

Form **990**

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

OMB No. 1545-0047

**2023**  
Open to Public Inspection

Department of the Treasury  
Internal Revenue Service

Do not enter social security numbers on this form as it may be made public.  
Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

**A For the 2023 calendar year, or tax year beginning , and ending**

**B** Check if applicable:  
 Address change  
 Name change  
 Initial return  
 Final return/terminated  
 Amended return  
 Application pending

**C** Name of organization: **Batten Disease Support & Research Association**  
 Doing business as: \_\_\_\_\_  
 Number and street (or P.O. box if mail is not delivered to street address): **104 Mill Street, Suite G** Room/suite: \_\_\_\_\_  
 City or town, state or province, country, and ZIP or foreign postal code: **Columbus OH 43219**

**D** Employer identification number: **\*\*-\*\*\*7792**

**E** Telephone number: **800-448-4570**

**F** Name and address of principal officer:  
**Amy Fenton Parker**  
**104 Mill Street, Suite G**  
**Gahanna OH 43230**

**G** Gross receipts\$ **746,147**

**H(a)** Is this a group return for subordinates?  Yes  No  
**H(b)** Are all subordinates included?  Yes  No  
 If "No," attach a list. See instructions

**I** Tax-exempt status:  501(c)(3)  501(c) ( ) (insert no.)  4947(a)(1) or  527

**J** Website: **N/A** **H(c)** Group exemption number: \_\_\_\_\_

**K** Form of organization:  Corporation  Trust  Association  Other

**L** Year of formation: **1987** **M** State of legal domicile: **OH**

**Part I Summary**

<b>Activities &amp; Governance</b>	<b>1</b> Briefly describe the organization's mission or most significant activities: <b>Our long-term vision is a world without Batten disease. Our mission is to support Batten families, fund and facilitate research and advocate for treatments and a cure.</b>		
	<b>2</b> Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.		
	<b>3</b> Number of voting members of the governing body (Part VI, line 1a)	<b>3</b>	<b>14</b>
	<b>4</b> Number of independent voting members of the governing body (Part VI, line 1b)	<b>4</b>	<b>14</b>
	<b>5</b> Total number of individuals employed in calendar year 2023 (Part V, line 2a)	<b>5</b>	<b>4</b>
	<b>6</b> Total number of volunteers (estimate if necessary)	<b>6</b>	<b>45</b>
	<b>7a</b> Total unrelated business revenue from Part VIII, column (C), line 12	<b>7a</b>	<b>0</b>
<b>b</b> Net unrelated business taxable income from Form 990-T, Part I, line 11	<b>7b</b>	<b>0</b>	
<b>Revenue</b>	<b>8</b> Contributions and grants (Part VIII, line 1h)	Prior Year	Current Year
	<b>9</b> Program service revenue (Part VIII, line 2g)	<b>1,064,250</b>	<b>724,656</b>
	<b>10</b> Investment income (Part VIII, column (A), lines 3, 4, and 7d)	<b>6,000</b>	<b>0</b>
	<b>11</b> Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	<b>19,641</b>	<b>21,491</b>
	<b>12</b> Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	<b>1,099,485</b>	<b>746,147</b>
<b>Expenses</b>	<b>13</b> Grants and similar amounts paid (Part IX, column (A), lines 1-3)	<b>40,000</b>	<b>82,000</b>
	<b>14</b> Benefits paid to or for members (Part IX, column (A), line 4)	<b>0</b>	<b>0</b>
	<b>15</b> Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	<b>291,497</b>	<b>312,694</b>
	<b>16a</b> Professional fundraising fees (Part IX, column (A), line 11e)	<b>0</b>	<b>0</b>
	<b>b</b> Total fundraising expenses (Part IX, column (D), line 25)	<b>66,942</b>	
	<b>17</b> Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	<b>526,805</b>	<b>557,342</b>
<b>18</b> Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	<b>858,302</b>	<b>952,036</b>	
<b>19</b> Revenue less expenses. Subtract line 18 from line 12	<b>241,183</b>	<b>-205,889</b>	
<b>Net Assets or Fund Balances</b>	<b>20</b> Total assets (Part X, line 16)	Beginning of Current Year	End of Year
	<b>21</b> Total liabilities (Part X, line 26)	<b>1,291,125</b>	<b>1,203,251</b>
	<b>22</b> Net assets or fund balances. Subtract line 21 from line 20	<b>17,543</b>	<b>82,983</b>
		<b>1,273,582</b>	<b>1,120,268</b>

**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: **Amy Fenton Parker** Date: \_\_\_\_\_  
 Type or print name and title: **President & CEO**

**Paid Preparer Use Only**

Print/Type preparer's name: **Donald Wells** Preparer's signature: **Donald Wells** Date: **08/30/24** Check  if self-employed PTIN: **\*\*\*\*\***

Firm's name: **Wells CPA LLC.** Firm's EIN: **\*\* - \*\*\*1346**  
 Firm's address: **215 N Front St Ste 110 Columbus, OH 43215** Phone no.: **614-396-8974**

May the IRS discuss this return with the preparer shown above? See instructions  Yes  No

For Paperwork Reduction Act Notice, see the separate instructions.

**Part III Statement of Program Service Accomplishments**

Check if Schedule O contains a response or note to any line in this Part III

**1** Briefly describe the organization's mission:  
**Our long-term vision is a world without Batten disease. Our mission is to support Batten families, fund and facilitate research and advocate for treatments and a cure.**

**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 \$ **585,142** including grants of \$ **82,000** ) (Revenue \$ )  
**Programs such as the sibling program, Family Help Fund, parent/mentors and the general bereavement program all will help to alleviate stress and hardship on families whose loved ones are victims of Batten disease.**

**4b** (Code: ) (Expenses \$ including grants of \$ ) (Revenue \$ )  
**Grants were given for research for a cure for Batten Disease.**

**4c** (Code: ) (Expenses \$ including grants of \$ ) (Revenue \$ )  
**Conferences and conventions held for research, discussions and support for a cure for Batten disease.**

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

**4e** Total program service expenses **585,142**

**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>	X	
2	Is the organization required to complete Schedule B, Schedule of Contributors? See instructions	X	
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>		X
4	<b>Section 501(c)(3) organizations.</b> 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>		X
5	Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Rev. Proc. 98-19? <i>If "Yes," complete Schedule C, Part III</i>		X
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>		X
7	Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? <i>If "Yes," complete Schedule D, Part II</i>		X
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>		X
9	Did the organization report an amount in Part X, line 21, for escrow or custodial account liability; serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? <i>If "Yes," complete Schedule D, Part IV</i>		X
10	Did the organization, directly or through a related organization, hold assets in donor-restricted endowments or in quasi-endowments? <i>If "Yes," complete Schedule D, Part V</i>		X
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>	X	
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>		X
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>		X
d	Did the organization report an amount for other assets in Part X, line 15, that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part IX</i>		X
e	Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X</i>		X
f	Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? <i>If "Yes," complete Schedule D, Part X</i>		X
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>		X
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>		X
13	Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E</i>		X
14a	Did the organization maintain an office, employees, or agents outside of the United States?		X
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>		X
15	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? <i>If "Yes," complete Schedule F, Parts II and IV</i>	X	
16	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? <i>If "Yes," complete Schedule F, Parts III and IV</i>		X
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>		X
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>		X
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>		X
20a	Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H</i>		X
b	If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?		
21	Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>	X	

**Part IV Checklist of Required Schedules (continued)**

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

**Part V Statements Regarding Other IRS Filings and Tax Compliance**

Check if Schedule O contains a response or note to any line in this Part V

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

<b>Part V Statements Regarding Other IRS Filings and Tax Compliance</b> <i>(continued)</i>		Yes	No
<b>2a</b>	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	<b>2a</b>	<b>4</b>
<b>b</b>	If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	<b>2b</b>	<b>X</b>
<b>3a</b>	Did the organization have unrelated business gross income of \$1,000 or more during the year?	<b>3a</b>	<b>X</b>
<b>b</b>	If "Yes," has it filed a Form 990-T for this year? <i>If "No" to line 3b, provide an explanation on Schedule O</i>	<b>3b</b>	
<b>4a</b>	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?	<b>4a</b>	<b>X</b>
<b>b</b>	If "Yes," enter the name of the foreign country See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).		
<b>5a</b>	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	<b>5a</b>	<b>X</b>
<b>b</b>	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	<b>5b</b>	<b>X</b>
<b>c</b>	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?	<b>5c</b>	
<b>6a</b>	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions?	<b>6a</b>	<b>X</b>
<b>b</b>	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	<b>6b</b>	
<b>7</b>	<b>Organizations that may receive deductible contributions under section 170(c).</b>		
<b>a</b>	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?	<b>7a</b>	<b>X</b>
<b>b</b>	If "Yes," did the organization notify the donor of the value of the goods or services provided?	<b>7b</b>	
<b>c</b>	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?	<b>7c</b>	<b>X</b>
<b>d</b>	If "Yes," indicate the number of Forms 8282 filed during the year	<b>7d</b>	
<b>e</b>	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	<b>7e</b>	<b>X</b>
<b>f</b>	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	<b>7f</b>	<b>X</b>
<b>g</b>	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	<b>7g</b>	<b>X</b>
<b>h</b>	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?	<b>7h</b>	<b>X</b>
<b>8</b>	<b>Sponsoring organizations maintaining donor advised funds.</b> Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?	<b>8</b>	
<b>9</b>	<b>Sponsoring organizations maintaining donor advised funds.</b>		
<b>a</b>	Did the sponsoring organization make any taxable distributions under section 4966?	<b>9a</b>	
<b>b</b>	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?	<b>9b</b>	
<b>10</b>	<b>Section 501(c)(7) organizations.</b> Enter:		
<b>a</b>	Initiation fees and capital contributions included on Part VIII, line 12	<b>10a</b>	
<b>b</b>	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities	<b>10b</b>	
<b>11</b>	<b>Section 501(c)(12) organizations.</b> Enter:		
<b>a</b>	Gross income from members or shareholders	<b>11a</b>	
<b>b</b>	Gross income from other sources. (Do not net amounts due or paid to other sources against amounts due or received from them.)	<b>11b</b>	
<b>12a</b>	<b>Section 4947(a)(1) non-exempt charitable trusts.</b> Is the organization filing Form 990 in lieu of Form 1041?	<b>12a</b>	
<b>b</b>	If "Yes," enter the amount of tax-exempt interest received or accrued during the year	<b>12b</b>	
<b>13</b>	<b>Section 501(c)(29) qualified nonprofit health insurance issuers.</b>		
<b>a</b>	Is the organization licensed to issue qualified health plans in more than one state? <b>Note:</b> See the instructions for additional information the organization must report on Schedule O.	<b>13a</b>	
<b>b</b>	Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans	<b>13b</b>	
<b>c</b>	Enter the amount of reserves on hand	<b>13c</b>	
<b>14a</b>	Did the organization receive any payments for indoor tanning services during the tax year?	<b>14a</b>	<b>X</b>
<b>b</b>	If "Yes," has it filed a Form 720 to report these payments? <i>If "No," provide an explanation on Schedule O</i>	<b>14b</b>	
<b>15</b>	Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or excess parachute payment(s) during the year? If "Yes," see instructions and file Form 4720, Schedule N.	<b>15</b>	<b>X</b>
<b>16</b>	Is the organization an educational institution subject to the section 4968 excise tax on net investment income? If "Yes," complete Form 4720, Schedule O.	<b>16</b>	<b>X</b>
<b>17</b>	<b>Section 501(c)(21) organizations.</b> Did the trust, any disqualified or other person engage in any activities that would result in the imposition of an excise tax under section 4951, 4952 or 4953? If "Yes," complete Form 6069.	<b>17</b>	

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

**Section A. Governing Body and Management**

		Yes	No
<b>1a</b>	Enter the number of voting members of the governing body at the end of the tax year If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain on Schedule O.		
<b>1b</b>	Enter the number of voting members included on line 1a, above, who are independent		
<b>2</b>	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?		<b>X</b>
<b>3</b>	Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors, trustees, or key employees to a management company or other person?		<b>X</b>
<b>4</b>	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?		<b>X</b>
<b>5</b>	Did the organization become aware during the year of a significant diversion of the organization's assets?		<b>X</b>
<b>6</b>	Did the organization have members or stockholders?		<b>X</b>
<b>7a</b>	Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body?		<b>X</b>
<b>b</b>	Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?		<b>X</b>
<b>8</b>	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:		
<b>a</b>	The governing body?	<b>X</b>	
<b>b</b>	Each committee with authority to act on behalf of the governing body?	<b>X</b>	
<b>9</b>	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses on Schedule O		<b>X</b>

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

		Yes	No
<b>10a</b>	Did the organization have local chapters, branches, or affiliates?	<b>X</b>	
<b>b</b>	If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes?	<b>X</b>	
<b>11a</b>	Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?	<b>X</b>	
<b>b</b>	Describe on Schedule O the process, if any, used by the organization to review this Form 990.		
<b>12a</b>	Did the organization have a written conflict of interest policy? If "No," go to line 13	<b>X</b>	
<b>b</b>	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	<b>X</b>	
<b>c</b>	Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe on Schedule O how this was done	<b>X</b>	
<b>13</b>	Did the organization have a written whistleblower policy?	<b>X</b>	
<b>14</b>	Did the organization have a written document retention and destruction policy?	<b>X</b>	
<b>15</b>	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?		
<b>a</b>	The organization's CEO, Executive Director, or top management official		<b>X</b>
<b>b</b>	Other officers or key employees of the organization		<b>X</b>
	If "Yes" to line 15a or 15b, describe the process on Schedule O. See instructions.		
<b>16a</b>	Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year?		<b>X</b>
<b>b</b>	If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements?		

**Section C. Disclosure**

- 17** List the states with which a copy of this Form 990 is required to be filed **None**
- 18** Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, and 990-T (section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.  
 Own website    Another's website    Upon request    Other (explain on Schedule O)
- 19** Describe on Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.
- 20** State the name, address, and telephone number of the person who possesses the organization's books and records.

**Amy Fenton Parker**  
**Gahanna**

**104 Mill Street, Suite G**

**OH 43230**

**800-448-4570**

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

Check if Schedule O contains a response or note to any line in this Part VII

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

**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, box 6 of Form 1099-MISC, and/or box 1 of Form 1099-NEC) of more than \$100,000 from the organization and any related organizations.
- List all of the organization's **former** officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations. See the instructions for the order in which to list the persons above.

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC/1099-NEC)	(E) Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(1) Amy Fenton Parker ..... President & CEO	40.00 ..... 0.00			X				98,500	0	0
(2) Darlene Royalty ..... Board Chair	1.00 ..... 0.00	X		X				0	0	0
(3) Barbara Wuebbels ..... Board Vice Chair	1.00 ..... 0.00	X		X				0	0	0
(4) Barbara McDonough ..... Secretary	1.00 ..... 0.00	X		X				0	0	0
(5) Fred Surrey ..... Treasurer	1.00 ..... 0.00	X		X				0	0	0
(6) John Ireland ..... Sibling Rep.	1.00 ..... 0.00	X						0	0	0
(7) Donna Fogle ..... Director	1.00 ..... 0.00	X						0	0	0
(8) Tony Ferrandino ..... Director	1.00 ..... 0.00	X						0	0	0
(9) Wayne Kiefer ..... Director	1.00 ..... 0.00	X						0	0	0
(10) Kate Haller ..... Director	1.00 ..... 0.00	X						0	0	0
(11) David Pearce ..... Director	1.00 ..... 0.00	X						0	0	0

**Part VII Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees** (continued)

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC/1099-NEC)	(E) Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(12) <b>Kyleen Douglas</b>										
(12) Director	1.00 0.00	X					0	0	0	
(13) <b>Suzette James</b>										
(13) Director	1.00 0.00	X					0	0	0	
(14) <b>Fernanda Leal-Pardinas</b>										
(14) Director	1.00 0.00	X					0	0	0	
(15) <b>John Patterson</b>										
(15) Director	1.00 0.00	X					0	0	0	
(16)										
(17)										
(18)										
(19)										
<b>1b Subtotal</b>							<b>98,500</b>			
<b>c Total from continuation sheets to Part VII, Section A</b>										
<b>d Total (add lines 1b and 1c)</b>							<b>98,500</b>			

**2** Total number of individuals (including but not limited to those listed above) who received more than \$100,000 of reportable compensation from the organization **0**

	Yes	No
<b>3</b> Did the organization list any <b>former</b> officer, director, trustee, key employee, or highest compensated employee on line 1a? <i>If "Yes," complete Schedule J for such individual</i>		<b>X</b>
<b>4</b> 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>		<b>X</b>
<b>5</b> Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? <i>If "Yes," complete Schedule J for such person</i>		<b>X</b>

**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. Report compensation for the calendar year ending with or within the organization's tax year.

(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 of compensation from the organization **0**



**Part VIII Statement of Revenue**

Check if Schedule O contains a response or note to any line in this Part VIII

		(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512-514	
<b>Contributions, Gifts, Grants and Other Similar Amounts</b>	<b>1a</b> Federated campaigns	<b>1a</b>				
	<b>b</b> Membership dues	<b>1b</b>				
	<b>c</b> Fundraising events	<b>1c</b>				
	<b>d</b> Related organizations	<b>1d</b>				
	<b>e</b> Government grants (contributions)	<b>1e</b>				
	<b>f</b> All other contributions, gifts, grants, and similar amounts not included above	<b>1f</b>	724,656			
	<b>g</b> Noncash contributions included in lines 1a-1f	<b>1g</b>	\$ 6,192			
	<b>h Total.</b> Add lines 1a-1f		724,656			
<b>Program Service Revenue</b>	<b>2a</b>	Business Code				
	<b>b</b>					
	<b>c</b>					
	<b>d</b>					
	<b>e</b>					
	<b>f</b> All other program service revenue					
	<b>g Total.</b> Add lines 2a-2f					
<b>Other Revenue</b>	<b>3</b> Investment income (including dividends, interest, and other similar amounts)		21,491	21,491		
	<b>4</b> Income from investment of tax-exempt bond proceeds					
	<b>5</b> Royalties					
	<b>6a</b> Gross rents	<b>6a</b>	(i) Real			
			(ii) Personal			
	<b>b</b> Less: rental expenses	<b>6b</b>				
	<b>c</b> Rental inc. or (loss)	<b>6c</b>				
	<b>d</b> Net rental income or (loss)					
	<b>7a</b> Gross amount from sales of assets other than inventory	<b>7a</b>	(i) Securities			
			(ii) Other			
	<b>b</b> Less: cost or other basis and sales exps.	<b>7b</b>				
	<b>c</b> Gain or (loss)	<b>7c</b>				
	<b>d</b> Net gain or (loss)					
<b>8a</b> Gross income from fundraising events (not including \$ of contributions reported on line 1c). See Part IV, line 18	<b>8a</b>					
<b>b</b> Less: direct expenses	<b>8b</b>					
<b>c</b> Net income or (loss) from fundraising events						
<b>9a</b> Gross income from gaming activities. See Part IV, line 19	<b>9a</b>					
<b>b</b> Less: direct expenses	<b>9b</b>					
<b>c</b> Net income or (loss) from gaming activities						
<b>10a</b> Gross sales of inventory, less returns and allowances	<b>10a</b>					
<b>b</b> Less: cost of goods sold	<b>10b</b>					
<b>c</b> Net income or (loss) from sales of inventory						
<b>Miscellaneous Revenue</b>	<b>11a</b>	Business Code				
	<b>b</b>					
	<b>c</b>					
	<b>d</b> All other revenue					
	<b>e Total.</b> Add lines 11a-11d					
<b>12 Total revenue.</b> See instructions		746,147	21,491	0	0	

**Part IX Statement of Functional Expenses**

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

Check if Schedule O contains a response or note to any line in this Part IX

<b>Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.</b>	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
<b>1</b> Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	52,000	52,000		
<b>2</b> Grants and other assistance to domestic individuals. See Part IV, line 22				
<b>3</b> Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16	30,000	30,000		
<b>4</b> Benefits paid to or for members				
<b>5</b> Compensation of current officers, directors, trustees, and key employees	98,500	45,201	35,946	17,353
<b>6</b> Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)				
<b>7</b> Other salaries and wages	184,332	84,617	73,927	25,788
<b>8</b> Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
<b>9</b> Other employee benefits	9,732		9,732	
<b>10</b> Payroll taxes	20,130	9,159	7,455	3,516
<b>11</b> Fees for services (nonemployees):				
<b>a</b> Management				
<b>b</b> Legal				
<b>c</b> Accounting	22,350		22,350	
<b>d</b> Lobbying				
<b>e</b> Professional fundraising services. See Part IV, line 17				
<b>f</b> Investment management fees	2,778		2,778	
<b>g</b> Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O.)	32,985	2,949	27,932	2,104
<b>12</b> Advertising and promotion				
<b>13</b> Office expenses	65,702	12,578	44,742	8,382
<b>14</b> Information technology	70,850	49,857	16,195	4,798
<b>15</b> Royalties				
<b>16</b> Occupancy	25,336		25,336	
<b>17</b> Travel	108,751	101,946	6,265	540
<b>18</b> Payments of travel or entertainment expenses for any federal, state, or local public officials				
<b>19</b> Conferences, conventions, and meetings	117,008	116,708	300	
<b>20</b> Interest				
<b>21</b> Payments to affiliates				
<b>22</b> Depreciation, depletion, and amortization	11,623		11,623	
<b>23</b> Insurance	7,071	25	7,046	
<b>24</b> Other expenses. Itemize expenses not covered above. (List miscellaneous expenses on line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
<b>a</b> Program Expenses	77,095	77,095		
<b>b</b> Bank Fees	7,026	57	6,947	22
<b>c</b> Fundraising Expenses	4,357	85		4,272
<b>d</b> Meals	2,903	1,802	934	167
<b>e</b> All other expenses	1,507	1,063	444	
<b>25</b> Total functional expenses. Add lines 1 through 24e	952,036	585,142	299,952	66,942
<b>26</b> 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 or note to any line in this Part X

		(A) Beginning of year		(B) End of year
<b>Assets</b>	<b>1</b> Cash—non-interest-bearing	<b>810,980</b>	<b>1</b>	<b>445,787</b>
	<b>2</b> Savings and temporary cash investments		<b>2</b>	
	<b>3</b> Pledges and grants receivable, net		<b>3</b>	
	<b>4</b> Accounts receivable, net	<b>26,000</b>	<b>4</b>	<b>43,630</b>
	<b>5</b> Loans and other receivables from any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		<b>5</b>	
	<b>6</b> Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B)		<b>6</b>	
	<b>7</b> Notes and loans receivable, net		<b>7</b>	
	<b>8</b> Inventories for sale or use		<b>8</b>	
	<b>9</b> Prepaid expenses and deferred charges	<b>4,282</b>	<b>9</b>	<b>4,282</b>
	<b>10a</b> Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	<b>10a</b> <b>100,514</b>		
	<b>b</b> Less: accumulated depreciation	<b>10b</b> <b>66,152</b>	<b>45,985</b>	<b>10c</b> <b>34,362</b>
	<b>11</b> Investments—publicly traded securities	<b>397,068</b>	<b>11</b>	<b>668,380</b>
	<b>12</b> Investments—other securities. See Part IV, line 11		<b>12</b>	
	<b>13</b> Investments—program-related. See Part IV, line 11		<b>13</b>	
	<b>14</b> Intangible assets		<b>14</b>	
	<b>15</b> Other assets. See Part IV, line 11	<b>6,810</b>	<b>15</b>	<b>6,810</b>
<b>16 Total assets.</b> Add lines 1 through 15 (must equal line 33)	<b>1,291,125</b>	<b>16</b>	<b>1,203,251</b>	
<b>Liabilities</b>	<b>17</b> Accounts payable and accrued expenses	<b>17,543</b>	<b>17</b>	<b>26,983</b>
	<b>18</b> Grants payable		<b>18</b>	<b>56,000</b>
	<b>19</b> Deferred revenue		<b>19</b>	
	<b>20</b> Tax-exempt bond liabilities		<b>20</b>	
	<b>21</b> Escrow or custodial account liability. Complete Part IV of Schedule D		<b>21</b>	
	<b>22</b> Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		<b>22</b>	
	<b>23</b> Secured mortgages and notes payable to unrelated third parties		<b>23</b>	
	<b>24</b> Unsecured notes and loans payable to unrelated third parties		<b>24</b>	
	<b>25</b> 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		<b>25</b>	
	<b>26 Total liabilities.</b> Add lines 17 through 25	<b>17,543</b>	<b>26</b>	<b>82,983</b>
<b>Net Assets or Fund Balances</b>	<b>Organizations that follow FASB ASC 958, check here <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33.</b>			
	<b>27</b> Net assets without donor restrictions	<b>416,780</b>	<b>27</b>	<b>997,221</b>
	<b>28</b> Net assets with donor restrictions	<b>856,802</b>	<b>28</b>	<b>123,047</b>
	<b>Organizations that do not follow FASB ASC 958, check here <input type="checkbox"/> and complete lines 29 through 33.</b>			
	<b>29</b> Capital stock or trust principal, or current funds		<b>29</b>	
	<b>30</b> Paid-in or capital surplus, or land, building, or equipment fund		<b>30</b>	
	<b>31</b> Retained earnings, endowment, accumulated income, or other funds		<b>31</b>	
	<b>32 Total net assets or fund balances</b>	<b>1,273,582</b>	<b>32</b>	<b>1,120,268</b>
<b>33 Total liabilities and net assets/fund balances</b>	<b>1,291,125</b>	<b>33</b>	<b>1,203,251</b>	

**Part XI Reconciliation of Net Assets**

Check if Schedule O contains a response or note to any line in this Part XI

<b>1</b>	Total revenue (must equal Part VIII, column (A), line 12)	<b>1</b>	<b>746,147</b>
<b>2</b>	Total expenses (must equal Part IX, column (A), line 25)	<b>2</b>	<b>952,036</b>
<b>3</b>	Revenue less expenses. Subtract line 2 from line 1	<b>3</b>	<b>-205,889</b>
<b>4</b>	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	<b>4</b>	<b>1,273,582</b>
<b>5</b>	Net unrealized gains (losses) on investments	<b>5</b>	<b>32,835</b>
<b>6</b>	Donated services and use of facilities	<b>6</b>	
<b>7</b>	Investment expenses	<b>7</b>	
<b>8</b>	Prior period adjustments	<b>8</b>	<b>19,740</b>
<b>9</b>	Other changes in net assets or fund balances (explain on Schedule O)	<b>9</b>	
<b>10</b>	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B))	<b>10</b>	<b>1,120,268</b>

**Part XII Financial Statements and Reporting**

Check if Schedule O contains a response or note to any line in this Part XII

		Yes	No
<b>1</b>	Accounting method used to prepare the Form 990: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other If the organization changed its method of accounting from a prior year or checked "Other," explain on Schedule O.		
<b>2a</b>	Were the organization's financial statements compiled or reviewed by an independent accountant? If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both. <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		<b>X</b>
<b>2b</b>	Were the organization's financial statements audited by an independent accountant? If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both. <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		<b>X</b>
<b>2c</b>	If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? If the organization changed either its oversight process or selection process during the tax year, explain on Schedule O.		
<b>3a</b>	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Uniform Guidance, 2 C.F.R. Part 200, Subpart F?		<b>X</b>
<b>3b</b>	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why on Schedule O and describe any steps taken to undergo such audits		

SCHEDULE A (Form 990)

Public Charity Status and Public Support

OMB No. 1545-0047

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

2023

Department of the Treasury Internal Revenue Service

Attach to Form 990 or Form 990-EZ.

Open to Public Inspection

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

Name of the organization: Batten Disease Support & Research Association; Employer identification number: \*\*-\*\*\*7792

Part I Reason for Public Charity Status. (All organizations must complete this part.) See instructions.

The organization is not a private foundation because it is: (For lines 1 through 12, check only one box.)

- 1 A church, convention of churches, or association of churches described in section 170(b)(1)(A)(i).
2 A school described in section 170(b)(1)(A)(ii).
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).
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).
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).
8 A community trust described in section 170(b)(1)(A)(vi).
9 An agricultural research organization described in section 170(b)(1)(A)(ix) operated in conjunction with a land-grant college or university or a non-land-grant college of agriculture.
10 X 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.
11 An organization organized and operated exclusively to test for public safety.
12 An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2).
a Type I. A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization.
b Type II. A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s).
c Type III functionally integrated. A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions).
d Type III non-functionally integrated. A supporting organization operated in connection with its supported organization(s) that is not functionally integrated.
e Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization.
f Enter the number of supported organizations
g Provide the following information about the supported organization(s).

Table with 6 columns: (i) Name of supported organization, (ii) EIN, (iii) Type of organization, (iv) Is the organization listed in your governing document?, (v) Amount of monetary support, (vi) Amount of other support. Rows (A) through (E) and 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

Table with 7 columns: Calendar year (or fiscal year beginning in), (a) 2019, (b) 2020, (c) 2021, (d) 2022, (e) 2023, (f) Total. Rows include: 1 Gifts, grants, contributions, and membership fees received; 2 Tax revenues levied for the organization's benefit; 3 The value of services or facilities furnished by a governmental unit; 4 Total. Add lines 1 through 3; 5 The portion of total contributions by each person; 6 Public support. Subtract line 5 from line 4.

Section B. Total Support

Table with 7 columns: Calendar year (or fiscal year beginning in), (a) 2019, (b) 2020, (c) 2021, (d) 2022, (e) 2023, (f) Total. Rows include: 7 Amounts from line 4; 8 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources; 9 Net income from unrelated business activities; 10 Other income. Do not include gain or loss from the sale of capital assets; 11 Total support. Add lines 7 through 10.

12 Gross receipts from related activities, etc. (see instructions) 12
13 First 5 years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here

Section C. Computation of Public Support Percentage

14 Public support percentage for 2023 (line 6, column (f) divided by line 11, column (f)) 14 %
15 Public support percentage from 2022 Schedule A, Part II, line 14 15 %
16a 33 1/3% support test — 2023. 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 — 2022. 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
17a 10%-facts-and-circumstances test — 2023. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the facts-and-circumstances test, check this box and stop here. Explain in Part VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization
b 10%-facts-and-circumstances test — 2022. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the facts-and-circumstances test, check this box and stop here. Explain in Part VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization
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 III Support Schedule for Organizations Described in Section 509(a)(2)

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

Section A. Public Support

Table with 7 columns: Calendar year (or fiscal year beginning in), (a) 2019, (b) 2020, (c) 2021, (d) 2022, (e) 2023, (f) Total. Rows include: 1 Gifts, grants, contributions, and membership fees received; 2 Gross receipts from admissions, merchandise sold or services performed; 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; 5 The value of services or facilities furnished by a governmental unit; 6 Total. Add lines 1 through 5; 7a Amounts included on lines 1, 2, and 3 received from disqualified persons; 7b Amounts included on lines 2 and 3 received from other than disqualified persons; 7c Add lines 7a and 7b; 8 Public support. (Subtract line 7c from line 6.)

Section B. Total Support

Table with 7 columns: Calendar year (or fiscal year beginning in), (a) 2019, (b) 2020, (c) 2021, (d) 2022, (e) 2023, (f) Total. Rows include: 9 Amounts from line 6; 10a Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources; 10b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975; 10c Add lines 10a and 10b; 11 Net income from unrelated business activities not included on line 10b; 12 Other income. Do not include gain or loss from the sale of capital assets; 13 Total support. (Add lines 9, 10c, 11, and 12.); 14 First 5 years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here.

Section C. Computation of Public Support Percentage

Table with 2 columns: Description, Percentage. Row 15: Public support percentage for 2023 (line 8, column (f), divided by line 13, column (f)) 95.25%. Row 16: Public support percentage from 2022 Schedule A, Part III, line 15 96.61%.

Section D. Computation of Investment Income Percentage

Table with 2 columns: Description, Percentage. Row 17: Investment income percentage for 2023 (line 10c, column (f), divided by line 13, column (f)) 3%. Row 18: Investment income percentage from 2022 Schedule A, Part III, line 17 2%.

- 19a 33 1/3% support tests — 2023. 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 [X].
b 33 1/3% support tests — 2022. 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 Supporting Organizations**

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

**Section A. All Supporting Organizations**

	Yes	No
<b>1</b> Are all of the organization's supported organizations listed by name in the organization's governing documents? <i>If "No," describe in Part VI how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.</i>		
<b>2</b> Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? <i>If "Yes," explain in Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).</i>		
<b>3a</b> Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? <i>If "Yes," answer lines 3b and 3c below.</i>		
<b>b</b> Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? <i>If "Yes," describe in Part VI when and how the organization made the determination.</i>		
<b>c</b> Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? <i>If "Yes," explain in Part VI what controls the organization put in place to ensure such use.</i>		
<b>4a</b> Was any supported organization not organized in the United States ("foreign supported organization")? <i>If "Yes," and if you checked box 12a or 12b in Part I, answer lines 4b and 4c below.</i>		
<b>b</b> Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? <i>If "Yes," describe in Part VI how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.</i>		
<b>c</b> Did the organization support any foreign supported organization that does not have an IRS determination under sections 501(c)(3) and 509(a)(1) or (2)? <i>If "Yes," explain in Part VI what controls the organization used to ensure that all support to the foreign supported organization was used exclusively for section 170(c)(2)(B) purposes.</i>		
<b>5a</b> Did the organization add, substitute, or remove any supported organizations during the tax year? <i>If "Yes," answer lines 5b and 5c below (if applicable). Also, provide detail in Part VI, including (i) the names and EIN numbers of the supported organizations added, substituted, or removed; (ii) the reasons for each such action; (iii) the authority under the organization's organizing document authorizing such action; and (iv) how the action was accomplished (such as by amendment to the organizing document).</i>		
<b>b Type I or Type II only.</b> Was any added or substituted supported organization part of a class already designated in the organization's organizing document?		
<b>c Substitutions only.</b> Was the substitution the result of an event beyond the organization's control?		
<b>6</b> Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? <i>If "Yes," provide detail in Part VI.</i>		
<b>7</b> Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (as defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? <i>If "Yes," complete Part I of Schedule L (Form 990).</i>		
<b>8</b> Did the organization make a loan to a disqualified person (as defined in section 4958) not described on line 7? <i>If "Yes," complete Part I of Schedule L (Form 990).</i>		
<b>9a</b> Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons, as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? <i>If "Yes," provide detail in Part VI.</i>		
<b>b</b> Did one or more disqualified persons (as defined on line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? <i>If "Yes," provide detail in Part VI.</i>		
<b>c</b> Did a disqualified person (as defined on line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? <i>If "Yes," provide detail in Part VI.</i>		
<b>10a</b> Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? <i>If "Yes," answer line 10b below.</i>		
<b>b</b> Did the organization have any excess business holdings in the tax year? <i>(Use Schedule C, Form 4720, to determine whether the organization had excess business holdings.)</i>		



Part IV Supporting Organizations (continued)

Table with 3 columns: Question, Yes, No. Row 11: Has the organization accepted a gift or contribution from any of the following persons? Sub-rows 11a, 11b, 11c.

Section B. Type I Supporting Organizations

Table with 3 columns: Question, Yes, No. Row 1: Did the governing body, members of the governing body, officers acting in their official capacity, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's officers, directors, or trustees at all times during the tax year? Row 2: Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization?

Section C. Type II Supporting Organizations

Table with 3 columns: Question, Yes, No. Row 1: Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)?

Section D. All Type III Supporting Organizations

Table with 3 columns: Question, Yes, No. Row 1: Did the organization provide to each of its supported organizations, by the last day of the fifth month of the organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the organization's governing documents in effect on the date of notification, to the extent not previously provided? Row 2: Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported organization(s) or (ii) serving on the governing body of a supported organization? Row 3: By reason of the relationship described on line 2, above, did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year?

Section E. Type III Functionally Integrated Supporting Organizations

Table with 3 columns: Question, Yes, No. Row 1: Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions). Sub-rows a, b, c. Row 2: Activities Test. Answer lines 2a and 2b below. Sub-rows a, b. Row 3: Parent of Supported Organizations. Answer lines 3a and 3b below. Sub-rows a, b.

**Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations**

**1**  Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970 (*explain in Part VI*). See instructions. All other Type III non-functionally integrated supporting organizations must complete Sections A through E.

<b>Section A – Adjusted Net Income</b>		(A) Prior Year	(B) Current Year (optional)
<b>1</b>	Net short-term capital gain	<b>1</b>	
<b>2</b>	Recoveries of prior-year distributions	<b>2</b>	
<b>3</b>	Other gross income (see instructions)	<b>3</b>	
<b>4</b>	Add lines 1 through 3.	<b>4</b>	
<b>5</b>	Depreciation and depletion	<b>5</b>	
<b>6</b>	Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions)	<b>6</b>	
<b>7</b>	Other expenses (see instructions)	<b>7</b>	
<b>8</b>	<b>Adjusted Net Income</b> (subtract lines 5, 6, and 7 from line 4)	<b>8</b>	

<b>Section B – Minimum Asset Amount</b>		(A) Prior Year	(B) Current Year (optional)
<b>1</b>	Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year):		
<b>a</b>	Average monthly value of securities	<b>1a</b>	
<b>b</b>	Average monthly cash balances	<b>1b</b>	
<b>c</b>	Fair market value of other non-exempt-use assets	<b>1c</b>	
<b>d</b>	<b>Total</b> (add lines 1a, 1b, and 1c)	<b>1d</b>	
<b>e</b>	<b>Discount</b> claimed for blockage or other factors ( <i>explain in detail in Part VI</i> ):		
<b>2</b>	Acquisition indebtedness applicable to non-exempt-use assets	<b>2</b>	
<b>3</b>	Subtract line 2 from line 1d.	<b>3</b>	
<b>4</b>	Cash deemed held for exempt use. Enter 0.015 of line 3 (for greater amount, see instructions).	<b>4</b>	
<b>5</b>	Net value of non-exempt-use assets (subtract line 4 from line 3)	<b>5</b>	
<b>6</b>	Multiply line 5 by 0.035.	<b>6</b>	
<b>7</b>	Recoveries of prior-year distributions	<b>7</b>	
<b>8</b>	<b>Minimum Asset Amount</b> (add line 7 to line 6)	<b>8</b>	

<b>Section C – Distributable Amount</b>			Current Year
<b>1</b>	Adjusted net income for prior year (from Section A, line 8, column A)	<b>1</b>	
<b>2</b>	Enter 0.85 of line 1.	<b>2</b>	
<b>3</b>	Minimum asset amount for prior year (from Section B, line 8, column A)	<b>3</b>	
<b>4</b>	Enter greater of line 2 or line 3.	<b>4</b>	
<b>5</b>	Income tax imposed in prior year	<b>5</b>	
<b>6</b>	<b>Distributable Amount.</b> Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions).	<b>6</b>	

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

**Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations** *(continued)*

Section D – Distributions	Current Year
<b>1</b> Amounts paid to supported organizations to accomplish exempt purposes	<b>1</b>
<b>2</b> Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	<b>2</b>
<b>3</b> Administrative expenses paid to accomplish exempt purposes of supported organizations	<b>3</b>
<b>4</b> Amounts paid to acquire exempt-use assets	<b>4</b>
<b>5</b> Qualified set-aside amounts (prior IRS approval required— <i>provide details in Part VI</i> )	<b>5</b>
<b>6</b> Other distributions ( <i>describe in Part VI</i> ). See instructions.	<b>6</b>
<b>7 Total annual distributions.</b> Add lines 1 through 6.	<b>7</b>
<b>8</b> Distributions to attentive supported organizations to which the organization is responsive ( <i>provide details in Part VI</i> ). See instructions.	<b>8</b>
<b>9</b> Distributable amount for 2022 from Section C, line 6	<b>9</b>
<b>10</b> Line 8 amount divided by line 9 amount	<b>10</b>

Section E – Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2023	(iii) Distributable Amount for 2023
<b>1</b> Distributable amount for 2023 from Section C, line 6			
<b>2</b> Underdistributions, if any, for years prior to 2023 (reasonable cause required— <i>explain in Part VI</i> ). See instructions.			
<b>3</b> Excess distributions carryover, if any, to 2023			
<b>a</b> From 2018 .....			
<b>b</b> From 2019 .....			
<b>c</b> From 2020 .....			
<b>d</b> From 2021 .....			
<b>e</b> From 2022 .....			
<b>f Total</b> of lines 3a through 3e			
<b>g</b> Applied to underdistributions of prior years			
<b>h</b> Applied to 2023 distributable amount			
<b>i</b> Carryover from 2018 not applied (see instructions)			
<b>j</b> Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
<b>4</b> Distributions for 2023 from Section D, line 7: \$			
<b>a</b> Applied to underdistributions of prior years			
<b>b</b> Applied to 2023 distributable amount			
<b>c</b> Remainder. Subtract lines 4a and 4b from line 4.			
<b>5</b> Remaining underdistributions for years prior to 2023, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, <i>explain in Part VI</i> . See instructions.			
<b>6</b> Remaining underdistributions for 2023. Subtract lines 3h and 4b from line 1. For result greater than zero, <i>explain in Part VI</i> . See instructions.			
<b>7 Excess distributions carryover to 2024.</b> Add lines 3j and 4c.			
<b>8</b> Breakdown of line 7:			
<b>a</b> Excess from 2019 .....			
<b>b</b> Excess from 2020 .....			
<b>c</b> Excess from 2021 .....			
<b>d</b> Excess from 2022 .....			
<b>e</b> Excess from 2023 .....			

**Part VI** **Supplemental Information.** Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; Part III, line 12; Part IV, Section A, lines 1, 2, 3b, 3c, 4b, 4c, 5a, 6, 9a, 9b, 9c, 11a, 11b, and 11c; Part IV, Section B, lines 1 and 2; Part IV, Section C, line 1; Part IV, Section D, lines 2 and 3; Part IV, Section E, lines 1c, 2a, 2b, 3a, and 3b; Part V, line 1; Part V, Section B, line 1e; Part V, Section D, lines 5, 6, and 8; and Part V, Section E, lines 2, 5, and 6. Also complete this part for any additional information. (See instructions.)

**Part III, Line 12 - Other Income Detail**

**Sales** \$ **44,864**

Schedule B (Form 990)

Department of the Treasury Internal Revenue Service

Schedule of Contributors

Attach to Form 990, 990-EZ, or 990-PF. Go to www.irs.gov/Form990 for the latest information.

OMB No. 1545-0047

2023

Name of the organization: Batten Disease Support & Research Association. Employer identification number: \*\*-\*\*\*7792

Organization type (check one):

- Filers of: Form 990 or 990-EZ. Section: [X] 501(c)( 3 ) (enter number) organization. [ ] 4947(a)(1) nonexempt charitable trust not treated as a private foundation. [ ] 527 political organization. Form 990-PF. [ ] 501(c)(3) exempt private foundation. [ ] 4947(a)(1) nonexempt charitable trust treated as a private foundation. [ ] 501(c)(3) taxable private foundation.

Check if your organization is covered by the General Rule or a Special Rule.

Note: Only a section 501(c)(7), (8), or (10) organization can check boxes for both the General Rule and a Special Rule. See instructions.

General Rule

- [X] For an organization filing Form 990, 990-EZ, or 990-PF that received, during the year, contributions totaling \$5,000 or more (in money or property) from any one contributor. Complete Parts I and II. See instructions for determining a contributor's total contributions.

Special Rules

- [ ] For an organization described in section 501(c)(3) filing Form 990 or 990-EZ that met the 33 1/3% support test of the regulations under sections 509(a)(1) and 170(b)(1)(A)(vi), that checked Schedule A (Form 990), Part II, line 13, 16a, or 16b, and that received from any one contributor, during the year, total contributions of the greater of (1) \$5,000; or (2) 2% of the amount on (i) Form 990, Part VIII, line 1h; or (ii) Form 990-EZ, line 1. Complete Parts I and II. [ ] For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, total contributions of more than \$1,000 exclusively for religious, charitable, scientific, literary, or educational purposes, or for the prevention of cruelty to children or animals. Complete Parts I (entering "N/A" in column (b) instead of the contributor name and address), II, and III. [ ] For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions exclusively for religious, charitable, etc., purposes, but no such contributions totaled more than \$1,000. If this box is checked, enter here the total contributions that were received during the year for an exclusively religious, charitable, etc., purpose. Don't complete any of the parts unless the General Rule applies to this organization because it received nonexclusively religious, charitable, etc., contributions totaling \$5,000 or more during the year \$ .....

Caution: An organization that isn't covered by the General Rule and/or the Special Rules doesn't file Schedule B (Form 990), but it must answer "No" on Part IV, line 2, of its Form 990; or check the box on line H of its Form 990-EZ or on its Form 990-PF, Part I, line 2, to certify that it doesn't meet the filing requirements of Schedule B (Form 990).

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

Schedule B (Form 990) (2023)

Name of organization

**Batten Disease Support**

Employer identification number

**\*\* - \*\*\*7792**

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

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
1	Americaon Endowment Foundation 5700 Darrow Rd Hudson OH 44326	\$ 5,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
2	Barbara Wuebbels 10423 North 42nd Place Phoenix AZ 85028	\$ 6,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
3	BDSRA Southeast Chapter 6304 Bayswater Trl Raleigh NC 27612-6606	\$ 5,832	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
4	Beyond Batten Disease Foundation PO Box 50221 Austin TX 78763	\$ 55,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
5	CHOC Children's Hospital 1201 W la Veta Avenue Orange CA 92868	\$ 5,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
6	Drew's Hope Research Foundation 36 Atkinson Lane Newtown PA 18940	\$ 44,500	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)

Name of organization

**Batten Disease Support**

Employer identification number

**\*\* - \*\*\*7792**

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

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
7	David Pearce 2301 East 60th St N Sioux Falls SD 57104	\$ 5,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
8	Easter Foundation, Inc. PO Box 5501 De Pere WI 54115	\$ 15,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
9	Fidelity Charitable PO Box 770001 Cincinnati OH 45277	\$ 7,750	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
10	Facebook 1 Hacker Way Menlo Park CA 94025	\$ 13,407	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
11	ForeBatten Foundation 112312 US Hwy 501 N Suite 107-117 Chapel Hill NC 27517	\$ 65,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
12	Greater Houston Community Foundation 515 Post Oak Blvd Houston TX 77027	\$ 10,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)

Name of organization

**Batten Disease Support**

Employer identification number

**\*\* - \*\*\*7792**

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

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
13	Gary & Becky Clayton 117 Norwood Dr Lumberton TX 77657-7137	\$ 5,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
14	Haley's Heroes 1805 22nd Street Salem OR 97302	\$ 5,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
15	JCR Pharmaceuticals 3-19 Kasuga-cho Ashiya . 659-0021	\$ 5,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
16	John Patterson 20 Charred Oak Ln East Windsor NJ 08520	\$ 5,200	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
17	Kevin Lumm Memorial Fund PO Box 44 Maugansville MD 21767	\$ 5,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
18	Metro NY/NJ Chapter BDSRA 1044 Edgegrove Avenue Staten Island NY 10309	\$ 23,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)



Name of organization

**Batten Disease Support**

Employer identification number

**\*\* - \*\*\*7792**

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

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
19	Neurogene 535 W 24th Street, Floor 5 New York NY 10011	\$ 5,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
20	North Coast Litho 4701 Manufacturing Road Cleveland OH 44135	\$ 5,741	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
21	Noah's Hope-Hope 4 Bridget 4930 Northcott Avenue Downers Grove IL 60515	\$ 37,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
22	Our Promise to Nicholas Foundation PO Box 10106 Bedford NH 03110	\$ 25,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
23	Rush 1700 W Van Buren St Chicago IL 60612	\$ 5,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
24	REGENXBIO Inc. 9884 Medical Center Dr Rockville MD 20850	\$ 20,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)

Name of organization

**Batten Disease Support**

Employer identification number

**\*\* - \*\*\*7792**

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

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
25	The Cru Foundation 100 Lake Hart Drive #3600 Orlando FL 32832	\$ 35,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
26	Warren Pfohl 27508 Riverbank Dr Bonita Springs FL 34134	\$ 10,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
		\$ .....	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
		\$ .....	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
		\$ .....	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
		\$ .....	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)

SCHEDULE D (Form 990)

Department of the Treasury Internal Revenue Service

Supplemental Financial Statements

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

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

OMB No. 1545-0047

2023

Open to Public Inspection

Name of the organization

Batten Disease Support & Research Association

Employer identification number

\*\*-\*\*\*7792

Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts

Complete if the organization answered "Yes" on Form 990, Part IV, line 6.

Table with 3 columns: Question, (a) Donor advised funds, (b) Funds and other accounts. Rows include total number at end of year, aggregate value of contributions, aggregate value of grants, and questions about donor advisement.

Part II Conservation Easements

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

Table with 3 columns: Question, (a) Donor advised funds, (b) Funds and other accounts. Rows include purpose of conservation easements, total number of easements, and questions about monitoring and reporting.

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets

Complete if the organization answered "Yes" on Form 990, Part IV, line 8.

Table with 3 columns: Question, (a) Donor advised funds, (b) Funds and other accounts. Rows include questions about reporting art and historical treasures.

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

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

- a**  Public exhibition
- b**  Scholarly research
- c**  Preservation for future generations
- d**  Loan or exchange program
- 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" on Form 990, Part IV, line 9, or reported an amount on Form 990, Part X, line 21.

**1a** Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X?  Yes  No

**b** If "Yes," explain the arrangement in Part XIII and complete the following table.

- c** Beginning balance .....
- d** Additions during the year .....
- e** Distributions during the year .....
- f** Ending balance .....

	Amount
<b>1c</b>	
<b>1d</b>	
<b>1e</b>	
<b>1f</b>	

**2a** Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability?  Yes  No

**b** If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided on Part XIII

**Part V Endowment Funds**

Complete if the organization answered "Yes" on Form 990, Part IV, line 10.

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
<b>1a</b> Beginning of year balance .....					
<b>b</b> Contributions .....					
<b>c</b> Net investment earnings, gains, and losses .....					
<b>d</b> Grants or scholarships .....					
<b>e</b> Other expenditures for facilities and programs .....					
<b>f</b> Administrative expenses .....					
<b>g</b> 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** Term endowment ..... %

The percentages on lines 2a, 2b, and 2c should equal 100%.

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

- (i)** Unrelated organizations? .....
- (ii)** Related organizations? .....

	Yes	No
<b>3a(i)</b>		
<b>3a(ii)</b>		
<b>3b</b>		

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

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

**Part VI Land, Buildings, and Equipment**

Complete if the organization answered "Yes" on Form 990, Part IV, line 11a. See Form 990, Part X, line 10.

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
<b>1a</b> Land .....				
<b>b</b> Buildings .....				
<b>c</b> Leasehold improvements .....				
<b>d</b> Equipment .....		<b>100,514</b>	<b>66,152</b>	<b>34,362</b>
<b>e</b> Other .....				
<b>Total.</b> Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, line 10c, column (B))				<b>34,362</b>

**Part VII Investments – Other Securities**

Complete if the organization answered "Yes" on Form 990, Part IV, line 11b. See Form 990, Part X, line 12.

(a) Description of security or category (including name of security)	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1) Financial derivatives		
(2) Closely held equity interests		
(3) Other		
(A)		
(B)		
(C)		
(D)		
(E)		
(F)		
(G)		
(H)		
<b>Total.</b> (Column (b) must equal Form 990, Part X, line 12, col. (B))		

**Part VIII Investments – Program Related**

Complete if the organization answered "Yes" on Form 990, Part IV, line 11c. See Form 990, Part X, line 13.

(a) Description of investment	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1)		
(2)		
(3)		
(4)		
(5)		
(6)		
(7)		
(8)		
(9)		
<b>Total.</b> (Column (b) must equal Form 990, Part X, line 13, col. (B))		

**Part IX Other Assets**

Complete if the organization answered "Yes" on Form 990, Part IV, line 11d. See Form 990, Part X, line 15.

(a) Description	(b) Book value
(1)	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
<b>Total.</b> (Column (b) must equal Form 990, Part X, line 15, col. (B))	

**Part X Other Liabilities**

Complete if the organization answered "Yes" on Form 990, Part IV, line 11e or 11f. See Form 990, Part X, line 25.

1. (a) Description of liability	(b) Book value
(1) Federal income taxes	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
<b>Total.</b> (Column (b) must equal Form 990, Part X, line 25, col. (B))	

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

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

Complete if the organization answered "Yes" on Form 990, Part IV, line 12a.

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

**Part XII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return**

Complete if the organization answered "Yes" on Form 990, Part IV, line 12a.

<b>1</b> Total expenses and losses per audited financial statements .....		<b>1</b>	
<b>2</b> Amounts included on line 1 but not on Form 990, Part IX, line 25:			
<b>a</b> Donated services and use of facilities .....	<b>2a</b>		
<b>b</b> Prior year adjustments .....	<b>2b</b>		
<b>c</b> Other losses .....	<b>2c</b>		
<b>d</b> Other (Describe in Part XIII.) .....	<b>2d</b>		
<b>e</b> Add lines <b>2a</b> through <b>2d</b> .....		<b>2e</b>	
<b>3</b> Subtract line <b>2e</b> from line <b>1</b> .....		<b>3</b>	
<b>4</b> Amounts included on Form 990, Part IX, line 25, but not on line 1:			
<b>a</b> Investment expenses not included on Form 990, Part VIII, line 7b .....	<b>4a</b>		
<b>b</b> Other (Describe in Part XIII.) .....	<b>4b</b>		
<b>c</b> Add lines <b>4a</b> and <b>4b</b> .....		<b>4c</b>	
<b>5</b> Total expenses. Add lines <b>3</b> and <b>4c</b> . ( <i>This must equal Form 990, Part I, line 18.</i> ) .....		<b>5</b>	

**Part XIII Supplemental Information**

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

.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....



**SCHEDULE F  
(Form 990)**

**Statement of Activities Outside the United States**

OMB No. 1545-0047

**2023**

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

**Open to Public Inspection**

Department of the Treasury  
Internal Revenue Service

Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

Name of the organization

**Batten Disease Support  
& Research Association**

Employer identification number

**\*\* - \*\*\* 7792**

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

**1 For grantmakers.** Does the organization maintain records to substantiate the amount of its grants and other assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance?  Yes  No

**2 For grantmakers.** Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.

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

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in the region	(d) Activities conducted in the region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in the region	(f) Total expenditures for and investments in the region
(1)					
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					
(8)					
(9)					
(10)					
(11)					
(12)					
(13)					
(14)					
(15)					
(16)					
(17)					
<b>3a</b> Subtotal					
<b>b</b> Total from continuation sheets to Part I					
<b>c Totals</b> (add lines 3a and 3b)					

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule F (Form 990) 2023



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

1	(a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of noncash assistance	(h) Description of noncash assistance	(i) Method of valuation (book, FMV, appraisal, other)
(1)				Research	30,000				CASH
(2)									
(3)									
(4)									
(5)									
(6)									
(7)									
(8)									
(9)									
(10)									
(11)									
(12)									
(13)									
(14)									
(15)									
(16)									

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

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" on Form 990, Part IV, line 16.

Part III can be duplicated if additional space is needed.

(a) Type of grant or assistance	(b) Region	(c) Number of recipients	(d) Amount of cash grant	(e) Manner of cash disbursement	(f) Amount of noncash assistance	(g) Description of noncash assistance	(h) Method of valuation (book, FMV, appraisal, other)
(1)							
(2)							
(3)							
(4)							
(5)							
(6)							
(7)							
(8)							
(9)							
(10)							
(11)							
(12)							
(13)							
(14)							
(15)							
(16)							
(17)							
(18)							

**Part IV Foreign Forms**

- 1 Was the organization a U.S. transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see the Instructions for Form 926)* .....  Yes  No
  
- 2 Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to separately file Form 3520, Annual Return To Report Transactions With Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see the Instructions for Forms 3520 and 3520-A; don't file with Form 990)* .....  Yes  No
  
- 3 Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons With Respect to Certain Foreign Corporations (see the Instructions for Form 5471)* .....  Yes  No
  
- 4 Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see the Instructions for Form 8621)* .....  Yes  No
  
- 5 Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign Partnerships (see the Instructions for Form 8865)* .....  Yes  No
  
- 6 Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to separately file Form 5713, International Boycott Report (see the Instructions for Form 5713; don't file with Form 990)* .....  Yes  No



**SCHEDULE I  
(Form 990)**

**Grants and Other Assistance to Organizations,  
Governments, and Individuals in the United States**  
Complete if the organization answered "Yes" on Form 990, Part IV, line 21 or 22.  
Attach to Form 990.  
Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest information.

OMB No. 1545-0047

**2023**

**Open to Public  
Inspection**

Department of the Treasury  
Internal Revenue Service

Name of the organization

**Batten Disease Support  
& Research Association**

Employer identification number  
**\*\*-\*\*\*7792**

**Part I General Information on Grants and Assistance**

- 1 Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance?  Yes  No
- 2 Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States.

**Part II Grants and Other Assistance to Domestic Organizations and Domestic Governments.** Complete if the organization answered "Yes" on Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Part II can be duplicated if additional space is needed.

1	(a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of noncash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
(1)	<b>University of Rochester 601 Elmwood Avenue Rochester NY 14642</b>	<b>** - ***3209</b>	<b>501c3</b>	<b>52,000</b>		<b>Cash</b>		<b>Research</b>
(2)								
(3)								
(4)								
(5)								
(6)								
(7)								
(8)								
(9)								

- 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

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule I (Form 990) 2023

**Part III Grants and Other Assistance to Domestic Individuals.** Complete if the organization answered "Yes" on Form 990, Part IV, line 22.

Part III can be duplicated if additional space is needed.

(a) Type of grant or assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of noncash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance
1					
2					
3					
4					
5					
6					
7					

**Part IV Supplemental Information.** Provide the information required in Part I, line 2; Part III, column (b); and any other additional information.

**Part I, Line 2 - Procedures for Monitoring the Use of Grant Funds**

A mid-term and final report are requested to demonstrate that the grant funds are spent properly.

**SCHEDULE O  
(Form 990)**

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 990-EZ or to provide any additional information.

Attach to Form 990 or Form 990-EZ.

Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest information.

OMB No. 1545-0047

**2023**

**Open to Public  
Inspection**

Name of the organization <b>Batten Disease Support &amp; Research Association</b>	Employer identification number <b>**-***7792</b>
--	---

**Form 990, Part VI, Line 11b - Organization's Process to Review Form 990**  
 The governing body will receive and review the return prior to filing.

**Form 990, Part VI, Line 12c - Enforcement of Conflicts Policy**  
 Officers, directors and key employees are required to annually sign a  
 letter of agreement with conflict of interest policies and guidelines and  
 disclose all relationships with other entities.

**Form 990, Part VI, Line 19 - Governing Documents Disclosure Explanation**  
 Record requests are individually reviewed and approved by the Board.  
 Form 990's are made available upon request and also on organization  
 website, [bdsrafoundation.org](http://bdsrafoundation.org)