Enter the number of voting members that are independent	1b	3	
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	Yes	
3	Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors or trustees, or key employees to a management company or other person?	3		No
4	Did the organization make any significant changes to its organizational documents since the prior Form 990 was filed?	4		No
5	Did the organization become aware during the year of a material diversion of the organization's assets?	5		No
6	Does the organization have members or stockholders?	6		No
7a	Does the organization have members, stockholders, or other persons who may elect one or more members of the governing body?	7a		No
b	Are any decisions of the governing body subject to approval by members, stockholders, or other persons?	7b		No
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following			
a	The governing body?	8a	Yes	
b	Each committee with authority to act on behalf of the governing body?	8b	Yes	
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		No

Section B. Policies

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

			Yes	No
10a	Does the organization have local chapters, branches, or affiliates?	10a		No
b	If "Yes," does the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with those of the organization?	10b		
11	Has the organization provided a copy of this Form 990 to all members of its governing body before filing the form?	11	Yes	
11A	Describe in Schedule O the process, if any, used by the organization to review the Form 990			
12a	Does the organization have a written conflict of interest policy? If "No," go to line 13	12a	Yes	
b	Are officers, directors or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	12b	Yes	
c	Does the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this is done	12c	Yes	
13	Does the organization have a written whistleblower policy?	13	Yes	
14	Does the organization have a written document retention and destruction policy?	14	Yes	
15	Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision?			
a	The organization's CEO, Executive Director, or top management official	15a	Yes	
b	Other officers or key employees of the organization	15b		No
	If "Yes" to line a or b, 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?	16a		No
b	If "Yes," has the organization adopted a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and taken steps to safeguard the organization's exempt status with respect to such arrangements?	16b		

Section C. Disclosure

17	List the States with which a copy of this Form 990 is required to be filed▶
18	Section 6104 requires an organization to make its Form 1023 (or 1024 if applicable), 990, and 990-T (501(c) (3)s only) available for public inspection. Indicate how you make these available. Check all that apply. ☐ Own website ☐ Another's website ☒ Upon request
19	Describe in Schedule O whether (and if so, how), the organization makes its governing documents, conflict of interest policy, and financial statements available to the public. See Additional Data Table.
20	State the name, physical address, and telephone number of the person who possesses the books and records of the organization ▶ SUZANNE KHO 3300 DUVAL RDSTE 110 AUSTIN, TX 78759 (512) 275-2600

Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees

• 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

☐ Check this box if the organization did not compensate any current or former officer, director, trustee or key employee

[illegible]

1b	Total	85,000	
----	-------	--------	--

2 Total number of individuals (including but not limited to those listed above) who received more than \$100,000 in reportable compensation from the organization0

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

Section B. Independent Contractors

1	Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization		
	(A) Name and business address	(B) Description of services	(C) Compensation
2	Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 in compensation from the organization		

Part VIII

Statement of Revenue

				(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512, 513, or 514
Contributions, gifts, grants and other similar amounts	1a	Federated campaigns . . .	1a				
	b	Membership dues	1b				
	c	Fundraising events	1c				
	d	Related organizations	1d				
	e	Government grants (contributions)	1e				
	f	All other contributions, gifts, grants, and similar amounts not included above	1f	514,210			
	g	Noncash contributions included in lines 1a-1f \$ 3,849					
	h	Total. Add lines 1a-1f			514,210		
Program Service Revenue	2a		Business Code				
	b						
	c						
	d						
	e						
	f	All other program service revenue					
	g	Total. Add lines 2a-2f					
	Other Revenue	3	Investment income (including dividends, interest and other similar amounts)		52	52	
4		Income from investment of tax-exempt bond proceeds . .					
5		Royalties					
6a		Gross Rents	(i) Real	(ii) Personal			
b		Less rental expenses					
c		Rental income or (loss)					
d		Net rental income or (loss)					
7a		Gross amount from sales of assets other than inventory	(i) Securities	(ii) Other			
b		Less cost or other basis and sales expenses					
c		Gain or (loss)					
d		Net gain or (loss)			2	2	
8a		Gross income from fundraising events (not including \$ _____ of contributions reported on line 1c) See Part IV, line 18	a	168,972			
b		Less direct expenses	b	69,965			
c		Net income or (loss) from fundraising events . .			99,007	99,007	
9a		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				
11a							
b							
c							
d	All other revenue						
e	Total. Add lines 11a-11d						
12	Total revenue. See Instructions			613,271	99,061		

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) but are not required to complete columns (B), (C), and (D).

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.		(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1	Grants and other assistance to governments and organizations in the U S See Part IV, line 21	1,522,019	1,522,019		
2	Grants and other assistance to individuals in the U S See Part IV, line 22				
3	Grants and other assistance to governments, organizations, and individuals outside the U S See Part IV, lines 15 and 16				
4	Benefits paid to or for members				
5	Compensation of current officers, directors, trustees, and key employees	85,000	51,000	12,750	21,250
6	Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)				
7	Other salaries and wages	30,093	12,037	6,019	12,037
8	Pension plan contributions (include section 401(k) and section 403(b) employer contributions)				
9	Other employee benefits	6,872	3,764	1,121	1,987
10	Payroll taxes	8,163	4,471	1,331	2,361
11	Fees for services (non-employees)				
a	Management				
b	Legal	932	510	152	270
c	Accounting	1,350	739	220	391
d	Lobbying				
e	Professional fundraising See Part IV, line 17				
f	Investment management fees				
g	Other	62,950	48,112	3,450	11,388
12	Advertising and promotion	13,546	7,419	2,209	3,918
13	Office expenses	1,897	1,039	309	549
14	Information technology				
15	Royalties				
16	Occupancy				
17	Travel	16,588	12,882	1,534	2,172
18	Payments of travel or entertainment expenses for any federal, state, or local public officials				
19	Conferences, conventions, and meetings	2,135	1,169	348	618
20	Interest				
21	Payments to affiliates				
22	Depreciation, depletion, and amortization	782	428	128	226
23	Insurance	3,257	1,784	531	942
24	Other expenses Itemize expenses not covered above (Expenses grouped together and labeled miscellaneous may not exceed 5% of total expenses shown on line 25 below)				
a	Bank/Credit Card Fees	6,321	3,462	1,031	1,828
b	Dues & Subscriptions	1,035	567	169	299
c	Event Costs	13,719	0	0	13,719
d	Meals & Entertainment	3,147	1,009	1,110	1,028
e	Postage & Shipping	2,601	556	496	1,549
f	All other expenses	11,724	2,188	1,501	8,035
25	Total functional expenses. Add lines 1 through 24f	1,794,131	1,675,155	34,409	84,567
26	Joint costs. Check here ☐ if following SOP 98-2 Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation				

Part X

Balance Sheet

					(A)		(B)
					Beginning of year		End of year
Assets	1	Cash—non-interest-bearing			6,259	1	421,954
	2	Savings and temporary cash investments			843,582	2	
	3	Pledges and grants receivable, net				3	
	4	Accounts receivable, net			320	4	409
	5	Receivables from current and former officers, directors, trustees, key employees, and highest compensated employees. Complete Part II of Schedule L				5	
	6	Receivables from other disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B). Complete Part II of Schedule L				6	
	7	Notes and loans receivable, net				7	
	8	Inventories for sale or use				8	
	9	Prepaid expenses and deferred charges				9	
	10a	Land, buildings, and equipment. cost or other basis. Complete Part VI of Schedule D	10a	2,932			
	b	Less accumulated depreciation	10b	782	2,932	10c	2,150
	11	Investments—publicly traded securities				11	
	12	Investments—other securities. See Part IV, line 11				12	
	13	Investments—program-related. See Part IV, line 11				13	
	14	Intangible assets				14	
	15	Other assets. See Part IV, line 11				15	
	16	Total assets. Add lines 1 through 15 (must equal line 34)			853,093	16	424,513
Liabilities	17	Accounts payable and accrued expenses			29,257	17	54,023
	18	Grants payable				18	328,768
	19	Deferred revenue				19	
	20	Tax-exempt bond liabilities				20	
	21	Escrow or custodial account liability. Complete Part IV of Schedule D				21	
	22	Payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons. Complete Part II of Schedule L				22	400,000
	23	Secured mortgages and notes payable to unrelated third parties				23	
	24	Unsecured notes and loans payable to unrelated third parties				24	
	25	Other liabilities. Complete Part X of Schedule D				25	
	26	Total liabilities. Add lines 17 through 25			29,257	26	782,791
Net Assets or Fund Balances	Organizations that follow SFAS 117, check here ☒ and complete lines 27 through 29, and lines 33 and 34.						
	27	Unrestricted net assets			823,836	27	-383,278
	28	Temporarily restricted net assets				28	25,000
	29	Permanently restricted net assets				29	
	Organizations that do not follow SFAS 117, check here ☐ and complete lines 30 through 34.						
	30	Capital stock or trust principal, or current funds				30	
	31	Paid-in or capital surplus, or land, building or equipment fund				31	
	32	Retained earnings, endowment, accumulated income, or other funds				32	
	33	Total net assets or fund balances			823,836	33	-358,278
	34	Total liabilities and net assets/fund balances			853,093	34	424,513

Part XI **Financial Statements and Reporting**

	Yes	No
1 Accounting method used to prepare the Form 990 ☐ Cash ☒ Accrual ☐ Other _____ If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule O		
2a Were the organization's financial statements compiled or reviewed by an independent accountant? . . .		No
b Were the organization's financial statements audited by an independent accountant?		No
c If "Yes," to 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O		
d If "Yes" to line 2a or 2b, check a box below to indicate whether the financial statements for the year were issued on a consolidated basis, separate basis, or both ☐ Separate basis ☐ Consolidated basis ☐ Both consolidated and separated basis		
3a As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133?		No
b If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits . . .		

SCHEDULE A

(Form 990 or 990EZ)

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.

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

OMB No 1545-0047

2009

Open to Public
Inspection

Name of the organization BEYOND BATTEN DISEASE FOUNDATION	Employer identification number 26-3223661
--	--

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 11, check only one box)

- 1

☐

A church, convention of churches, or association of churches **section 170(b)(1)(A)(i).**
- 2

☐

A school described in **section 170(b)(1)(A)(ii).** (Attach Schedule E)
- 3

☐

A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii).**
- 4

☐

A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii).** Enter the hospital's name, city, and state
- 5

☐

An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv).** (Complete Part II)
- 6

☐

A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v).**
- 7

☒

An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi)** (Complete Part II)
- 8

☐

A community trust described in **section 170(b)(1)(A)(vi)** (Complete Part II)
- 9

☐

An organization that normally receives (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions—subject to certain exceptions, and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975 See **section 509(a)(2).** (Complete Part III)
- 10

☐

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 that describes the type of supporting organization and complete lines 11e through 11h

a

☐

Type I

b

☐

Type II

c

☐

Type III - Functionally integrated

d

☐

Type III - Other
- e

☐

By checking this box, I certify that the organization is not controlled directly or indirectly by one or more disqualified persons other than foundation managers and other than one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2)
- f

☐

If the organization received a written determination from the IRS that it is a Type I, Type II or Type III supporting organization, check this box
- g

☐

Since August 17, 2006, has the organization accepted any gift or contribution from any of the following persons?

(i)

a person who directly or indirectly controls, either alone or together with persons described in (ii) and (iii) below, the governing body of the the supported organization?

(ii)

a family member of a person described in (i) above?

(iii)

a 35% controlled entity of a person described in (i) or (ii) above?
- h

☐

Provide the following information about the supported organization(s)

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1- 9 above or IRC section (see instructions))	(iv) Is the organization in col (i) listed in your governing document?		(v) Did you notify the organization in col (i) of your support?		(vi) Is the organization in col (i) organized in the U S ?		(vii) Amount of support?
			Yes	No	Yes	No	Yes	No	
Total									

Part II

Support Schedule for Organizations Described in IRC 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.)

Section A. Public Support

Calendar year (or fiscal year beginning in)	(a) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")				1,290,974	683,182	1,974,156
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
3 The value of services or facilities furnished by a governmental unit to the organization without charge						
4 Total. Add lines 1 through 3				1,290,974	683,182	1,974,156
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						1,974,156

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(f) Total
7 Amounts from line 4				1,290,974	683,182	1,974,156
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources				5,159	54	5,213
9 Net income from unrelated business activities, whether or not the business is regularly carried on						
10 Other income (Explain in Part IV) Do not include gain or loss from the sale of capital assets						
11 Total support (Add lines 7 through 10)						1,979,369

12 Gross receipts from related activities, etc (See instructions)

12

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

☒

Section C. Computation of Public Support Percentage

14 Public Support Percentage for 2009 (line 6 column (f) divided by line 11 column (f))	14	0 %
15 Public Support Percentage for 2008 Schedule A, Part II, line 14	15	

16a 33 1/3% support test—2009. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization

☒

b 33 1/3% support test—2008. If the organization did not check the box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization

☒

17a 10%-facts-and-circumstances test—2009. If the organization did not check a box on line 13, 16a, or 16b and line 14 is 10% or more, and if the organization meets the "facts and circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts and circumstances" test The organization qualifies as a publicly supported organization

☒

b 10%-facts-and-circumstances test—2008. If the organization did not check a box on line 13, 16a, 16b, or 17a and line 15 is 10% or more, and if the organization meets the "facts and circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts and circumstances" test The organization qualifies as a publicly supported organization

☒

18 Private Foundation If the organization did not check a box on line 13, 16a, 16b, 17a or 17b, check this box and see instructions

☒

Part IIISupport Schedule for Organizations Described in IRC 509(a)(2)
(Complete only if you checked the box on line 9 of Part I.)

Section A. Public Support

Calendar year (or fiscal year beginning in)	(a) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(f) Total
1Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")						
2Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3Gross receipts from activities that are not an unrelated trade or business under section 513						
4Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5The value of services or facilities furnished by a governmental unit to the organization without charge						
6Total. Add lines 1 through 5						
7aAmounts included on lines 1, 2, and 3 received from disqualified persons						
bAmounts 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						
cAdd lines 7a and 7b						
8Public Support (Subtract line 7c from line 6)						0

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(f) Total
9Amounts from line 6						
10aGross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						
bUnrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
cAdd lines 10a and 10b						
11Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)						
13Total support (Add lines 9, 10c, 11 and 12.)						
14First Five Years If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a 501(c)(3) organization, check this box and stop here						

Section C. Computation of Public Support Percentage

15Public Support Percentage for 2009 (line 8 column (f) divided by line 13 column (f))	15	0 %
16Public support percentage from 2008 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage

17Investment income percentage for 2009 (line 10c column (f) divided by line 13 column (f))	17	0 %
18Investment income percentage from 2008 Schedule A, Part III, line 17	18	
19a33 1/3% support tests—2009. If the organization did not check the box on line 14, and line 15 is more than 33 1/3% and line 17 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization		
b33 1/3% support tests—2008. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3% and line 18 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization		
20Private Foundation If the organization did not check a box on line 14, 19a or 19b, check this box and see instructions		

Part IV

Supplemental Information. Supplemental Information. Complete this part to provide the explanation required by Part II, line 10; Part II, line 17a or 17b; or Part III, line 12. Provide any other additional information. See instructions

Additional Data

Software ID:

Software Version:

EIN: 26-3223661

Name: BEYOND BATTEN DISEASE FOUNDATION

Form 990, Part IX - Statement of Functional Expenses - 24a - 24e Other Expenses

<i>Do not include amounts reported on line 6b, 8b, 9b, and 10b of Part VIII.</i>	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
Bank/Credit Card Fees	6,321	3,462	1,031	1,828
Dues & Subscriptions	1,035	567	169	299
Event Costs	13,719	0	0	13,719
Meals & Entertainment	3,147	1,009	1,110	1,028
Postage & Shipping	2,601	556	496	1,549

SCHEDULE D

(Form 990)

Department of the Treasury
Internal Revenue Service

Supplemental Financial Statements

▶ **Complete if the organization answered "Yes," to Form 990, Part IV, line 6, 7, 8, 9, 10, 11, or 12.**
▶ **Attach to Form 990. ▶ See separate instructions.**

OMB No 1545-0047

2009

Open to Public
Inspection

Name of the organization
BEYOND BATTEN DISEASE FOUNDATION

Employer identification number

26-3223661

Part I

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

	(a) Donor advised funds	(b) Funds and other accounts
1	Total number at end of year	1
2	Aggregate contributions to (during year)	283,829
3	Aggregate grants from (during year)	
4	Aggregate value at end of year	234,673
5	Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control? ☒ Yes ☐ No	
6	Did the organization inform all grantees, donors, and donor advisors in writing that grant funds may be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit? ☒ Yes ☐ No	

Part II

Conservation Easements. Complete if the organization answered "Yes" to 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 pleasure)

☐ Preservation of an historically importantly land area

☐ Protection of natural habitat

☐ Preservation of a certified historic structure

☐ Preservation of open space

2

Complete lines 2a–2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year

	Held at the End of the Year
a	Total number of conservation easements
b	Total acreage restricted by conservation easements
c	Number of conservation easements on a certified historic structure included in (a)
d	Number of conservation easements included in (c) acquired after 8/17/06

3

Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the taxable year ▶ _____

4

Number of states where property subject to conservation easement is located ▶ _____

5

Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds?

☐ Yes ☐ No

6

Staff and volunteer hours devoted to monitoring, inspecting and enforcing conservation easements during the year ▶ _____

7

Amount of expenses incurred in monitoring, inspecting, and enforcing conservation easements during the year ▶ \$ _____

8

Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and 170(h)(4)(B)(ii)?

☐ Yes ☐ No

9

In Part XIV, describe how the organization reports conservation easements in its revenue and expense statement, and balance sheet, and include, if applicable, the text of the footnote to the organization’s financial statements that describes the organization’s accounting for conservation easements

Part III

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

1a

If the organization elected, as permitted under SFAS 116, not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education or research in furtherance of public service, provide, in Part XIV, the text of the footnote to its financial statements that describes these items

b

If the organization elected, as permitted under SFAS 116, to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items

(i) Revenues included in Form 990, Part VIII, line 1

▶ \$ _____

(ii) Assets included in Form 990, Part X

▶ \$ _____

2

If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under SFAS 116 relating to these items

a

Revenues included in Form 990, Part VIII, line 1

▶ \$ _____

b

Assets included in Form 990, Part X

▶ \$ _____

For Privacy Act and Paperwork Reduction Act Notice, see the Intructions for Form 990

Cat No 52283D

Schedule D (Form 990) 2009

Part III

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

3

Using the organization's accession and other records, check any of the following that are a significant use of its collection items (check all that apply)

a

☐ Public exhibition

b

☐ Scholarly research

c

☐ Preservation for future generations

d

☐ Loan or exchange programs

e

☐ Other

4

Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIV

5

During the year, did the organization solicit or receive donations of art, historical treasures or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection?

☐ Yes

☐ No

Part IV

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

1a

Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X?

☐ Yes

☐ No

b

If "Yes," explain the arrangement in Part XIV and complete the following table

c

Beginning balance

d

Additions during the year

e

Distributions during the year

f

Ending balance

	Amount
1c	
1d	
1e	
1f	

2a

Did the organization include an amount on Form 990, Part X, line 21?

☐ Yes

☐ No

b

If "Yes," explain the arrangement in Part XIV

Part V

Endowment Funds. Complete if the organization answered "Yes" to Form 990, Part IV, line 10.

	(a)Current Year	(b)Prior Year	(c)Two Years Back	(d)Three Years Back	(e)Four Years Back
1a	Beginning of year balance				
b	Contributions				
c	Investment earnings or 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 year end balance held as

a

Board designated or quasi-endowment ▶ %

b

Permanent endowment ▶ %

c

Term endowment ▶ %

3a

Are there endowment funds not in the possession of the organization that are held and administered for the organization by

(i) unrelated organizations

(ii) related organizations

3a(i)

Yes

No

3a(ii)

b

If "Yes" to 3a(ii), are the related organizations listed as required on Schedule R?

3b

4

Describe in Part XIV the intended uses of the organization's endowment funds

Part VI

Investments—Land, Buildings, and Equipment. See Form 990, Part X, line 10.

Description of investment	(a) Cost or other basis (investment)	(b)Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a	Land			
b	Buildings			
c	Leasehold improvements			
d	Equipment	2,932	782	2,150
e	Other			
Total.	Add lines 1a-1e (Column (d) should equal Form 990, Part X, column (B), line 10(c).) ▶			2,150

Part XI

Reconciliation of Change in Net Assets from Form 990 to Financial Statements

1	Total revenue (Form 990, Part VIII, column (A), line 12)	1	
2	Total expenses (Form 990, Part IX, column (A), line 25)	2	
3	Excess or (deficit) for the year Subtract line 2 from line 1	3	
4	Net unrealized gains (losses) on investments	4	
5	Donated services and use of facilities	5	
6	Investment expenses	6	
7	Prior period adjustments	7	
8	Other (Describe in Part XIV)	8	
9	Total adjustments (net) Add lines 4 - 8	9	
10	Excess or (deficit) for the year per financial statements Combine lines 3 and 9	10	

Part XII

Reconciliation of Revenue per Audited Financial Statements With Revenue per Return

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

Part XIII

Reconciliation of Expenses per Audited Financial Statements With Expenses per Return

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

Part XIV

Supplemental Information

Complete this part to provide the descriptions required for Part II, lines 3, 5, and 9, Part III, lines 1a and 4, Part IV, lines 1b and 2b, Part V, line 4, Part X, Part XI, line 8, Part XII, lines 2d and 4b, and Part XIII, lines 2d and 4b. Also complete this part to provide any additional information.

Identifier	Return Reference	Explanation
------------	------------------	-------------

SCHEDULE G
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Supplemental Information Regarding
Fundraising or Gaming Activities

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

OMB No. 1545-0047

2009

Open to Public Inspection

Name of the organization
BEYOND BATTEN DISEASE FOUNDATION

Employer identification number
26-3223661

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

1

Indicate whether the organization raised funds through any of the following activities. Check all that apply.

a

☐ Mail solicitations

e

☐ Solicitation of non-government grants

b

☐ Internet and e-mail solicitations

f

☐ Solicitation of government grants

c

☐ Phone solicitations

g

☐ Special fundraising events

d

☐ In-person solicitations

2a

Did the organization have a written or oral agreement with any individual (including officers, directors, trustees or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising activities?

☐ Yes ☐ No

b

If "Yes," list the ten highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization. Form 990-EZ filers are not required to complete this table.

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

3

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

Part II Fundraising Events. Complete if the organization answered "Yes" to Form 990, Part IV, line 18, or reported more than \$15,000 on Form 990-EZ, line 6a. List events with gross receipts greater than \$5,000.

		(a) Event #1	(b) Event #2	(c) Other Events	(d) Total Events
		Golf Event (event type)	Gala Event (event type)	(total number)	(Add col (a) through col (c))
Revenue	1	Gross receipts	40,030	128,942	168,972
	2	Less Charitable contributions			
	3	Gross income (line 1 minus line 2)	40,030	128,942	168,972
Direct Expenses	4	Cash prizes			
	5	Non-cash prizes	4,179	2,467	6,646
	6	Rent/facility costs	18,810	5,111	23,921
	7	Food and beverages		29,925	29,925
	8	Entertainment		5,200	5,200
	9	Other direct expenses		4,273	4,273
	10	Direct expense summary Add lines 4 through 9 in column (d)			69,965
	11	Net income summary Combine lines 3, column d, and line 10.			99,007

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

		(a) Bingo	(b) Pull tabs/Instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming
					(Add col (a) through col (c))
Revenue	1	Gross revenue			
	2	Cash prizes			
Direct Expenses	3	Non-cash prizes			
	4	Rent/facility costs			
	5	Other direct expenses			
	6	Volunteer labor	☐ Yes _____ % ☐ No	☐ Yes _____ % ☐ No	
7 Direct expense summary Add lines 2 through 5 in column (d)					
8 Net gaming income summary Combine lines 1, column d, and line 7					

		Yes	No
9	Enter the state(s) in which the organization operates gaming activities _____		
a	Is the organization licensed to operate gaming activities in each of these states?	9a	
b	If "No," Explain _____ _____		
10a	Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year?	10a	
b	If "Yes," Explain _____ _____		
11	Does the organization operate gaming activities with nonmembers?	11	
12	Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity formed to administer charitable gaming?	12	

		Yes	No
13	Indicate the percentage of gaming activity operated in		
a	The organization's facility 13a		
b	An outside facility 13b		
14	Enter the name and address of the person who prepares the organization's gaming/special events books and records		
Name ►			
Address ►			
15a	Does the organization have a contract with a third party from whom the organization receives gaming revenue?	15a	
b	If "Yes," enter the amount of gaming revenue received by the organization ► \$ _____ and the amount of gaming revenue retained by the third party ► \$ _____		
c	If "Yes," enter name and address		
Name ►			
Address ►			
16	Gaming manager information		
Name ►			
Gaming manager compensation ► \$ _____			
Description of services provided ►			
☐ Director/officer ☐ Employee ☐ Independent contractor			
17	Mandatory distributions		
a	Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license?	17a	
b	Enter the amount of distributions required under state law distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year ► \$		

Schedule I
(Form 990)

Department of the Treasury
Internal Revenue Service

Grants and Other Assistance to Organizations,
Governments and Individuals in the United States

Complete if the organization answered "Yes," to Form 990, Part IV, line 21 or 22.
▶ Attach to Form 990

OMB No 1545-0047

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Part I

General Information on Grants and Assistance

- 1

Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance?

Yes

No
- 2

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

Part II

Grants and Other Assistance to Governments and Organizations in the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 21 for any recipient that received more than \$5,000. Check this box if no one recipient received more than \$5,000. Use Part IV and Schedule I-1 (Form 990) if additional space is needed ▶

(a) Name and address of organization or government	(b) EIN	(c) IRC Code section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
NATIONAL CENTER FOR GENOME RESOURCES2935 RODEO PARK DRIVE EAST SANTA FE,NM 87505	850418280	501(c)3	1,266,814				See Sched O
TEXAS CHILDRENS HOSPITALPO BOX 300630 HOUSTON,TX 77230	741100555	501(c)3	250,000				See Sched O

2

Enter total number of section 501(c)(3) and government organizations

3

Enter total number of other organizations

Schedule L
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Transactions with Interested Persons

▶ Complete if the organization answered "Yes" on Form 990, Part IV, lines 25a, 25b, 26, 27, 28a, 28b, or 28c, or Form 990-EZ, Part V lines 38a or 40b.
▶ Attach to Form 990 or Form 990-EZ. ▶ See separate instructions.

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Part I Excess Benefit Transactions (section 501(c)(3) and section 501 (c)(4) organizations only).

Complete if the organization answered "Yes" on Form 990, Part IV, line 25a or 25b, or Form 990-EZ, Part V, line 40b

1	(a) Name of disqualified person	(b) Description of transaction	(c) Corrected?
			YesNo

2 Enter the amount of tax imposed on the organization managers or disqualified persons during the year under section 4958 ▶ \$

3 Enter the amount of tax, if any, on line 2, above, reimbursed by the organization ▶ \$

Part II Loans to and/or From Interested Persons.

Complete if the organization answered "Yes" on Form 990, Part IV, line 26, or Form 990-EZ, Part V, line 38a

(a) Name of interested person and purpose	(b) Loan to or from the organization?		(c) Original principal amount	(d) Balance due	(e) In default?		(f) Approved by board or committee?		(g) Written agreement?	
	To	From			Yes	No	Yes	No	Yes	No
MARK CHANDLER Carrier Screening	X		200,000	200,000		No	Yes		Yes	
MICHAEL SPAIN Carrier Screening	X		200,000	200,000		No	Yes		Yes	
Total ▶	\$		400,000							

Part III Grants or Assistance Benefitting Interested Persons.

Complete if the organization answered "Yes" on Form 990, Part IV, line 27.

(a) Name of interested person	(b) Relationship between interested person and the organization	(c) Amount of grant or type of assistance
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Part IV Business Transactions Involving Interested Persons.

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

(a) Name of interested person	(b) Relationship between interested person and the organization	(c) Amount of transaction	(d) Description of transaction	(e) Sharing of organization's revenues?
				YesNo

SCHEDULE O

(Form 990)

Department of the Treasury
Internal Revenue Service

Supplemental Information to Form 990

Complete to provide information for responses to specific questions on
Form 990 or to provide any additional information.
▶ Attach to Form 990.

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Identifier	Return Reference	Explanation
Pt VI-A, Line 2		Craig Benson is the founder of the Foundation Craig Benson and Dr
		Mark Chandler are both directors in an unrelated for profit
		company, Rules-Based Medicine Craig Benson and Patrick
		McClain are officers of Rules-Based Medicine Dr Kyle
		Janek and Dr Mark Chandler are both officers in an unrelated
		for profit company, Biophysical Corporation There are
		no business relationships betw een the Foundation and the
		for profit companies listed above

Identifier	Return Reference	Explanation
Pt VI-A, Line 8a		All meetings w ere documented by Board minutes

Pt VI-B, Line 11A The Form 990 is provided to all Board Members and officers for review before filing Pt VI-B, Line 12c Each director is required to annually sign a statement affirming that they have received a copy of the Bylaws containing the Conflict of Interest Policy, have read and understand the Policy, and have agreed to comply with the policy Pt VI-B, Line 15 Executive Director/President's compensation is reviewed by the Board of Directors

Identifier	Return Reference	Explanation
Pt VI-C, Line 19		The governing documents and conflict of interest policy are

not available to the public and the financial statements are available to the public upon request Sched I, Purpose Develop a low-cost screening test for genetic diseases Sched I, Purpose Research funding for Juvenile Batten disease research
For Paperwork Reduction Act Notice, see the Instructions for Form 990 Cat No 51056K Schedule O (Form 990) 2009