

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

OMB No. 1545-0047
2020
 Open to Public Inspection

A For the 2020 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): **2780 Airport Drive, Suite 342**
 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
2780 Airport Drive
Columbus OH 43219

G Gross receipts: **1,228,607**

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**

K Form of organization: Corporation Trust Association Other ▶


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

Part I Summary

Activities & Governance	1 Briefly describe the organization's mission or most significant activities: 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 Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.		
	3 Number of voting members of the governing body (Part VI, line 1a)	3	12
	4 Number of independent voting members of the governing body (Part VI, line 1b)	4	12
	5 Total number of individuals employed in calendar year 2020 (Part V, line 2a)	5	6
	6 Total number of volunteers (estimate if necessary)	6	2
	7a Total unrelated business revenue from Part VIII, column (C), line 12	7a	0
b Net unrelated business taxable income from Form 990-T, Part I, line 11	7b	0	
Revenue	8 Contributions and grants (Part VIII, line 1h)	Prior Year 883,058	Current Year 968,030
	9 Program service revenue (Part VIII, line 2g)	236,958	236,958
	10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)	47,608	23,619
	11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	22,945	0
	12 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	953,611	1,228,607
Expenses	13 Grants and similar amounts paid (Part IX, column (A), lines 1-3)	95,328	95,328
	14 Benefits paid to or for members (Part IX, column (A), line 4)	0	0
	15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	237,758	285,804
	16a Professional fundraising fees (Part IX, column (A), line 11e)	0	0
	b Total fundraising expenses (Part IX, column (D), line 25) ▶ 115,057	115,057	115,057
	17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	511,249	336,887
18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	749,007	718,019	
19 Revenue less expenses. Subtract line 18 from line 12	204,604	510,588	
Net Assets or Fund Balances	20 Total assets (Part X, line 16)	Beginning of Current Year 815,440	End of Year 1,028,529
	21 Total liabilities (Part X, line 26)	356,783	79,405
	22 Net assets or fund balances. Subtract line 21 from line 20	458,657	949,124

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:  Date: **9/9/21**
Amy Fenton Parker **President & CEO**
 Type or print name and title

Paid Preparer Use Only

Print/Type preparer's name: **Donald Wells** Preparer's signature: **Donald Wells** Date: **09/09/21** Check if self-employed PTIN: *********

Firm's name: **Wells CPA LLC.** Firm's EIN: **** - ***1346**

Firm's address: **6500 Busch Blvd Ste 120 Columbus, OH 43229** Phone no.: **614-396-8974**

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

Part IV Checklist of Required Schedules

	Yes	No
1 Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? If "Yes," complete Schedule A	<input checked="" type="checkbox"/>	
2 Is the organization required to complete Schedule B, Schedule of Contributors (see instructions)?	<input checked="" type="checkbox"/>	
3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I		<input checked="" type="checkbox"/>
4 Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? If "Yes," complete Schedule C, Part II		<input checked="" type="checkbox"/>
5 Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? If "Yes," complete Schedule C, Part III		<input checked="" type="checkbox"/>
6 Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? If "Yes," complete Schedule D, Part I		<input checked="" type="checkbox"/>
7 Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? If "Yes," complete Schedule D, Part II		<input checked="" type="checkbox"/>
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III		<input checked="" type="checkbox"/>
9 Did the organization report an amount in Part X, line 21, for escrow or custodial account liability, serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? If "Yes," complete Schedule D, Part IV		<input checked="" type="checkbox"/>
10 Did the organization, directly or through a related organization, hold assets in donor-restricted endowments or in quasi endowments? If "Yes," complete Schedule D, Part V		<input checked="" type="checkbox"/>
11 If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable.		
a Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D, Part VI	<input checked="" type="checkbox"/>	
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? If "Yes," complete Schedule D, Part VII		<input checked="" type="checkbox"/>
c Did the organization report an amount for investments—program related in Part X, line 13, that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VIII		<input checked="" type="checkbox"/>
d Did the organization report an amount for other assets in Part X, line 15, that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part IX		<input checked="" type="checkbox"/>
e Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X		<input checked="" type="checkbox"/>
f Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? If "Yes," complete Schedule D, Part X		<input checked="" type="checkbox"/>
12a Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI and XII		<input checked="" type="checkbox"/>
b Was the organization included in consolidated, independent audited financial statements for the tax year? If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional		<input checked="" type="checkbox"/>
13 Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E		<input checked="" type="checkbox"/>
14a Did the organization maintain an office, employees, or agents outside of the United States?		<input checked="" type="checkbox"/>
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? If "Yes," complete Schedule F, Parts I and IV		<input checked="" type="checkbox"/>
15 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? If "Yes," complete Schedule F, Parts II and IV	<input checked="" type="checkbox"/>	
16 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? If "Yes," complete Schedule F, Parts III and IV		<input checked="" type="checkbox"/>
17 Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? If "Yes," complete Schedule G, Part I See instructions		<input checked="" type="checkbox"/>
18 Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? If "Yes," complete Schedule G, Part II		<input checked="" type="checkbox"/>
19 Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? If "Yes," complete Schedule G, Part III		<input checked="" type="checkbox"/>
20a Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H		<input checked="" type="checkbox"/>
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? If "Yes," complete Schedule I, Parts I and II	<input checked="" type="checkbox"/>	

Part V Statements Regarding Other IRS Filings and Tax Compliance (continued)

		Yes	No
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return 2a 6		
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns? Note: If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)	X	
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?		X
b	If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation on Schedule O		
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?		X
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).		
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?		X
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?		X
c	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?		
6a	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions?		X
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?		
7	Organizations that may receive deductible contributions under section 170(c).		
a	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?		X
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?		
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?		X
d	If "Yes," indicate the number of Forms 8282 filed during the year 7d		
e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?		X
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?		X
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?		X
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?		X
8	Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?		
9	Sponsoring organizations maintaining donor advised funds.		
a	Did the sponsoring organization make any taxable distributions under section 4966?		
b	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?		
10	Section 501(c)(7) organizations. Enter:		
a	Initiation fees and capital contributions included on Part VIII, line 12 10a		
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities 10b		
11	Section 501(c)(12) organizations. Enter:		
a	Gross income from members or shareholders 11a		
b	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them.) 11b		
12a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?		
b	If "Yes," enter the amount of tax-exempt interest received or accrued during the year 12b		
13	Section 501(c)(29) qualified nonprofit health insurance issuers.		
a	Is the organization licensed to issue qualified health plans in more than one state? Note: See the instructions for additional information the organization must report on Schedule O.		
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 13b		
c	Enter the amount of reserves on hand 13c		
14a	Did the organization receive any payments for indoor tanning services during the tax year?		X
b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation on Schedule O		
15	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.		X
16	Is the organization an educational institution subject to the section 4968 excise tax on net investment income? If "Yes," complete Form 4720, Schedule O.		X

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 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations.
- List all of the organization's **former** officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's **former** directors or trustees that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations. See 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 per week for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(1) Darlene Royalty	1.00									
President	0.00	X		X			0	0	0	
(2) Barbara Wuebbels	1.00									
Vice President	0.00	X		X			0	0	0	
(3) Donna Fogle	1.00									
Secretary	0.00	X		X			0	0	0	
(4) Bob Jensen	1.00									
Treasurer	0.00	X		X			0	0	0	
(5) John Ireland	1.00									
SIB Representative	0.00	X		X			0	0	0	
(6) Brock Benroth	1.00									
Director	0.00	X					0	0	0	
(7) Mike Collins	1.00									
Director	0.00	X					0	0	0	
(8) Tony Ferrandino	1.00									
Director	0.00	X					0	0	0	
(9) Kate Haller	1.00									
Director	0.00	X					0	0	0	
(10) Barbara McDonough	1.00									
Director	0.00	X					0	0	0	
(11) Trent Lewis	1.00									
Director	0.00	X					0	0	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	
Contributions, Gifts, Grants and Other Similar Amounts	1a Federated campaigns	1a				
	b Membership dues	1b				
	c Fundraising events	1c				
	d Related organizations	1d				
	e Government grants (contributions)	1e				
	f All other contributions, gifts, grants, and similar amounts not included above	1f	968,030			
	g Noncash contributions included in lines 1a-1f	1g	\$ 5,228			
	h Total. Add lines 1a-1f		968,030			
	Program Service Revenue	2a Program Service Fees	Business Code 900099	236,958	236,958	
b						
c						
d						
e						
f All other program service revenue						
g Total. Add lines 2a-2f			236,958			
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)		23,619	23,619		
	4 Income from investment of tax-exempt bond proceeds					
	5 Royalties					
	6a Gross rents	(i) Real				
		(ii) Personal				
		6a				
	b Less: rental expenses	6b				
	c Rental inc. or (loss)	6c				
	d Net rental income or (loss)					
	7a Gross amount from sales of assets other than inventory	(i) Securities				
		(ii) Other				
		7a				
	b Less: cost or other basis and sales exps.	7b				
	c Gain or (loss)	7c				
	d Net gain or (loss)					
8a Gross income from fundraising events (not including \$ of contributions reported on line 1c). See Part IV, line 18						
	8a					
	b Less: direct expenses	8b				
c Net income or (loss) from fundraising events						
9a Gross income from gaming activities. See Part IV, line 19						
	9a					
	b Less: direct expenses	9b				
c Net income or (loss) from gaming activities						
10a Gross sales of inventory, less returns and allowances						
	10a					
	b Less: cost of goods sold	10b				
c Net income or (loss) from sales of inventory						
Miscellaneous Revenue	11a	Business Code				
	b					
	c					
	d All other revenue					
	e Total. Add lines 11a-11d					
12 Total revenue. See instructions		1,228,607	260,577	0	0	

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	
Assets	1	Cash—non-interest-bearing	45,879	1	184,309
	2	Savings and temporary cash investments		2	
	3	Pledges and grants receivable, net		3	
	4	Accounts receivable, net	363,982	4	307,269
	5	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		5	
	6	Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B)		6	
	7	Notes and loans receivable, net		7	
	8	Inventories for sale or use		8	
	9	Prepaid expenses and deferred charges		9	
	10a	Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	97,310		
	10b	Less: accumulated depreciation	31,417		
	10c		76,958	10c	65,893
	11	Investments—publicly traded securities	323,061	11	465,498
	12	Investments—other securities. See Part IV, line 11		12	
	13	Investments—program-related. See Part IV, line 11		13	
	14	Intangible assets		14	
15	Other assets. See Part IV, line 11	5,560	15	5,560	
16	Total assets. Add lines 1 through 15 (must equal line 33)	815,440	16	1,028,529	
Liabilities	17	Accounts payable and accrued expenses	154,051	17	25,163
	18	Grants payable		18	
	19	Deferred revenue	202,732	19	
	20	Tax-exempt bond liabilities		20	
	21	Escrow or custodial account liability. Complete Part IV of Schedule D		21	
	22	Loans and other payables to 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		22	
	23	Secured mortgages and notes payable to unrelated third parties		23	
	24	Unsecured notes and loans payable to unrelated third parties		24	54,242
	25	Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24). Complete Part X of Schedule D		25	
	26	Total liabilities. Add lines 17 through 25	356,783	26	79,405
Net Assets or Fund Balances	Organizations that follow FASB ASC 958, check here <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33.				
	27	Net assets without donor restrictions	204,524	27	694,991
	28	Net assets with donor restrictions	254,133	28	254,133
	Organizations that do not follow FASB ASC 958, check here <input type="checkbox"/> and complete lines 29 through 33.				
	29	Capital stock or trust principal, or current funds		29	
	30	Paid-in or capital surplus, or land, building, or equipment fund		30	
	31	Retained earnings, endowment, accumulated income, or other funds		31	
	32	Total net assets or fund balances	458,657	32	949,124
33	Total liabilities and net assets/fund balances	815,440	33	1,028,529	

SCHEDULE A
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support

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

▶ Attach to Form 990 or Form 990-EZ.

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

OMB No. 1545-0047

2020

Open to Public Inspection

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)**. (Attach Schedule E (Form 990 or 990-EZ).)
- 3 A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii)**.
- 4 A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii)**. Enter the hospital's name, city, and state:
- 5 An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv)**. (Complete Part II.)
- 6 A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v)**.
- 7 An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi)**. (Complete Part II.)
- 8 A community trust described in **section 170(b)(1)(A)(vi)**. (Complete Part II.)
- 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 (see instructions). Enter the name, city, and state of the college or university:
- 10 An organization that normally receives: (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions, subject to certain exceptions; and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See **section 509(a)(2)**. (Complete Part III.)
- 11 An organization organized and operated exclusively to test for public safety. See **section 509(a)(4)**.
- 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)**. See **section 509(a)(3)**. Check the box in lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g.
 - 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. **You must complete Part IV, Sections A and B.**
 - 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). **You must complete Part IV, Sections A and C.**
 - c **Type III functionally integrated.** A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions). **You must complete Part IV, Sections A, D, and E.**
 - d **Type III non-functionally integrated.** A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions). **You must complete Part IV, Sections A and D, and Part V.**
 - 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).

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1-10 above (see instructions))	(iv) Is the organization listed in your governing document?		(v) Amount of monetary support (see instructions)	(vi) Amount of other support (see instructions)
			Yes	No		
(A)						
(B)						
(C)						
(D)						
(E)						
Total						

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

Schedule A (Form 990 or 990-EZ) 2020

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

Calendar year (or fiscal year beginning in) ▶	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	834,676	834,109	967,924	883,058	968,030	4,487,797
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose					236,958	236,958
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5	834,676	834,109	967,924	883,058	1,204,988	4,724,755
7a Amounts included on lines 1, 2, and 3 received from disqualified persons					3,370	3,370
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
c Add lines 7a and 7b					3,370	3,370
8 Public support. (Subtract line 7c from line 6.)						4,721,385

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
9 Amounts from line 6	834,676	834,109	967,924	883,058	1,204,988	4,724,755
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources	9,107	78	-13,024	47,608	23,619	67,388
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b	9,107	78	-13,024	47,608	23,619	67,388
11 Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)				22,945		22,945
13 Total support. (Add lines 9, 10c, 11, and 12.)	843,783	834,187	954,900	953,611	1,228,607	4,815,088

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

15 Public support percentage for 2020 (line 8, column (f), divided by line 13, column (f))	15	98.05%
16 Public support percentage from 2019 Schedule A, Part III, line 15	16	98.17%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2020 (line 10c, column (f), divided by line 13, column (f))	17	1%
18 Investment income percentage from 2019 Schedule A, Part III, line 17	18	1%

19a 33 1/3% support tests—2020. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization

b 33 1/3% support tests—2019. 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 (continued)

	Yes	No
11 Has the organization accepted a gift or contribution from any of the following persons?		
a A person who directly or indirectly controls, either alone or together with persons described in lines 11b and 11c below, the governing body of a supported organization?		
b A family member of a person described in line 11a above?		
c A 35% controlled entity of a person described in line 11a or 11b above? <i>If "Yes" to line 11a, 11b, or 11c, provide detail in Part VI.</i>		

Section B. Type I Supporting Organizations

	Yes	No
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? <i>If "No," describe in Part VI how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove officers, directors, or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.</i>		
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? <i>If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised, or controlled the supporting organization.</i>		

Section C. Type II Supporting Organizations

	Yes	No
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)? <i>If "No," describe in Part VI how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s).</i>		

Section D. All Type III Supporting Organizations

	Yes	No
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?		
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? <i>If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).</i>		
3 By reason of the relationship described in 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? <i>If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.</i>		

Section E. Type III Functionally-Integrated Supporting Organizations

1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).		
a <input type="checkbox"/> The organization satisfied the Activities Test. Complete line 2 below.		
b <input type="checkbox"/> The organization is the parent of each of its supported organizations. Complete line 3 below.		
c <input type="checkbox"/> The organization supported a governmental entity. Describe in Part VI how you supported a governmental entity (see instructions).		
2 Activities Test. Answer lines 2a and 2b below.		
a Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? <i>If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.</i>		
b Did the activities described in line 2a, above, constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? <i>If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.</i>		
3 Parent of Supported Organizations. Answer lines 3a and 3b below.		
a Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? <i>If "Yes" or "No," provide details in Part VI.</i>		
b Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? <i>If "Yes," describe in Part VI the role played by the organization in this regard.</i>		

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

Section D – Distributions		Current Year		
1	Amounts paid to supported organizations to accomplish exempt purposes			
2	Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity			
3	Administrative expenses paid to accomplish exempt purposes of supported organizations			
4	Amounts paid to acquire exempt-use assets			
5	Qualified set-aside amounts (prior IRS approval required—provide details in Part VI)			
6	Other distributions (describe in Part VI). See instructions.			
7	Total annual distributions. Add lines 1 through 6.			
8	Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI). See instructions.			
9	Distributable amount for 2020 from Section C, line 6			
10	Line 8 amount divided by line 9 amount			
Section E – Distribution Allocations (see instructions)		(i) Excess Distributions	(ii) Underdistributions Pre-2020	(iii) Distributable Amount for 2020
1	Distributable amount for 2020 from Section C, line 6			
2	Underdistributions, if any, for years prior to 2020 (reasonable cause required—explain in Part VI). See instructions.			
3	Excess distributions carryover, if any, to 2020			
a	From 2015			
b	From 2016			
c	From 2017			
d	From 2018			
e	From 2019			
f	Total of lines 3a through 3e			
g	Applied to underdistributions of prior years			
h	Applied to 2020 distributable amount			
i	Carryover from 2015 not applied (see instructions)			
j	Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
4	Distributions for 2020 from Section D, line 7: \$			
a	Applied to underdistributions of prior years			
b	Applied to 2020 distributable amount			
c	Remainder. Subtract lines 4a and 4b from line 4.			
5	Remaining underdistributions for years prior to 2020, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, explain in Part VI. See instructions.			
6	Remaining underdistributions for 2020 Subtract lines 3h and 4b from line 1. For result greater than zero, explain in Part VI. See instructions.			
7	Excess distributions carryover to 2021. Add lines 3j and 4c.			
8	Breakdown of line 7:			
a	Excess from 2016			
b	Excess from 2017			
c	Excess from 2018			
d	Excess from 2019			
e	Excess from 2020			

Schedule B
 (Form 990, 990-EZ,
 or 990-PF)
 Department of the Treasury
 Internal Revenue Service

Schedule of Contributors

OMB No. 1545-0047

2020

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

Name of the organization Batten Disease Support & Research Association	Employer identification number **-***7792
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Organization type (check one):

- | | | |
|--------------------|---|--|
| Filers of: | Section: | |
| Form 990 or 990-EZ | <input checked="" type="checkbox"/> 501(c)(3) (enter number) organization | |
| | <input type="checkbox"/> 4947(a)(1) nonexempt charitable trust not treated as a private foundation | |
| | <input type="checkbox"/> 527 political organization | |
| Form 990-PF | <input type="checkbox"/> 501(c)(3) exempt private foundation | |
| | <input type="checkbox"/> 4947(a)(1) nonexempt charitable trust treated as a private foundation | |
| | <input type="checkbox"/> 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

- 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 or 990-EZ), 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, 990-EZ, or 990-PF), 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, 990-EZ, or 990-PF).

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	Tom Cornell 1462 18th Street NW Saint Paul MN 55112	\$ 12,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
8	Gregg Froio 25 Aberdeen Drive Sicklerville NJ 08081	\$ 10,050	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
9	Our Promise to Nicholas Foundation PO Box 10106 Bedford NH 03110	\$ 10,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
10	Rita Garvey 3011 Salisbury Court Wexford PA 15090	\$ 10,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
11	The Cru Foundation 100 Lake Hart Drive #3600 Orlando FL 32832	\$ 10,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
12	Abeona Therapeutics 3333 Lee Parkway, Suite 600 Dallas TX 75219	\$ 7,500	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
19	Beyond Batten Disease Foundation PO Box 50221 Austin TX 78763	\$ 5,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
20	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.)
21	Paul Hunter and Constance Hunter Charitable Foundation 800 S Nova Road, Suite Q Ormond Beach FL 32174	\$ 5,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
22	Kent Schmidt 901 Kinkead Road McAlester OK 74501	\$ 5,000	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
23	Katherine Sproger 5002 Camp Meeting Road Center Valley PA 18034	\$ 5,000	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.)

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.

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2020

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 2 columns: (a) Donor advised funds, (b) Funds and other accounts. Rows include: 1 Total number at end of year, 2 Aggregate value of contributions to (during year), 3 Aggregate value of grants from (during year), 4 Aggregate value at end of year, 5 Did the organization inform all donors... Yes No, 6 Did the organization inform all grantees... Yes No.

Part II Conservation Easements.

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

Table with 2 columns: Held at the End of the Tax Year. Rows include: 1 Purpose(s) of conservation easements, 2 Complete lines 2a through 2d, 3 Number of conservation easements modified, 4 Number of states where property subject to conservation easement is located, 5 Does the organization have a written policy..., 6 Staff and volunteer hours..., 7 Amount of expenses..., 8 Does each conservation easement..., 9 In Part XIII, describe how the organization reports...

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 2 columns: Revenue, Assets. Rows include: 1a If the organization elected, as permitted under FASB ASC 958, not to report..., 1b If the organization elected, as permitted under FASB ASC 958, to report..., 2 If the organization received or held works of art, historical treasures, or other similar assets for financial gain...

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)		
Total. (Column (b) must equal Form 990, Part X, col. (B) line 12.) ▶		

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)		
Total. (Column (b) must equal Form 990, Part X, col. (B) line 13.) ▶		

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)	
Total. (Column (b) must equal Form 990, Part X, col. (B) line 15.) ▶	

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)	
Total. (Column (b) must equal Form 990, Part X, col. (B) line 25.) ▶	

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

Schedule F (Form 990) 2020 **Batten Disease Support**

-*7792

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	45,328	WIRE TRANSFER			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 **1**

3 Enter total number of other organizations or entities **1**

Part IV Foreign Forms

- 1** Was the organization a U.S. transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926)* Yes No
- 2** Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to 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 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 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 Instructions for Form 8621)* Yes No
- 5** Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign Partnerships (see Instructions for Form 8865)* Yes No
- 6** Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to separately file Form 5713, International Boycott Report (see Instructions for Form 5713; don't file with Form 990)* Yes No

Schedule F (Form 990) 2020

**SCHEDULE I
(Form 990)**

Department of the Treasury
Internal Revenue Service

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

OMB No. 1545-0047
2020
**Open to Public
Inspection**

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 non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
(1)	Washington University 1 Brookings Drive St. Louis MO 63130	** - *** 3611	501c3	10,000		CASH		Research
(2)	University of North Carolina 103 South Building Campus Chapel Hill NC 27599	** - *** 1393	501c3	40,000		CASH		Research
(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 ▶

SCHEDULE O
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

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

▶ Attach to Form 990 or 990-EZ.

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

OMB No. 1545-0047

2020

**Open to Public
Inspection**

Name of the organization **Batten Disease Support
& Research Association**

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

Form 990, Part VI, Line 8b - Documentation by Committee Explanation

No committees of BDSRA have the authority to act on behalf of the Board.

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, Part XI, Line 9 - Other Changes in Net Assets Explanation

Accounts Payable Adjustments \$ -20,121