

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.

A For the **2019** calendar year, or tax year beginning and ending

B Check if applicable: <input type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial return <input type="checkbox"/> Final return/terminated <input type="checkbox"/> Amended return <input type="checkbox"/> Application pending	C Name of organization THE BARTH SYNDROME FOUNDATION		D Employer identification number 22-3755704
	Doing business as		E Telephone number 855-662-2784
	Number and street (or P.O. box if mail is not delivered to street address)	Room/suite	
	2005 PALMER AVENUE		G Gross receipts \$ 1,636,375.
	City or town, state or province, country, and ZIP or foreign postal code LARCHMONT, NY 10538		H(a) Is this a group return for subordinates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No H(b) Are all subordinates included? <input type="checkbox"/> Yes <input type="checkbox"/> No If "No," attach a list. (see instructions) H(c) Group exemption number ▶

F Name and address of principal officer: **EMILY MILLIGAN**
SAME AS C ABOVE

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

J Website: ▶ **WWW.BARTHSYNDROME.ORG**

K Form of organization: Corporation Trust Association Other ▶ **L** Year of formation: **2000** **M** State of legal domicile: **DE**

Part I Summary		Prior Year	Current Year
Activities & Governance	1 Briefly describe the organization's mission or most significant activities: 1) TO PROMOTE AWARENESS OF BARTH SYNDROME; 2) TO EDUCATE AND SUPPORT PHYSICIANS, RESEARCH CENTERS,		
	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 2019 (Part V, line 2a)	5	5
	6 Total number of volunteers (estimate if necessary)	6	200
	7a Total unrelated business revenue from Part VIII, column (C), line 12	7a	0.
b Net unrelated business taxable income from Form 990-T, line 39	7b	0.	
Revenue	8 Contributions and grants (Part VIII, line 1h)	1,997,067.	935,649.
	9 Program service revenue (Part VIII, line 2g)	156,766.	0.
	10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)	137,262.	200,113.
	11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	0.	0.
	12 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	2,291,095.	1,135,762.
Expenses	13 Grants and similar amounts paid (Part IX, column (A), lines 1-3)	253,199.	416,917.
	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)	479,527.	561,697.
	16a Professional fundraising fees (Part IX, column (A), line 11e)	0.	0.
	b Total fundraising expenses (Part IX, column (D), line 25) ▶ 74,333.		
	17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	422,584.	322,762.
18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	1,155,310.	1,301,376.	
19 Revenue less expenses. Subtract line 18 from line 12	1,135,785.	-165,614.	
Net Assets or Fund Balances	20 Total assets (Part X, line 16)	Beginning of Current Year 4,750,350.	End of Year 4,993,243.
	21 Total liabilities (Part X, line 26)	159,079.	286,825.
	22 Net assets or fund balances. Subtract line 21 from line 20	4,591,271.	4,706,418.

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
	EMILY MILLIGAN, EXECUTIVE DIRECTOR Type or print name and title	

Paid Preparer Use Only	Print/Type preparer's name EDWARD K. BALTAZAR, CPA	Preparer's signature 	Date 5-28-2020	Check if self-employed <input type="checkbox"/>	PTIN P00988228
	Firm's name ▶ DORFMAN ABRAMS MUSIC, LLC	Firm's EIN ▶ 22-1655803	Firm's address ▶ 250 PEHLE AVE., SUITE 702 SADDLE BROOK, NJ 07663		
			Phone no. 201-403-9750		

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

Part III Statement of Program Service Accomplishments

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

1 Briefly describe the organization's mission: THE BARTH SYNDROME FOUNDATION IS AN ENGAGED, GLOBAL COMMUNITY WHOSE MISSION IS SAVING LIVES THROUGH EDUCATION, ADVANCES IN TREATMENT, AND FINDING A CURE FOR BARTH SYNDROME.

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 [X] No

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services? [] Yes [X] No

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 \$ 481,422. including grants of \$ 216,917.) (Revenue \$) THE BARTH SYNDROME SCIENCE, MEDICINE & RESEARCH PROGRAM IN 2019 WAS COMPRISED OF A) THE BSF RESEARCH PROGRAM TO FOSTER SCIENTIFIC AND CLINICAL INVESTIGATIONS INTO BARTH SYNDROME TO FACILITATE THE DEVELOPMENT OF A SPECIFIC TREATMENT OR A CURE FOR THIS DISEASE, AND B) THE BARTH SYNDROME MEDICAL DATABASE AND BIO-REPOSITORY FOR THE COLLECTION AND STORAGE OF MEDICAL INFORMATION/SAMPLES ON INDIVIDUALS WITH BARTH SYNDROME OVER TIME TO GAIN A BETTER UNDERSTANDING OF THE DISEASE.

4b (Code:) (Expenses \$ 0. including grants of \$ 0.) (Revenue \$) THIS CONFERENCE, HELD EVERY TWO YEARS, BRINGS AFFECTED FAMILIES, RESEARCH SCIENTISTS AND CLINICIANS TOGETHER IN ONE PLACE AT A TIME SO THAT THEY MAY COLLABORATE AND SHARE THEIR KNOWLEDGE TO GAIN A GREATER UNDERSTANDING OF BARTH SYNDROME AND LEARN ABOUT THE LATEST DISCOVERIES AND SCIENTIFIC RESEARCH AVAILABLE. FAMILIES HAVE A UNIQUE OPPORTUNITY TO BE SEEN BY THE WORLD'S GREATEST EXPERTS, THEREBY, CONTRIBUTING DIRECTLY TO THE SEARCH FOR A CURE BY PROVIDING INFORMATION AND TISSUE SAMPLES. (NOT HELD FOR CALENDAR YEAR END 2019)

4c (Code:) (Expenses \$ 200,000. including grants of \$ 200,000.) (Revenue \$) THE WILL MCCURDY FUND FOR THE ADVANCEMENT OF THERAPIES FOR BARTH SYNDROME WILL BE USED EXCLUSIVELY FOR THE DEVELOPMENT OF THERAPIES DESIGNED TO PREVENT, ALLEVIATE, OR ELIMINATE THE SYMPTOMS OF BARTH SYNDROME.

4d Other program services (Describe on Schedule O.) (Expenses \$ 385,792. including grants of \$) (Revenue \$)

4e Total program service expenses 1,067,214.

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 <i>Schedule B, Schedule of Contributors?</i>	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 Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? <i>If "Yes," complete Schedule C, Part II</i>		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 Revenue Procedure 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</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?		
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?		
d Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?		
25a Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <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
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
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
28 Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions, for applicable filing thresholds, conditions, and exceptions):		
a A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? <i>If "Yes," complete Schedule L, Part IV</i>		X
b A family member of any individual described in line 28a? <i>If "Yes," complete Schedule L, Part IV</i>		X
c A 35% controlled entity of one or more individuals and/or organizations described in lines 28a or 28b? <i>If "Yes," complete Schedule L, Part IV</i>		X
29 Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i>	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
31 Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>		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
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
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
35a Did the organization have a controlled entity within the meaning of section 512(b)(13)?		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>		
36 Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i>		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
38 Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19?	X	

Note: All Form 990 filers are required to complete Schedule O

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		
b Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable		
c Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?		

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 5		
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	X	
Note: If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)			
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?		
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?		
8	Sponsoring organizations maintaining donor advised funds. 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?	12a	
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.	13a	
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?	14a	X
b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation on Schedule O	14b	
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.	15	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.	16	X

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
1a	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.		
	1a 12		
b	Enter the number of voting members included on line 1a, above, who are independent		
	1b 12		
2	Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee?		X
3	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?		X
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?		X
5	Did the organization become aware during the year of a significant diversion of the organization's assets?		X
6	Did the organization have members or stockholders?		X
7a	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?		X
b	Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?		X
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:		
a	The governing body?	X	
b	Each committee with authority to act on behalf of the governing body?	X	
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses on Schedule O		X

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

		Yes	No
10a	Did the organization have local chapters, branches, or affiliates?		X
b	If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes?		
10b			
11a	Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?	X	
b	Describe in Schedule O the process, if any, used by the organization to review this Form 990.		
12a	Did the organization have a written conflict of interest policy? If "No," go to line 13	X	
b	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	X	
c	Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done	X	
12c		X	
13	Did the organization have a written whistleblower policy?	X	
14	Did the organization have a written document retention and destruction policy?	X	
15	Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision?		
a	The organization's CEO, Executive Director, or top management official	X	
b	Other officers or key employees of the organization	X	
	If "Yes" to line 15a or 15b, describe the process in Schedule O (see instructions).		
16a	Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year?		X
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?		
16b			

Section C. Disclosure

- 17** List the states with which a copy of this Form 990 is required to be filed **NJ, MA, NY, CT, IL, TN, PA, VA, CA, FL, MD, UT**
- 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 **NATALIE COHN - 855-662-2784**
2005 PALMER AVE, LARCHMONT, NY 10538

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 (list any hours for related organizations below 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) MATTHEW BLUMENTHAL BOARD MEMBER	2.00	X					0.	0.	0.	
(2) FLORENCE MANNES BOARD MEMBER	2.00	X					0.	0.	0.	
(3) MEGAN BRANAGH BOARD MEMBER	2.00	X					0.	0.	0.	
(4) DAVID AXELROD, M.D. BOARD MEMBER	2.00	X					0.	0.	0.	
(5) CATHARINE LYNNE RITTER BOARD MEMBER TERM 9/2019	2.00	X					0.	0.	0.	
(6) BRUCE J. DEVELLE BOARD MEMBER	2.00	X					0.	0.	0.	
(7) NICOLE DERUSHA-MACKAY BOARD MEMBER	2.00	X					0.	0.	0.	
(8) BRANDI DAGUE BOARD MEMBER	2.00	X					0.	0.	0.	
(9) MICHELLE FLOREZ BOARD MEMBER	2.00	X					0.	0.	0.	
(10) PETER VAN LOO BOARD MEMBER	2.00	X					0.	0.	0.	
(11) SUSAN A. MCCORMACK CHAIR	2.00	X		X			0.	0.	0.	
(12) KEVIN G. WOODWARD TREASURER	2.00	X		X			0.	0.	0.	
(13) JOHN WILKINS SECRETARY	2.00	X		X			0.	0.	0.	
(14) EMILY MILLIGAN EXECUTIVE DIRECTOR	35.00			X			190,000.	0.	0.	
(15) MATTHEW TOTH DIR OF SCIENCE	35.00				X		110,808.	0.	8,389.	

Part VIII Statement of Revenue

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

			(A)	(B)	(C)	(D)	
			Total revenue	Related or exempt function revenue	Unrelated business revenue	Revenue excluded from tax under sections 512 - 514	
Contributions, Gifts, Grants and Other Similar Amounts	1 a 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	935,649.				
	g Noncash contributions included in lines 1a-1f	1g	\$ 34,142.				
	h Total. Add lines 1a-1f		935,649.				
Program Service Revenue	2 a _____	Business Code					
	b _____						
	c _____						
	d _____						
	e _____						
	f All other program service revenue						
	g Total. Add lines 2a-2f						
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)		121,894.			121,894.	
	4 Income from investment of tax-exempt bond proceeds						
	5 Royalties						
	6 a Gross rents	6a	(i) Real				
			(ii) Personal				
	b Less: rental expenses ...	6b					
	c Rental income or (loss)	6c					
	d Net rental income or (loss)						
	7 a Gross amount from sales of assets other than inventory	7a	(i) Securities	578,832.			
			(ii) Other				
	b Less: cost or other basis and sales expenses	7b	500,613.				
	c Gain or (loss)	7c	78,219.				
d Net gain or (loss)		78,219.			78,219.		
8 a 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							
9 a Gross income from gaming activities. See Part IV, line 19	9a						
b Less: direct expenses	9b						
c Net income or (loss) from gaming activities							
10 a 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	11 a _____	Business Code					
	b _____						
	c _____						
	d All other revenue						
	e Total. Add lines 11a-11d						
12 Total revenue. See instructions			1,135,762.	0.	0.	200,113.	

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

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	336,917.	336,917.		
2 Grants and other assistance to domestic individuals. See Part IV, line 22				
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16	80,000.	80,000.		
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	190,000.	114,000.	28,500.	47,500.
6 Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)				
7 Other salaries and wages	313,283.	296,874.	16,409.	
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
9 Other employee benefits	24,711.	22,010.	1,503.	1,198.
10 Payroll taxes	33,703.	30,020.	2,050.	1,633.
11 Fees for services (nonemployees):				
a Management				
b Legal				
c Accounting	48,483.		48,483.	
d Lobbying				
e Professional fundraising services. See Part IV, line 17				
f Investment management fees				
g Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Sch O.)	107,741.	90,470.	12,679.	4,592.
12 Advertising and promotion				
13 Office expenses	74,854.	25,002.	33,788.	16,064.
14 Information technology				
15 Royalties				
16 Occupancy				
17 Travel	52,901.	48,646.	2,853.	1,402.
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings				
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization				
23 Insurance	3,801.		3,801.	
24 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.)				
a DUES AND FEES	18,144.	7,638.	8,712.	1,794.
b AUDIO VISUAL	12,125.	12,000.		125.
c MEALS	2,383.	2,287.	96.	
d MISCELLANEOUS	2,330.	1,350.	955.	25.
e All other expenses				
25 Total functional expenses. Add lines 1 through 24e	1,301,376.	1,067,214.	159,829.	74,333.
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation.				

Check here if following SOP 98-2 (ASC 958-720)

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	237,557.	1	384,847.
	2 Savings and temporary cash investments		2	
	3 Pledges and grants receivable, net		3	67,917.
	4 Accounts receivable, net	2,565.	4	30,649.
	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	2,699.	9	37,285.
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a 3,225.		
	b Less: accumulated depreciation	10b 3,225.	10c 0.	0.
	11 Investments - publicly traded securities	4,507,529.	11	4,472,545.
	12 Investments - other securities. See Part IV, line 11		12	
	13 Investments - program-related. See Part IV, line 11		13	
	14 Intangible assets		14	
	15 Other assets. See Part IV, line 11		15	
16 Total assets. Add lines 1 through 15 (must equal line 33)	4,750,350.	16	4,993,243.	
Liabilities	17 Accounts payable and accrued expenses	18,932.	17	26,869.
	18 Grants payable	140,147.	18	259,580.
	19 Deferred revenue		19	376.
	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	
	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	159,079.	26	286,825.
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	861,228.	27	914,227.
	28 Net assets with donor restrictions	3,730,043.	28	3,792,191.
	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	4,591,271.	32	4,706,418.
33 Total liabilities and net assets/fund balances	4,750,350.	33	4,993,243.	

Part XI Reconciliation of Net Assets

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	1,135,762.
2	Total expenses (must equal Part IX, column (A), line 25)	2	1,301,376.
3	Revenue less expenses. Subtract line 2 from line 1	3	-165,614.
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	4,591,271.
5	Net unrealized gains (losses) on investments	5	304,361.
6	Donated services and use of facilities	6	
7	Investment expenses	7	-23,600.
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain on Schedule O)	9	0.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B))	10	4,706,418.

Part XII Financial Statements and Reporting

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

		Yes	No
1	Accounting method used to prepare the Form 990: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other _____ If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule O.		
2a	Were the organization's financial statements compiled or reviewed by an independent accountant? _____ If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both: <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		X
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 checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis	X	
c	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.	X	
3a	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133? _____		X
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 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

2019

Open to Public Inspection

Name of the organization **THE BARTH SYNDROME FOUNDATION** Employer identification number **22-3755704**

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.

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

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

1 Purpose(s) of conservation easements held by the organization (check all that apply).
 Preservation of land for public use (for example, recreation or education) Preservation of a historically important land area
 Protection of natural habitat Preservation of a certified historic structure
 Preservation of open space

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

	Held at the End of the Tax Year
a Total number of conservation easements	2a
b Total acreage restricted by conservation easements	2b
c Number of conservation easements on a certified historic structure included in (a)	2c
d Number of conservation easements included in (c) acquired after 7/25/06, and not on a historic structure listed in the National Register	2d

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

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

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

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

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

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

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

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

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

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

b If the organization elected, as permitted under FASB ASC 958, to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items:

(i) Revenue included on Form 990, Part VIII, line 1

(ii) Assets included in Form 990, Part X

2 If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under FASB ASC 958 relating to these items:

a Revenue included on Form 990, Part VIII, line 1

b Assets included in Form 990, Part X

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:
- | | Amount |
|--|-----------|
| c Beginning balance | 1c |
| d Additions during the year | 1d |
| e Distributions during the year | 1e |
| f Ending balance | 1f |
- 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
1a Beginning of year balance					
b Contributions					
c Net investment earnings, gains, and losses					
d Grants or scholarships					
e Other expenditures for facilities and programs					
f Administrative expenses					
g End of year balance					

- 2** Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
- a** Board designated or quasi-endowment ▶ _____ %
 - b** Permanent endowment ▶ _____ %
 - c** 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:
- | | Yes | No |
|---|---------------|----|
| (i) Unrelated organizations | 3a(i) | |
| (ii) Related organizations | 3a(ii) | |
| b If "Yes" on line 3a(ii), are the related organizations listed as required on Schedule R? | 3b | |
- 4** Describe in Part XIII the intended uses of the organization's endowment funds.

Part VI Land, Buildings, and Equipment.

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
1a Land				
b Buildings				
c Leasehold improvements				
d Equipment		3,225.	3,225.	0.
e Other				
Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10c.)				0.

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. (Col. (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. (Col. (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...

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.

1	Total revenue, gains, and other support per audited financial statements		1	1,416,523.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
a	Net unrealized gains (losses) on investments	2a 304,361.		
b	Donated services and use of facilities	2b		
c	Recoveries of prior year grants	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d		2e	304,361.
3	Subtract line 2e from line 1		3	1,112,162.
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a 23,600.		
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b		4c	23,600.
5	Total revenue. Add lines 3 and 4c . (This must equal Form 990, Part I, line 12.)		5	1,135,762.

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.

1	Total expenses and losses per audited financial statements		1	1,301,376.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
a	Donated services and use of facilities	2a		
b	Prior year adjustments	2b		
c	Other losses	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d		2e	0.
3	Subtract line 2e from line 1		3	1,301,376.
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a		
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b		4c	0.
5	Total expenses. Add lines 3 and 4c . (This must equal Form 990, Part I, line 18.)		5	1,301,376.

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.

PART X, LINE 2:

THE ORGANIZATION IS A TAX-EXEMPT ORGANIZATION AS DEFINED BY SECTION 501(C)(3) OF THE INTERNAL REVENUE CODE, THOUGH IT IS SUBJECT TO TAX ON INCOME UNRELATED TO ITS EXEMPT PURPOSE, UNLESS THAT INCOME IS OTHERWISE EXCLUDED BY THE CODE. THE ORGANIZATION HAS PROCESSES PRESENTLY IN PLACE TO ENSURE THE MAINTENANCE OF ITS TAX-EXEMPT STATUS; TO IDENTIFY AND REPORT UNRELATED INCOME; TO DETERMINE ITS FILING AND TAX OBLIGATIONS IN JURISDICTIONS FOR WHICH IT HAS NEXUS; AND TO IDENTIFY AND EVALUATE OTHER MATTERS THAT MAY BE CONSIDERED TAX POSITIONS. THE ORGANIZATION HAS DETERMINED THAT THERE ARE NO MATERIAL UNCERTAIN TAX POSITIONS THAT REQUIRE RECOGNITION OR DISCLOSURE IN THE FINANCIAL STATEMENTS.

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)
		EUROPE	RESOLUTION OF THE UNDERLYING BASIS FOR THE IMPAIRED OXIDATION OF FATTY	30,000.		0.		
		EUROPE	IMPAIRED FATTY ACID UTILIZATION AND ALTERNATIVE SUBSTRATES IN BARTH	50,000.		0.		

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

3 Enter total number of other organizations or entities ▶ _____

SEE PART V FOR COLUMN (D) DESCRIPTIONS

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

Part V Supplemental Information

Provide the information required by Part I, line 2 (monitoring of funds); Part I, line 3, column (f) (accounting method; amounts of investments vs. expenditures per region); Part II, line 1 (accounting method); Part III (accounting method); and Part III, column (c) (estimated number of recipients), as applicable. Also complete this part to provide any additional information. See instructions.

PART II, COLUMN (D):

REGION: EUROPE

**(D) PURPOSE OF GRANT: RESOLUTION OF THE UNDERLYING BASIS FOR THE
IMPAIRED OXIDATION OF FATTY ACIDS IN BARTH SYNDROME**

REGION: EUROPE

**(D) PURPOSE OF GRANT: IMPAIRED FATTY ACID UTILIZATION AND ALTERNATIVE
SUBSTRATES IN BARTH SYNDROME**

**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

2019

**Open to Public
Inspection**

Name of the organization **THE BARTH SYNDROME FOUNDATION** Employer identification number **22-3755704**

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
BOSTON CHILDREN'S HOSPITAL 300 LONGWOOD AVE BOSTON, MA 02115		501(C)(3)	106,917.	0.			DISCOVERY OF GENETIC MODIFIERS OF BARTH SYNDROME
WAYNE STATE UNIVERSITY 5047 GULLEN MALL DETROIT, MI 48202	38-3555142	501(C)(3)	50,000.	0.			SUPPLEMENTATION OF CRITICAL METABOLITES IMPROVES TCA CYCLE FUNCTION AND VIABILITY OF
NEW YORK UNIVERSITY SCHOOL OF MEDICINE - 550 FIRST AVENUE - NEW YORK, NY 10016		501(C)(3)	30,000.	0.			CHARACTERIZATION OF HEMATOPOIETIC STEM AND PROGENITOR CELLS IN BARTH SYNDROME
UNIVERSITY OF CALIFORNIA REGENTS 607 CHARLES E. YOUNG DR E LOS ANGELES, CA 90095		501(C)(3)	100,000.	0.			DEUTERATED POLYUNSATURATED FATTY ACIDS AS PROTECTIVE THERAPY IN THE TREATMENT
MASSACHUSETTS GENERAL HOSPITAL 55 FRUIT STREET BOSTON, MA 02114		501(C)(3)	50,000.	0.			ADDRESS THE MECHANISM OF NEUTROPENIA IN PATIENTS WITH BARTH SYNDROME

- 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 **▶** _____

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

Schedule I (Form 990) (2019)

SEE PART IV FOR COLUMN (H) DESCRIPTIONS

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 non-cash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance

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:

PRIOR TO MAKING ANY PAYMENT, WE REQUIRE CERTIFICATION OF THE USE OF FUNDS FROM THE CONTRACTING OFFICER OF THE INSTITUTION RECEIVING THE GRANT ON BEHALF OF THE GRANT RECEPIENT. EVERY SIX MONTHS THEREAFTER, AND PRIOR TO ANY SUBSEQUENT PAYMENTS, THE CERTIFYING OFFICER OF THE INSTITUTION AND THE GRANT RECIPIENT MUST SIGN A DOCUMENT CERTIFYING THAT THE RESEARCH IS CONTINUING AS PLANNED AND THAT REASONABLE PROGRESS IS BEING MADE IN ACCORDANCE WITH THE ORIGINAL PROPOSAL. FOLLOWING COMPLETION OF THE WORK, A SUMMARY OF THE RESEARCH RESULTS IS REQUIRED TO BE SENT TO US AS WELL AS ANY

Part IV Supplemental Information

PUBLISHED FINDING.

PART II, LINE 1, COLUMN (H):

NAME OF ORGANIZATION OR GOVERNMENT: WAYNE STATE UNIVERSITY

(H) PURPOSE OF GRANT OR ASSISTANCE: SUPPLEMENTATION OF CRITICAL METABOLITES IMPROVES TCA CYCLE FUNCTION AND VIABILITY OF TFAZZIN-DEFICIENT CELLS

SUPPLEMENTATION OF CRITICAL METABOLITES IMPROVES TCA CYCLE FUNCTION AND VIABILITY OF TFAZZIN-DEFICIENT CELLS

SUPPLEMENTATION OF CRITICAL METABOLITES IMPROVES TCA CYCLE FUNCTION AND VIABILITY OF TFAZZIN-DEFICIENT CELLS

SUPPLEMENTATION OF CRITICAL METABOLITES IMPROVES TCA CYCLE FUNCTION AND VIABILITY OF TFAZZIN-DEFICIENT CELLS

NAME OF ORGANIZATION OR GOVERNMENT: UNIVERSITY OF CALIFORNIA REGENTS

(H) PURPOSE OF GRANT OR ASSISTANCE: DEUTERATED POLYUNSATURATED FATTY ACIDS AS PROTECTIVE THERAPY IN THE TREATMENT OF BARTH SYNDROME

**SCHEDULE J
(Form 990)**

Department of the Treasury
Internal Revenue Service

Compensation Information

For certain Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees

▶ Complete if the organization answered "Yes" on Form 990, Part IV, line 23.

▶ Attach to Form 990.

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

OMB No. 1545-0047

2019

Open to Public Inspection

Name of the organization

THE BARTH SYNDROME FOUNDATION

Employer identification number

22-3755704

Part I Questions Regarding Compensation

1a Check the appropriate box(es) if the organization provided any of the following to or for a person listed on Form 990, Part VII, Section A, line 1a. Complete Part III to provide any relevant information regarding these items.

- | | |
|--|--|
| <input type="checkbox"/> First-class or charter travel | <input type="checkbox"/> Housing allowance or residence for personal use |
| <input type="checkbox"/> Travel for companions | <input type="checkbox"/> Payments for business use of personal residence |
| <input type="checkbox"/> Tax indemnification and gross-up payments | <input type="checkbox"/> Health or social club dues or initiation fees |
| <input type="checkbox"/> Discretionary spending account | <input type="checkbox"/> Personal services (such as maid, chauffeur, chef) |

b If any of the boxes on line 1a are checked, did the organization follow a written policy regarding payment or reimbursement or provision of all of the expenses described above? If "No," complete Part III to explain

2 Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all directors, trustees, and officers, including the CEO/Executive Director, regarding the items checked on line 1a?

3 Indicate which, if any, of the following the organization used to establish the compensation of the organization's CEO/Executive Director. Check all that apply. Do not check any boxes for methods used by a related organization to establish compensation of the CEO/Executive Director, but explain in Part III.

- | | |
|---|---|
| <input checked="" type="checkbox"/> Compensation committee | <input checked="" type="checkbox"/> Written employment contract |
| <input type="checkbox"/> Independent compensation consultant | <input checked="" type="checkbox"/> Compensation survey or study |
| <input checked="" type="checkbox"/> Form 990 of other organizations | <input checked="" type="checkbox"/> Approval by the board or compensation committee |

4 During the year, did any person listed on Form 990, Part VII, Section A, line 1a, with respect to the filing organization or a related organization:

- a** Receive a severance payment or change-of-control payment?
- b** Participate in, or receive payment from, a supplemental nonqualified retirement plan?
- c** Participate in, or receive payment from, an equity-based compensation arrangement?
- If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.

Only section 501(c)(3), 501(c)(4), and 501(c)(29) organizations must complete lines 5-9.

5 For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the revenues of:

- a** The organization?
- b** Any related organization?
- If "Yes" on line 5a or 5b, describe in Part III.

6 For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the net earnings of:

- a** The organization?
- b** Any related organization?
- If "Yes" on line 6a or 6b, describe in Part III.

7 For persons listed on Form 990, Part VII, Section A, line 1a, did the organization provide any nonfixed payments not described on lines 5 and 6? If "Yes," describe in Part III

8 Were any amounts reported on Form 990, Part VII, paid or accrued pursuant to a contract that was subject to the initial contract exception described in Regulations section 53.4958-4(a)(3)? If "Yes," describe in Part III

9 If "Yes" on line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53.4958-6(c)?

	Yes	No
1b		
2		
4a		X
4b		X
4c		X
5a		X
5b		X
6a		X
6b		X
7		X
8		X
9		

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

Schedule J (Form 990) 2019

Part II Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees. Use duplicate copies if additional space is needed.

For each individual whose compensation must be reported on Schedule J, report compensation from the organization on row (i) and from related organizations, described in the instructions, on row (ii). Do not list any individuals that aren't listed on Form 990, Part VII.

Note: The sum of columns (B)(i)-(iii) for each listed individual must equal the total amount of Form 990, Part VII, Section A, line 1a, applicable column (D) and (E) amounts for that individual.

(A) Name and Title		(B) Breakdown of W-2 and/or 1099-MISC compensation			(C) Retirement and other deferred compensation	(D) Nontaxable benefits	(E) Total of columns (B)(i)-(D)	(F) Compensation in column (B) reported as deferred on prior Form 990
		(i) Base compensation	(ii) Bonus & incentive compensation	(iii) Other reportable compensation				
(1) EMILY MILLIGAN EXECUTIVE DIRECTOR	(i)	190,000.	0.	0.	0.	0.	190,000.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
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	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							

**SCHEDULE M
(Form 990)**

Noncash Contributions

OMB No. 1545-0047

2019

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

- ▶ Complete if the organizations answered "Yes" on Form 990, Part IV, lines 29 or 30.
- ▶ Attach to Form 990.
- ▶ Go to www.irs.gov/Form990 for instructions and the latest information.

Name of the organization **THE BARTH SYNDROME FOUNDATION** Employer identification number **22-3755704**

Part I		Types of Property		
	(a) Check if applicable	(b) Number of contributions or items contributed	(c) Noncash contribution amounts reported on Form 990, Part VIII, line 1g	(d) Method of determining noncash contribution amounts
1	Art - Works of art			
2	Art - Historical treasures			
3	Art - Fractional interests			
4	Books and publications			
5	Clothing and household goods			
6	Cars and other vehicles			
7	Boats and planes			
8	Intellectual property			
9	Securities - Publicly traded	X	5	34,142. FMV ON DATE RECEIVED
10	Securities - Closely held stock			
11	Securities - Partnership, LLC, or trust interests			
12	Securities - Miscellaneous			
13	Qualified conservation contribution - Historic structures			
14	Qualified conservation contribution - Other			
15	Real estate - Residential			
16	Real estate - Commercial			
17	Real estate - Other			
18	Collectibles			
19	Food inventory			
20	Drugs and medical supplies			
21	Taxidermy			
22	Historical artifacts			
23	Scientific specimens			
24	Archeological artifacts			
25	Other ()			
26	Other ()			
27	Other ()			
28	Other ()			

29 Number of Forms 8283 received by the organization during the tax year for contributions for which the organization completed Form 8283, Part IV, Donee Acknowledgement **29**

	Yes	No
30a During the year, did the organization receive by contribution any property reported in Part I, lines 1 through 28, that it must hold for at least three years from the date of the initial contribution, and which isn't required to be used for exempt purposes for the entire holding period?		X
b If "Yes," describe the arrangement in Part II.		
31 Does the organization have a gift acceptance policy that requires the review of any nonstandard contributions?		X
32a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash contributions?		X
b If "Yes," describe in Part II.		
33 If the organization didn't report an amount in column (c) for a type of property for which column (a) is checked, describe in Part II.		

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990. Schedule M (Form 990) 2019

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

2019

Open to Public
Inspection

Name of the organization

THE BARTH SYNDROME FOUNDATION

Employer identification number

22-3755704

FORM 990, PART I, LINE 1, DESCRIPTION OF ORGANIZATION MISSION:

AND ORGANIZATIONS ADDRESSING THE CAUSES, DIAGNOSIS, TREATMENT AND CURE
OF BARTH SYNDROME; AND 3) TO ASSIST IN THE SUPPORT OF THOSE SUFFERING
FROM BARTH SYNDROME AND THEIR FAMILIES.

FORM 990, PART III, LINE 4D, OTHER PROGRAM SERVICES:

COSTS RELATED TO AWARENESS. AWARENESS PROGRAMS TO ENSURE FAMILIES,
PHYSICIANS, AND RESEARCHERS ARE AWARE OF THE DISEASE.

EXPENSES \$ 385,792. INCLUDING GRANTS OF \$ 0. REVENUE \$ 0.

FORM 990, PART VI, SECTION B, LINE 11B:

THE FORM 990 IS SENT TO THE FULL BOARD OF DIRECTORS VIA EMAIL PRIOR TO
BEING FILED WITH IRS. ALL DIRECTORS ARE AFFORDED THE OPPORTUNITY TO ASK
QUESTIONS AND OFFER EDITS. THE DECISION OF WHETHER TO MAKE EDITS IS MADE BY
THE STAFF PERSON IN CHARGE OF FINANCES WITHIN THE ORGANIZATION IN
CONJUNCTION WITH CONSULTATION WITH OUR TAX PREPARER.

FORM 990, PART VI, SECTION B, LINE 12C:

EACH BOARD MEMBER AND ALL EMPLOYEES WHO CAN INFLUENCE THE ACTIONS OF BARTH
SYNDROME FOUNDATION (BSF) MUST FILL OUT AN ANNUAL DECLARATION STATING THAT
THEY HAD NO CONFLICTS OR IDENTIFYING THE NATURE OF THEIR INTERESTED PARTY
TRANSACTIONS. IT IS THE RESPONSIBILITY OF THE BOARD, OFFICERS, AND
MANAGEMENT EMPLOYEES TO SCRUTINIZE THEIR TRANSACTIONS AND OUTSIDE BUSINESS
INTERESTS AND RELATIONSHIPS FOR POTENTIAL CONFLICTS AND TO IMMEDIATELY MAKE
SUCH DISCLOSURES. THE BOARD SHALL DETERMINE WHETHER A CONFLICT EXISTS AND
IN THE CASE OF AN EXISTING CONFLICT, WHETHER THE CONTEMPLATED TRANSACTION

Name of the organization THE BARTH SYNDROME FOUNDATION	Employer identification number 22-3755704
--	---

MAY BE AUTHORIZED AS JUST, FAIR, AND REASONABLE TO BSF.

FORM 990, PART VI, SECTION B, LINE 15:

EACH YEAR, THE EXECUTIVE AND COMPENSATION COMMITTEES REVIEW COMPARABLE SALARIES BASED ON A RECOGNIZED STUDY, REVIEWS INFORMATION FROM OTHER COMPARABLE ORGANIZATIONS' 990'S, AND REVIEWS THE PERFORMANCE OF THE EXECUTIVE DIRECTOR AND THE KEY EMPLOYEES TO DETERMINE IF THE EXISTING SALARIES FALL WITHIN THESE RANGES. AFTER A DELIBERATION OF THIS MATTER, A NEW PROPOSED SALARY AND BENEFIT PACKAGE IS VOTED ON. THE MINUTES OF THE BOARD OF DIRECTORS REFLECT THE NATURE OF THIS PROCESS.

FORM 990, PART VI, LINE 17, LIST OF STATES RECEIVING COPY OF FORM 990:

NJ, MA, NY, CT, IL, TN, PA, VA, CA, FL, MD, UT, GA, KS, OH

FORM 990, PART VI, SECTION C, LINE 19:

THE FOUNDATION MAKES ITS GOVERNING DOCUMENTS, CONFLICT OF INTEREST AND OTHER POLICIES, AND FINANCIAL STATEMENTS AVAILABLE TO THE PUBLIC ON ITS WEBSITE AND/OR BY REQUEST.

FORM 990, PAGE 12, PART XII, LINE 2C

THE BOARD OF DIRECTORS IS RESPONSIBLE FOR OVERSIGHT OF THE AUDIT SELECTION OF THE INDEPENDENT ACCOUNTANT.