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

OMB No 1545-0047
2012
Open to Public Inspection

A For the 2012 calendar year, or tax year beginning 07-01-2012, 2012, and ending 06-30-2013

B Check if applicable: <input type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial return <input type="checkbox"/> Terminated <input type="checkbox"/> Amended return <input type="checkbox"/> 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 F Name and address of principal officer MARY BETH KISER 3300 DUVALSTE 110 AUSTIN, TX 78759	D Employer identification number 26-3223661 E Telephone number (512) 275-2600 G Gross receipts \$ 1,452,597
I Tax-exempt status <input checked="" type="checkbox"/> 501(c)(3) <input type="checkbox"/> 501(c) () (Insert no) <input type="checkbox"/> 4947(a)(1) or <input type="checkbox"/> 527		H(a) Is this a group return for affiliates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No H(b) Are all affiliates included? <input type="checkbox"/> Yes <input type="checkbox"/> No If "No," attach a list (see instructions) H(c) Group exemption number
J Website: www.beyondbatten.org		K Form of organization <input checked="" type="checkbox"/> Corporation <input type="checkbox"/> Trust <input type="checkbox"/> Association <input type="checkbox"/> Other L Year of formation 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 <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets		
	3	Number of voting members of the governing body (Part VI, line 1a)	3	3
	4	Number of independent voting members of the governing body (Part VI, line 1b)	4	5
	5	Total number of individuals employed in calendar year 2012 (Part V, line 2a)	5	9
	6	Total number of volunteers (estimate if necessary)	6	95
	7a	Total unrelated business revenue from Part VIII, column (C), line 12	7a	0
	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)	1,541,127	1,213,663
	10	Investment income (Part VIII, column (A), lines 3, 4, and 7d)	327	545
	11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	-336,368	59,364
	12	Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)	1,205,086	1,273,572
	Expenses	13	Grants and similar amounts paid (Part IX, column (A), lines 1–3)	320,206
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)	229,255	290,065
16a		Professional fundraising fees (Part IX, column (A), line 11e)	14,828	0
b		Total fundraising expenses (Part IX, column (D), line 25) <u>216,962</u>		
17		Other expenses (Part IX, column (A), lines 11a–11d, 11f–24e)	296,943	524,352
18	Total expenses Add lines 13–17 (must equal Part IX, column (A), line 25)	861,232	1,086,151	
19	Revenue less expenses Subtract line 18 from line 12	343,854	187,421	
Net Assets or Fund Balances	20	Total assets (Part X, line 16)	Beginning of Current Year	End of Year
	21	Total liabilities (Part X, line 26)	1,068,425	1,605,506
	22	Net assets or fund balances Subtract line 21 from line 20	1,407,931	1,598,839
			-339,506	6,667

Part II Signature Block

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

Sign Here	***** Signature of officer	2013-11-07 Date	
	MARY BETH KISER EXECUTIVE DIRECTOR Type or print name and title		
Paid Preparer Use Only	Print/Type preparer's name BRITT LEISSNER CPA	Preparer's signature	Date
	Firm's name BRITT LEISSNER CPA PLLC	Check <input type="checkbox"/> if self-employed PTIN	
	Firm's address 9442 CAPITAL OF TEXAS HWY NORTH PLA AUSTIN, TX 78759	Firm's EIN Phone no (512) 659-3368	

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

Part III Statement of Program Service Accomplishments

Check if Schedule O contains a response to any question in this Part III Yes No

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

4a (Code) (Expenses \$ 773,274 including grants of \$ 271,734) (Revenue \$ 1,213,663)
TO ACCELERATE THE DISCOVERY AND DEVELOPMENT OF MEDICINES TO PREVENT, TREAT AND CURE JUVENILE BATTEN DISEASE THIS IS DONE THROUGH THE GRANTING OF FUNDS AND CONTRACTING OF SERVICES WITH ACADEMIC INSTITUTIONS, BIOTECHNOLOGY COMPANIES, AND OTHER ORGANIZATIONS WITH THE CAPACITY TO ASSIST IN ACHIEVING OUR GOALS BBDF ALSO SPEARHEADS THE DEVELOPMENT OF THINK-TANK CONFERENCES AND UNIQUE PARTNERSHIPS TO DRIVE JUVENILE BATTEN DISEASE RESEARCH

4b (Code) (Expenses \$ including grants of \$) (Revenue \$)

4c (Code) (Expenses \$ including grants of \$) (Revenue \$)

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

4e Total program service expenses 773,274

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

Part IV Checklist of Required Schedules *(continued)*

<p>21 Did the organization report more than \$5,000 of grants and other assistance to any government or organization in the United States on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i></p>	<p>21</p>	<p>Yes</p>	
<p>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></p>	<p>22</p>	<p>Yes</p>	
<p>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></p>	<p>23</p>		<p>No</p>
<p>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 lines 24b through 24d and complete Schedule K. If "No," go to line 25</i></p>	<p>24a</p>		<p>No</p>
<p>b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?</p>	<p>24b</p>		
<p>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?</p>	<p>24c</p>		
<p>d Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?</p>	<p>24d</p>		
<p>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></p>	<p>25a</p>		<p>No</p>
<p>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></p>	<p>25b</p>		<p>No</p>
<p>26 Was a loan to or by a current or former officer, director, trustee, key employee, highest 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></p>	<p>26</p>	<p>Yes</p>	
<p>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? <i>If "Yes," complete Schedule L, Part III</i></p>	<p>27</p>		<p>No</p>
<p>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)</p>			
<p>a A current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i></p>	<p>28a</p>		<p>No</p>
<p>b A family member of a current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i></p>	<p>28b</p>		<p>No</p>
<p>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? <i>If "Yes," complete Schedule L, Part IV</i></p>	<p>28c</p>		<p>No</p>
<p>29 Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i></p>	<p>29</p>		<p>No</p>
<p>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></p>	<p>30</p>		<p>No</p>
<p>31 Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i></p>	<p>31</p>		<p>No</p>
<p>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></p>	<p>32</p>		<p>No</p>
<p>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></p>	<p>33</p>		<p>No</p>
<p>34 Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1</i></p>	<p>34</p>		<p>No</p>
<p>35a Did the organization have a controlled entity within the meaning of section 512(b)(13)?</p>	<p>35a</p>		<p>No</p>
<p>b If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i></p>	<p>35b</p>		<p>No</p>
<p>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></p>	<p>36</p>		
<p>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></p>	<p>37</p>		<p>No</p>
<p>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</p>	<p>38</p>	<p>Yes</p>	

Part V Statements Regarding Other IRS Filings and Tax Compliance

Check if Schedule O contains a response to any question in this Part V

		Yes	No
1a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable		
1b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable		
1c	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	Yes	
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return		
2b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns? Note. If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)	Yes	
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?		No
3b	If "Yes," has it filed a Form 990-T for this year? If "No," provide an explanation in Schedule O		
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)?		No
b	If "Yes," enter the name of the foreign country <input type="checkbox"/> _____ See instructions for 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?		No
5b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?		No
5c	If "Yes," to line 5a or 5b, did the organization file Form 8886-T?		
6a	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions?		No
6b	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).		
7a	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?	Yes	
7b	If "Yes," did the organization notify the donor of the value of the goods or services provided?	Yes	
7c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?		No
7d	If "Yes," indicate the number of Forms 8282 filed during the year		
7e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?		No
7f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?		No
7g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?		
7h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?		
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?		
9	Sponsoring organizations maintaining donor advised funds.		
9a	Did the organization make any taxable distributions under section 4966?		
9b	Did the organization make a distribution to a donor, donor advisor, or related person?		
10	Section 501(c)(7) organizations. Enter		
10a	Initiation fees and capital contributions included on Part VIII, line 12		
10b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities		
11	Section 501(c)(12) organizations. Enter		
11a	Gross income from members or shareholders		
11b	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them)		
12a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?		
12b	If "Yes," enter the amount of tax-exempt interest received or accrued during the year		
13	Section 501(c)(29) qualified nonprofit health insurance issuers.		
13a	Is the organization licensed to issue qualified health plans in more than one state? Note. See the instructions for additional information the organization must report on Schedule O		
13b	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		
13c	Enter the amount of reserves on hand		
14a	Did the organization receive any payments for indoor tanning services during the tax year?		No
14b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O		

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

Check if Schedule O contains a response to any question in this Part VI [X]

Section A. Governing Body and Management

Table with 3 columns: Question, Yes, No. Rows include: 1a (3), 1b (5), 2 (Yes), 3 (No), 4 (No), 5 (No), 6 (No), 7a (No), 7b (No), 8a (Yes), 8b (Yes), 9 (No).

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

Table with 3 columns: Question, Yes, No. Rows include: 10a (No), 10b, 11a (Yes), 11b, 12a (Yes), 12b (Yes), 12c (Yes), 13 (Yes), 14 (Yes), 15a (Yes), 15b (No), 16a (No), 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
19 Describe in Schedule O whether (and if so, how), the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year
20 State the name, physical address, and telephone number of the person who possesses the books and records of the organization

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

Check if Schedule O contains a response to any question in this Part VII

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

1a Complete this table for all persons required to be listed Report compensation for the calendar year ending with or within the organization's tax year

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

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

• List the organization's five **current** highest compensated employees (other than an officer, director, trustee or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations

• List all of the organization's **former** officers, key employees, or 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

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

(A) Name and Title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W- 2/1099-MISC)	(E) Reportable compensation from related organizations (W- 2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
(1) T CRAIG BENSON Director	20 00	X						0	0	0
(2) DR MARK CHANDLER Director	4 00	X						0	0	0
(3) DR KYLE L JANEK Director	4 00	X						0	0	0
(4) MARY BETH KISER President & Exec Dir	40 00			X				0	66,346	0
(5) PATRICK S MCCLAIN VP, Secr, Treasurer	1 00			X				0	0	0
(6) DANIELLE KERKOVICH Scientific Officer	40 00				X			0	129,006	0

Part VIII Statement of Revenue

Check if Schedule O contains a response to any question in this Part VIII

			(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512, 513, or 514	
Contributions, Gifts, Grants and Other Similar Amounts	1a	Federated campaigns 1a					
	b	Membership dues 1b					
	c	Fundraising events 1c	178,480				
	d	Related organizations 1d					
	e	Government grants (contributions) 1e					
	f	All other contributions, gifts, grants, and similar amounts not included above 1f	1,035,183				
	g	Noncash contributions included in lines 1a-1f \$ 1g	4,996				
	h	Total. Add lines 1a-1f h	1,213,663				
Program Service Revenue	2a	_____ Business Code _____					
	b	_____					
	c	_____					
	d	_____					
	e	_____					
	f	All other program service revenue					
	g	Total. Add lines 2a-2f g					
Other Revenue	3	Investment income (including dividends, interest, and other similar amounts) 3	545				
	4	Income from investment of tax-exempt bond proceeds 4					
	5	Royalties 5					
	6a	Gross rents	(i) Real				
			(ii) Personal				
			b Less rental expenses				
			c Rental income or (loss)				
	d	Net rental income or (loss) d					
	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) d					
	8a	Gross income from fundraising events (not including \$ 178,480 of contributions reported on line 1c) See Part IV, line 18 a					
			b Less direct expenses b	238,389			
c Net income or (loss) from fundraising events c			59,364			59,364	
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 c					
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 c					
Miscellaneous Revenue		Business Code					
11a	_____						
b	_____						
c	_____						
d	All other revenue d						
e	Total. Add lines 11a-11d e						
12	Total revenue. See Instructions 12	1,273,572	545		59,364		

Part IX Statement of Functional Expenses

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

Check if Schedule O contains a response to any question in this Part IX

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.		(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1	Grants and other assistance to governments and organizations in the United States. See Part IV, line 21				
2	Grants and other assistance to individuals in the United States. See Part IV, line 22	115,249	115,249		
3	Grants and other assistance to governments, organizations, and individuals outside the United States. See Part IV, lines 15 and 16	156,485	156,485		
4	Benefits paid to or for members				
5	Compensation of current officers, directors, trustees, and key employees	66,346	46,442	3,317	16,587
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	191,261	105,528	18,115	67,618
8	Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
9	Other employee benefits	13,676	9,710	684	3,282
10	Payroll taxes	18,782	11,194	1,531	6,057
11	Fees for services (non-employees)				
a	Management				
b	Legal	162,321	161,171	1,150	0
c	Accounting	3,939	2,797	197	945
d	Lobbying				
e	Professional fundraising services. See Part IV, line 17				
f	Investment management fees				
g	Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O)	60,089	53,691	4,544	1,854
12	Advertising and promotion	89,997	0	0	89,997
13	Office expenses	16,236	246	10,086	5,904
14	Information technology	1,780	760	176	844
15	Royalties				
16	Occupancy	8,383	2,795	2,794	2,794
17	Travel	82,034	29,293	48,200	4,541
18	Payments of travel or entertainment expenses for any federal, state, or local public officials				
19	Conferences, conventions, and meetings	780	390	390	0
20	Interest	56,677	56,677	0	0
21	Payments to affiliates				
22	Depreciation, depletion, and amortization	1,736	1,233	86	417
23	Insurance				
24	Other expenses. Itemize expenses not covered above (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O)				
a	Bank/Credit Card Fees	16,008	0	0	16,008
b	Research	19,080	19,080	0	0
c	Postage	5,292	533	4,645	114
d					
e	All other expenses				
25	Total functional expenses. Add lines 1 through 24e	1,086,151	773,274	95,915	216,962
26	Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here <input type="checkbox"/> if following SOP 98-2 (ASC 958-720)				

Part X Balance Sheet

Check if Schedule O contains a response to any question in this Part X

		(A) Beginning of year		(B) End of year
Assets	1 Cash—non-interest-bearing	1,055,958	1	1,592,035
	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 officers, directors, trustees, key employees, and highest compensated employees Complete Part II of Schedule L		5	
	6 Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing employers and sponsoring organizations of section 501(c)(9) voluntary employees' beneficiary organizations (see instructions) 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	10,970	9	10,844
	10a Land, buildings, and equipment cost or other basis Complete Part VI of Schedule D	6,810		
	b Less accumulated depreciation	4,183	1,497	2,627
	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)	1,068,425	16	1,605,506	
Liabilities	17 Accounts payable and accrued expenses	348,032	17	306,435
	18 Grants payable	336,666	18	605,411
	19 Deferred revenue		19	
	20 Tax-exempt bond liabilities		20	
	21 Escrow or custodial account liability Complete Part IV of Schedule D		21	
	22 Loans and other payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons Complete Part II of Schedule L	723,233	22	686,993
	23 Secured mortgages and notes payable to unrelated third parties		23	
	24 Unsecured notes and loans payable to unrelated third parties		24	
	25 Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24) Complete Part X of Schedule D		25	
	26 Total liabilities. Add lines 17 through 25	1,407,931	26	1,598,839
Net Assets or Fund Balances	Organizations that follow SFAS 117 (ASC 958), check here <input checked="" type="checkbox"/> and complete lines 27 through 29, and lines 33 and 34.			
	27 Unrestricted net assets	-339,506	27	6,667
	28 Temporarily restricted net assets		28	
	29 Permanently restricted net assets		29	
	Organizations that do not follow SFAS 117 (ASC 958), check here <input type="checkbox"/> 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	-339,506	33	6,667	
34 Total liabilities and net assets/fund balances	1,068,425	34	1,605,506	

Part XI Reconciliation of Net Assets

Check if Schedule O contains a response to any question in this Part XI

1	Total revenue (must equal Part VIII, column (A), line 12)	1	1,273,572
2	Total expenses (must equal Part IX, column (A), line 25)	2	1,086,151
3	Revenue less expenses Subtract line 2 from line 1	3	187,421
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	-339,506
5	Net unrealized gains (losses) on investments	5	
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	158,752
9	Other changes in net assets or fund balances (explain in Schedule O)	9	
10	Net assets or fund balances at end of year Combine lines 3 through 9 (must equal Part X, line 33, column (B))	10	6,667

Part XII Financial Statements and Reporting

Check if Schedule O contains a response to any question in this Part XII

	Yes	No
1 Accounting method used to prepare the Form 990 <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other _____ If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule O		
2a Were the organization's financial statements compiled or reviewed by an independent accountant? If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		No
2b Were the organization's financial statements audited by an independent accountant? If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both <input type="checkbox"/> Separate basis <input checked="" type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis	Yes	
2c If "Yes," to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O	Yes	
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
3b 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)

Public Charity Status and Public Support

OMB No 1545-0047

2012

Open to Public Inspection

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.

Department of the Treasury
Internal Revenue Service

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 described in **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 - Non-functionally integrated
- 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 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)

	Yes	No
11g(i)		
11g(ii)		
11g(iii)		

(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 monetary support
			Yes	No	Yes	No	Yes	No	
Total									

Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)
 (Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ▶	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")	1,290,974	683,182	829,046	1,541,127	1,213,663	5,557,992
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	829,046	1,541,127	1,213,663	5,557,992
5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f)						
6 Public support. Subtract line 5 from line 4						5,557,992

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
7 Amounts from line 4	1,290,974	683,182	829,046	1,541,127	1,213,663	5,557,992
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	5,159	54	369	327	545	6,454
9 Net income from unrelated business activities, whether or not the business is regularly carried on						
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)						
11 Total support (Add lines 7 through 10)						5,564,446

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 <input checked="" type="checkbox"/>		

Section C. Computation of Public Support Percentage

14 Public support percentage for 2012 (line 6, column (f) divided by line 11, column (f))	14	0 %
15 Public support percentage for 2011 Schedule A, Part II, line 14	15	

16a 33 1/3% support test—2012. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization <input type="checkbox"/>		
b 33 1/3% support test—2011. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization <input type="checkbox"/>		
17a 10%-facts-and-circumstances test—2012. 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 <input type="checkbox"/>		
b 10%-facts-and-circumstances test—2011. 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 <input type="checkbox"/>		
18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions <input type="checkbox"/>		

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

(Complete only if you checked the box on line 9 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ▶	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")						
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5						
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
c Add lines 7a and 7b						
8 Public support (Subtract line 7c from line 6)						0

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
9 Amounts from line 6						
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b						
11 Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)						
13 Total support. (Add lines 9, 10c, 11, and 12.)						
14 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a 501(c)(3) organization, check this box and stop here <input type="checkbox"/>						

Section C. Computation of Public Support Percentage

15 Public support percentage for 2012 (line 8, column (f) divided by line 13, column (f))	15	0 %
16 Public support percentage from 2011 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2012 (line 10c, column (f) divided by line 13, column (f))	17	0 %
18 Investment income percentage from 2011 Schedule A, Part III, line 17	18	

- 19a 33 1/3% support tests—2012.** If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and **stop here**. The organization qualifies as a publicly supported organization
- b 33 1/3% support tests—2011.** If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3% and line 18 is not more than 33 1/3%, check this box and **stop here**. The organization qualifies as a publicly supported organization
- 20 Private foundation.** If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions

Part IV **Supplemental Information.** Complete this part to provide the explanations required by Part II, line 10; Part II, line 17a or 17b; and Part III, line 12. Also complete this part for any additional information. (See instructions).

Facts And Circumstances Test

Explanation

SCHEDULE D (Form 990)

OMB No 1545-0047

Supplemental Financial Statements

2012

Open to Public Inspection

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

Department of the Treasury Internal Revenue Service

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.

Table with 3 columns: Line number, (a) Donor advised funds, (b) Funds and other accounts. Rows 1-4 showing total number at end of year, aggregate contributions, aggregate grants, and aggregate value.

- 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?
6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit?

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

Table with 2 columns: Line number, Held at the End of the Year. Rows 2a-2d.

- 3 Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year
4 Number of states where property subject to conservation easement is located
5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds?
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 section 170(h)(4)(B)(ii)?
9 In Part XIII, describe how the organization reports conservation easements in its revenue and expense statement, and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements

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

- 1a If the organization elected, as permitted under SFAS 116 (ASC 958), not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIII, the text of the footnote to its financial statements that describes these items
1b If the organization elected, as permitted under SFAS 116 (ASC 958), to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items
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 (ASC 958) relating to these items

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

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

- a** Public exhibition
- b** Scholarly research
- c** Preservation for future generations
- d** Loan or exchange programs
- e** Other

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

5 During the year, did the organization solicit or receive donations of art, historical treasures or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection? Yes No

Part IV Escrow and Custodial Arrangements. Complete if the organization answered "Yes" 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 XIII and complete the following table

	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 XIII. Check here if the explanation has been provided in Part XIII

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 Net investment earnings, gains, and losses					
d Grants or scholarships					
e Other expenditures for facilities and programs					
f Administrative expenses					
g End of year balance					

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

- a** Board designated or quasi-endowment ▶
 - b** Permanent endowment ▶
 - c** Temporarily restricted endowment ▶
- The percentages in lines 2a, 2b, and 2c should equal 100%

3a Are there endowment funds not in the possession of the organization that are held and administered for the organization by

	Yes	No
(i) unrelated organizations	3a(i)	
(ii) related organizations	3a(ii)	
b If "Yes" to 3a(ii), are the related organizations listed as required on Schedule R?	3b	

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

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

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements				
d Equipment	6,810		4,183	2,627
e Other				
Total. Add lines 1a through 1e (Column (d) must equal Form 990, Part X, column (B), line 10(c).)				2,627

Part VII Investments—Other Securities. See Form 990, Part X, line 12.

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

Part VIII Investments—Program Related. See Form 990, Part X, line 13.

(a) Description of investment type	(b) Book value	(c) Method of valuation Cost or end-of-year market value
Total. (Column (b) must equal Form 990, Part X, col (B) line 13.)		

Part IX Other Assets. See Form 990, Part X, line 15.

(a) Description	(b) Book value
Total. (Column (b) must equal Form 990, Part X, col.(B) line 15.)	

Part X Other Liabilities. See Form 990, Part X, line 25.

1	(a) Description of liability	(b) Book value
	Federal income taxes	
Total. (Column (b) must equal Form 990, Part X, col (B) line 25.)		

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

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

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 XIII)	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 XIII)	4b		
c	Add lines 4a and 4b		4c	
5	Total revenue Add lines 3 and 4c . (This must equal Form 990, Part I, line 12)		5	

Part XII 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 XIII)	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 XIII)	4b		
c	Add lines 4a and 4b		4c	
5	Total expenses Add lines 3 and 4c . (This must equal Form 990, Part I, line 18)		5	

Part XIII 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, line 2, Part XI, lines 2d and 4b, and Part XII, lines 2d and 4b Also complete this part to provide any additional information

Identifier	Return Reference	Explanation
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SCHEDULE F (Form 990)

Statement of Activities Outside the United States

OMB No 1545-0047

2012

Open to Public Inspection

Complete if the organization answered "Yes" to Form 990, Part IV, line 14b, 15, or 16. Attach to Form 990. See separate instructions.

Department of the Treasury Internal Revenue Service

Name of the organization BEYOND BATTEN DISEASE FOUNDATION

Employer identification number 26-3223661

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

1 For grantmakers. 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 For grantmakers. Describe in Part V the organization's procedures for monitoring the use of grant funds outside the United States.

3 Activities per Region (The following Part I, line 3 table can be duplicated if additional space is needed)

Table with 6 columns: (a) Region, (b) Number of offices in the region, (c) Number of employees, agents, and independent contractors in region, (d) Activities conducted in region (by type), (e) If activity listed in (d) is a program service, describe specific type of service(s) in region, (f) Total expenditures for and investments in region. Includes sub-totals and totals rows.

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

1	(a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of non-cash assistance	(h) Description of non-cash assistance	(i) Method of valuation (book, FMV, appraisal, other)
			Europe	Medical Research	26,485	Wire			
			Middle East	Medical Research	130,000	Wire			

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

3 Enter total number of other organizations or entities

Part III **Grants and Other Assistance to Individuals Outside the United States.** Complete if the organization answered "Yes" to Form 990, Part IV, line 16.
Part III can be duplicated if additional space is needed.

(a) Type of grant or assistance	(b) Region	(c) Number of recipients	(d) Amount of cash grant	(e) Manner of cash disbursement	(f) Amount of non-cash assistance	(g) Description of non-cash assistance	(h) Method of valuation (book, FMV, appraisal, other)
Medical Research	Europe	1					

Part IV Foreign Forms

- 1 Was the organization a U S transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926)* Yes No
- 2 Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to file Form 3520, Annual Return to Report Transactions with Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see Instructions for Forms 3520 and 3520-A)* Yes No
- 3 Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons with Respect to Certain Foreign Corporations. (see Instructions for Form 5471)* Yes No
- 4 Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund. (see Instructions for Form 8621)* Yes No
- 5 Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons with Respect to Certain Foreign Partnerships. (see Instructions for Form 8865)* Yes No
- 6 Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to file Form 5713, International Boycott Report (see Instructions for Form 5713).* Yes No

SCHEDULE G (Form 990 or 990-EZ)

Supplemental Information Regarding Fundraising or Gaming Activities

OMB No 1545-0047

2012

Open to Public Inspection

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. Form 990-EZ filers are not required to complete this part.

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

Department of the Treasury Internal Revenue Service

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.

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

- a Mail solicitations, b Internet and email solicitations, c Phone solicitations, d In-person solicitations, e Solicitation of non-government grants, f Solicitation of government grants, g Special fundraising events

2a Did the organization have a written or oral agreement with any individual... 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

Table with 6 columns: (i) Name and address of individual or entity (fundraiser), (ii) Activity, (iii) Did fundraiser have custody or control of contributions?, (iv) Gross receipts from activity, (v) Amount paid to (or retained by) fundraiser listed in col (i), (vi) Amount paid to (or retained by) organization. Includes a Total row at the bottom.

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 of fundraising event contributions and gross income on Form 990-EZ, lines 1 and 6b. List events with gross receipts greater than \$5,000.

		(a) Event #1	(b) Event #2	(c) Other events	(d) Total events
		<u>GOLF EVENTS</u> (event type)	<u>GALA EVENTS</u> (event type)	(total number)	(add col (a) through col (c))
Revenue	1 Gross receipts	66,080	232,576	118,213	416,869
	2 Less Contributions	28,292	99,576	50,612	178,480
	3 Gross income (line 1 minus line 2)	37,788	133,000	67,601	238,389
Direct Expenses	4 Cash prizes				
	5 Noncash prizes				
	6 Rent/facility costs	14,690	38,488	5,909	59,087
	7 Food and beverages	18,211	8,066	5,120	31,397
	8 Entertainment		10,895		10,895
	9 Other direct expenses	17,731	37,599	22,316	77,646
	10 Direct expense summary Add lines 4 through 9 in column (d) ▶				
11 Net income summary Combine line 3, column (d), and line 10 ▶					59,364

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))
		1 Gross revenue			
Direct Expenses	2 Cash prizes				
	3 Non-cash prizes				
	4 Rent/facility costs				
	5 Other direct expenses				
	6 Volunteer labor	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	
7 Direct expense summary Add lines 2 through 5 in column (d) ▶					
8 Net gaming income summary Combine lines 1 and 7 in column (d) ▶					

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? Yes No

b If "No," explain _____

.....

.....

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

b If "Yes," explain _____

.....

.....

Does the organization operate gaming activities with nonmembers? Yes No

12 Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity formed to administer charitable gaming? Yes No

13 Indicate the percentage of gaming activity operated in

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

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

Name ▶

Address ▶

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

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

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

Name ▶

Address ▶

16 Gaming manager information

Name ▶

Gaming manager compensation ▶ \$

Description of services provided ▶

Director/officer Employee Independent contractor

17 Mandatory distributions

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

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

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

Identifier	Return Reference	Explanation
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Schedule I (Form 990)

OMB No 1545-0047

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

2012

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

Open to Public Inspection

Department of the Treasury Internal Revenue Service

Name of the organization BEYOND BATTEN DISEASE FOUNDATION

Employer identification number 26-3223661

Part I General Information on Grants and Assistance

- 1 Does the organization maintain records to substantiate the amount of the grants or assistance...
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.

Table with 8 columns: (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, (g) Description of non-cash assistance, (h) Purpose of grant or assistance. Includes entries for ALBERT EINSTEIN COLLEGE and AMERICAN BRAIN FOUNDATION.

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

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

Part III can be duplicated if additional space is needed.

(a) Type of grant or assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of non-cash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of non-cash assistance

Part IV Supplemental Information.

Complete this part to provide the information required in Part I, line 2, Part III, column (b), and any other additional information

Identifier	Return Reference	Explanation
Pt I Line 2		Grantees are required to submit periodic progress reports, both narrative
Pt I Line 2		and financial, outlining their progress toward meeting the goals of their
Pt I Line 2		project, and describing all expenditures. The reports are reviewed to
Pt I Line 2		ensure compliance with the original scope of work and proposed budget.

Schedule L (Form 990 or 990-EZ)

Transactions with Interested Persons

OMB No 1545-0047

2012

Open to Public Inspection

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, line 38a or 40b. Attach to Form 990 or Form 990-EZ. See separate instructions.

Department of the Treasury Internal Revenue Service

Name of the organization BEYOND BATTEN DISEASE FOUNDATION

Employer identification number

26-3223661

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

Table with 4 columns: (a) Name of disqualified person, (b) Relationship between disqualified person and organization, (c) Description of transaction, (d) Corrected? (Yes/No)

2 Enter the amount of tax incurred by 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-EZ, Part V, line 38a, or Form 990, Part IV, line 26, or if the organization reported an amount on Form 990, Part X, line 5, 6, or 22

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

Part III Grants or Assistance Benefitting Interested Persons.

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

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

Part IV Business Transactions Involving Interested Persons.

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

(a) Name of interested person	(b) Relationship between interested person and the organization	(c) Amount of transaction	(d) Description of transaction	(e) Sharing of organization's revenues?	
				Yes	No

Part V Supplemental Information

Complete this part to provide additional information for responses to questions on Schedule L (see instructions)

Identifier	Return Reference	Explanation

SCHEDULE O
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

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

OMB No 1545-0047

2012

Open to Public Inspection

Name of the organization
BEYOND BATTEN DISEASE FOUNDATION

Employer identification number

26-3223661

Identifier	Return Reference	Explanation
Pt VI, 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, Biophysical Corporation Craig Benson and Patrick
		McClain are officers of Myriad RBM There are no business
		relationships between the Foundation and the for profit
		companies listed above
Pt VI, Line 8a		All meetings were documented by Board minutes
Pt VI, Line 11b		The Form 990 is provided to all Board Members and officers for review before filing
Pt VI, Line 12c		Each director and officer 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, Line 15a		Executive Director/President's compensation is reviewed by
		the Board of Directors
Pt VI, 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		Exploration of LMP in NCL disease
Sched I, Purpose		Patient-oriented research to develop treatments in juvenile Batten disease
Form 990, Part IX, Line 24f		STAFF DEVELOPMENT TELEPHONE PRINTING & PUBLICATIONS