

Return of Organization Exempt From Income Tax

2008

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code
(except black lung benefit trust or private foundation)

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

For the **2008** calendar year, or tax year beginning , **2008**, and ending

B Check if applicable:
 Address change
 Name change
 Initial return
 Termination
 Amended return
 Application pending

Please use IRS label or print or type. See specific instructions.
The Barth Syndrome Foundation, Inc.
 675 VFW Parkway #372
 Chestnut Hill, MA 02467

D Employer Identification Number
 22-3755704

E Telephone number
 (617) 469-6769

G Gross receipts \$ 861,745.

F Name and address of principal officer: **Linda Stundis**
 Same As C Above

H(a) Is this a group return for affiliates? Yes No
H(b) Are all affiliates included? Yes No
 If 'No,' attach a list. (see instructions)

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

J Website: **www.barthsyndrome.org**

K Type of organization: Corporation Trust Association Other

L Year of Formation: **2000** **M** State of legal domicile: **MA**

H(c) Group exemption number

Part I Summary

1 Briefly describe the organization's mission or most significant activities: <u>1) to promote awareness of Barth Syndrome; 2) to educate and support physicians, research centers and organizations addressing the causes, diagnosis, treatment and cure of Barth Syndrome; and 3) to assist in the support of families with children suffering from Barth Syndrome</u>		
2 Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its assets.		
Activities & Governance	3 Number of voting members of the governing body (Part VI, line 1a) 8	
	4 Number of independent voting members of the governing body (Part VI, line 1b) 7	
	5 Total number of employees (Part V, line 2a) 4	
	6 Total number of volunteers (estimate if necessary) 50	
	7a Total gross unrelated business revenue from Part VIII, line 12, column (C) 0.	
	7b Net unrelated business taxable income from Form 990-T, line 34 0.	
	8 Contributions and grants (Part VIII, line 1h)	Prior Year 674,457. Current Year 727,957.
9 Program service revenue (Part VIII, line 2g)		
10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)	116,505. 133,788.	
11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)		
12 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	790,962. 861,745.	
Expenses	13 Grants and similar amounts paid (Part IX, column (A), lines 1-3)	309,200. 253,894.
	14 Benefits paid to or for members (Part IX, column (A), line 4)	
	15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	216,749. 322,644.
	16a Professional fundraising fees (Part IX, column (A), line 11e)	
	b Total fundraising expenses (Part IX, column (D), line 25) 11,582.	
	17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24f)	164,382. 490,087.
	18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	690,331. 1,066,625.
19 Revenue less expenses. Subtract line 18 from line 12	100,631. -204,880.	
Net Assets or Fund Balances	20 Total assets (Part X, line 16)	Beginning of Year 2,613,769. End of Year 2,375,329.
	21 Total liabilities (Part X, line 26)	183,984. 150,424.
	22 Net assets or fund balances. Subtract line 21 from line 20	2,429,785. 2,224,905.

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: Stephen B McCurdy Date: 4-8-09
 Type or print name and title: STEPHEN B McCURDY - CHAIRMAN

Paid Preparer's Use Only

Preparer's signature: David C. Ashenfarb Date: _____
 Firm's name (or yours if self-employed), address, and ZIP + 4: SCHALL & ASHENFARB CPAS
350 5TH AVE STE 728
NEW YORK, NY 10118-0110

Check if self-employed: Preparer's identifying number (see instructions): P00535436
 EIN: 13-4036703
 Phone no.: (212) 268-2800

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

Part III Statement of Program Service Accomplishments (see instructions)

1 Briefly describe the organization's mission:

See Schedule O

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ?

Yes No

If 'Yes,' describe these new services on Schedule O.

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services?

Yes No

If 'Yes,' describe these changes on Schedule O.

4 Describe the exempt purpose achievements for each of the organization's three largest program services by expenses. Section 501(c)(3) and 501(c)(4) organizations and section 4947(a)(1) trusts are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.

4a (Code:) (Expenses \$ 473,533. including grants of \$ 253,894.) (Revenue \$)

See Schedule O

4b (Code:) (Expenses \$ 221,835. including grants of \$) (Revenue \$)

See Schedule O

4c (Code:) (Expenses \$ 111,073. including grants of \$) (Revenue \$)

Barth Registry and Repository (BRR)

As a rare disorder, easy access to an extensive collection of DNA, tissue samples and medical data provides a significant encouragement to prospective Barth syndrome researchers. These samples and data themselves provide the basis for research revealing consistencies and anomalies which help to further define the disorder and demonstrate and advance the development and dissemination of treatment guidelines. BSF is primarily responsible for facilitating the participation of its family members and the growth of the BRR, the maintenance and operation of which is the responsibility of the University of Florida under contract from BSF. 2008 marks the third year of BSF's BRR contract with the University of Florida.

4d Other program services. (Describe in Schedule O.) See Schedule O

(Expenses \$ 88,463. including grants of \$) (Revenue \$)

4e Total program service expenses ▶ \$ 894,904. (Must equal Part IX, Line 25, column (B).)

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.	X	
2	Is the organization required to complete Schedule B, Schedule of Contributors?	X	
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.		X
4	Section 501(c)(3) organizations. Did the organization engage in lobbying activities? If 'Yes,' complete Schedule C, Part II.		X
5	Section 501(c)(4), 501(c)(5), and 501(c)(6) organizations. Is the organization subject to the section 6033(e) notice and reporting requirement and proxy tax? If 'Yes,' complete Schedule C, Part III.		
6	Did the organization maintain any donor advised funds or any accounts where donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? If 'Yes,' complete Schedule D, Part I.		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? If 'Yes,' complete Schedule D, Part II.		X
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? If 'Yes,' complete Schedule D, Part III.		X
9	Did the organization report an amount in Part X, line 21; serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? If 'Yes,' complete Schedule D, Part IV.		X
10	Did the organization hold assets in term, permanent, or quasi-endowments? If 'Yes,' complete Schedule D, Part V.		X
11	Did the organization report an amount in Part X, lines 10, 12, 13, 15, or 25? If 'Yes,' complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable.		X
12	Did the organization receive an audited financial statement for the year for which it is completing this return that was prepared in accordance with GAAP? If 'Yes,' complete Schedule D, Parts XI, XII, and XIII.	X	
13	Is the organization a school described in section 170(b)(1)(A)(ii)? If 'Yes,' complete Schedule E.		X
14a	Did the organization maintain an office, employees, or agents outside of the U.S.?		X
14b	Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, and program service activities outside the U.S.? If 'Yes,' complete Schedule F, Part I.	X	
15	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or assistance to any organization or entity located outside the United States? If 'Yes,' complete Schedule F, Part II.	X	
16	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or assistance to individuals located outside the United States? If 'Yes,' complete Schedule F, Part III.		X
17	Did the organization report more than \$15,000 on Part IX, column (A), line 11e? If 'Yes,' complete Schedule G, Part I.		X
18	Did the organization report more than \$15,000 total on Part VIII, lines 1c and 8a? If 'Yes,' complete Schedule G, Part II.		X
19	Did the organization report more than \$15,000 on Part VIII, line 9a? If 'Yes,' complete Schedule G, Part III.		X
20	Did the organization operate one or more hospitals? If 'Yes,' complete Schedule H.		X
21	Did the organization report more than \$5,000 on Part IX, column (A), line 1? If 'Yes,' complete Schedule I, Parts I and II.	X	
22	Did the organization report more than \$5,000 on Part IX, column (A), line 2? If 'Yes,' complete Schedule I, Parts I and III.		X
23	Did the organization answer 'Yes' to Part VII, Section A, questions 3, 4, or 5? If 'Yes,' complete Schedule J.		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, and that was issued after December 31, 2002? If 'Yes,' answer questions 24b-24d and complete Schedule K. If 'No,' go to question 25.		X
24b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?		
24c	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?		
24d	Did the organization act as an 'on behalf of' issuer for bonds outstanding at any time during the year?		
25a	Section 501(c)(3) and 501(c)(4) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? If 'Yes,' complete Schedule L, Part I.		X
25b	Did the organization become aware that it had engaged in an excess benefit transaction with a disqualified person from a prior year? If 'Yes,' complete Schedule L, Part I.		X
26	Was a loan to or by a current or former officer, director, trustee, key employee, highly compensated employee, or disqualified person outstanding as of the end of the organization's tax year? If 'Yes,' complete Schedule L, Part II.		X
27	Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, or substantial contributor, or to a person related to such an individual? If 'Yes,' complete Schedule L, Part III.		X

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Part IV Checklist of Required Schedules (continued)

	Yes	No
28 During the tax year, did any person who is a current or former officer, director, trustee, or key employee:		
a Have a direct business relationship with the organization (other than as an officer, director, trustee, or employee), or an indirect business relationship through ownership of more than 35% in another entity (individually or collectively with other person(s) listed in Part VII, Section A)? <i>If 'Yes,' complete Schedule L, Part IV.</i>	28a	X
b Have a family member who had a direct or indirect business relationship with the organization? <i>If 'Yes,' complete Schedule L, Part IV.</i>	28b	X
c Serve as an officer, director, trustee, key employee, partner, or member of an entity (or a shareholder of a professional corporation) doing business with the organization? <i>If 'Yes,' complete Schedule L, Part IV.</i>	28c	X
29 Did the organization receive more than \$25,000 in non-cash contributions? <i>If 'Yes,' complete Schedule M.</i>	29	X
30 Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If 'Yes,' complete Schedule M.</i>	30	X
31 Did the organization liquidate, terminate, or dissolve and cease operations? <i>If 'Yes,' complete Schedule N, Part I.</i>	31	X
32 Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If 'Yes,' complete Schedule N, Part II.</i>	32	X
33 Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If 'Yes,' complete Schedule R, Part I.</i>	33	X
34 Was the organization related to any tax-exempt or taxable entity? <i>If 'Yes,' complete Schedule R, Parts II, III, IV, and V, line 1.</i>	34	X
35 Is any related organization a controlled entity within the meaning of section 512(b)(13)? <i>If 'Yes,' complete Schedule R, Part V, line 2.</i>	35	X
36 Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If 'Yes,' complete Schedule R, Part V, line 2.</i>	36	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>	37	X

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Form 990 (2008)

Part V Statements Regarding Other IRS Filings and Tax Compliance

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

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Part VI Governance, Management and Disclosure (Sections A, B, and C request information about policies not required by the Internal Revenue Code.)

Section A. Governing Body and Management

For each 'Yes' response to lines 2-7b below, and for a 'No' response to lines 8 or 9b below, describe the circumstances, processes, or changes in Schedule O. See instructions.

		Yes	No
1 a	Enter the number of voting members of the governing body.....		
1 b	Enter the number of voting members that are independent.....		
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 or trustees, or key employees to a management company or other person?.....		X
4	Did the organization make any significant changes to its organizational documents since the prior Form 990 was filed?.....		X
5	Did the organization become aware during the year of a material diversion of the organization's assets?.....		X
6	Does the organization have members or stockholders?.....		X
7 a	Does the organization have members, stockholders, or other persons who may elect one or more members of the governing body?.....		X
7 b	Are any decisions of the governing body subject to approval by members, stockholders, or other persons?.....		X
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:		
8 a	The governing body?.....	X	
8 b	Each committee with authority to act on behalf of the governing body?.....	X	
9 a	Does the organization have local chapters, branches, or affiliates?.....		X
9 b	If 'Yes,' does the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with those of the organization?.....		
10	Was a copy of the Form 990 provided to the organization's governing body before it was filed? All organizations must describe in Schedule O the process, if any, the organization uses to review the Form 990. See Schedule O.....	X	
11	Is there any officer, director or trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If 'Yes,' provide the names and addresses in Schedule O.....		X

Section B. Policies

	Yes	No
12 a	X	
12 b	X	
12 c	X	
13	X	
14	X	
15		
15 a	X	
15 b	X	
16 a		X
16 b		

Section C. Disclosures

- 17 List the states with which a copy of this Form 990 is required to be filed ▶ See Schedule O
- 18 Section 6104 requires an organization to make its Forms 1023 (or 1024 if applicable), 990, and 990-T (501(c)(3)s only) available for public inspection. Indicate how you make these available. Check all that apply.
 Own website Another's website Upon request
- 19 Describe in Schedule O whether (and if so, how) the organization makes its governing documents, conflict of interest policy, and financial statements available to the public.
- 20 State the name, physical address, and telephone number of the person who possesses the books and records of the organization:
 ▶ Linda Stundis 675 VFW Parkway, #372 Chestnut Hill MA 02467 (617) 469-6769

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

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

1 a Complete this table for all persons required to be listed. Use Schedule J-2 if additional space is needed.

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation, and **current** key employees. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
- 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) or 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 \$100,000 of reportable compensation from the organization and any related organizations.

List persons in the following order: individual trustees or directors; institutional trustees; officers; key employees; highest compensated employees; and former such persons.

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

(A) Name and Title	(B) Average hours per week	(C) Position (check all that apply)						(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			
Michaela Damin Board Member	20	X						0.	0.	0.
Stephen Kugelmann Board Member	10	X						0.	0.	0.
Katherine McCurdy Board Member	10	X						0.	0.	0.
Susan Osnos Board Member	10	X						0.	0.	0.
Susan Wilkins Board Member	10	X						0.	0.	0.
Stephen B. McCurdy Chairman	20	X		X				0.	0.	0.
Randy Buddemeyer Treasurer	40	X		X				0.	0.	0.
Valerie Bowen President	40	X		X	X			61,495.	0.	0.
Lynda Sedefian Secretary	40			X	X			40,462.	0.	4,661.
Linda Stundis Executive Direc	40			X	X			55,385.	0.	7,086.
Matthew Toth Dir of Science	40				X			117,600.	0.	11,325.

Part VIII Statement of Revenue

		(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512, 513, or 514
CONTRIBUTIONS, GIFTS, GRANTS AND OTHER SIMILAR AMOUNTS	1 a Federated campaigns	1 a			
	b Membership dues	1 b			
	c Fundraising events	1 c			
	d Related organizations	1 d			
	e Government grants (contributions)	1 e			
	f All other contributions, gifts, grants, and similar amounts not included above	1 f 727,957.			
	g Noncash contribns included in lns 1a-1f: \$				
	h Total. Add lines 1a-1f	727,957.			
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)		133,788.	
4 Income from investment of tax-exempt bond proceeds					
5 Royalties					
6 a Gross Rents		(i) Real (ii) Personal			
b Less: rental expenses					
c Rental income or (loss)					
d Net rental income or (loss)					
7 a Gross amount from sales of assets other than inventory		(i) Securities (ii) Other			
b Less: cost or other basis and sales expenses					
c Gain or (loss)					
d Net gain or (loss)					
8 a Gross income from fundraising events (not including \$ of contributions reported on line 1c). See Part IV, line 18		a			
b Less: direct expenses		b			
c Net income or (loss) from fundraising events					
9 a Gross income from gaming activities. See Part IV, line 19		a			
b Less: direct expenses		b			
c Net income or (loss) from gaming activities					
10 a Gross sales of inventory, less returns and allowances		a			
b Less: cost of goods sold	b				
c Net income or (loss) from sales of inventory					
Miscellaneous Revenue		Business Code			
11 a					
b					
c					
d All other revenue					
e Total. Add lines 11a-11d					
12 Total Revenue. Add lines 1h, 2g, 3, 4, 5, 6d, 7d, 8c, 9c, 10c, and 11e		861,745.	0.	0.	133,788.

Part IX Statement of Functional Expenses

Section 501(c)(3) and 501(c)(4) organizations must complete all columns.

All other organizations must complete column (A) but are not required to complete columns (B), (C), and (D).

<i>Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.</i>	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to governments and organizations in the U.S. See Part IV, line 21.	215,538.	215,538.		
2 Grants and other assistance to individuals in the U.S. See Part IV, line 22.				
3 Grants and other assistance to governments, organizations, and individuals outside the U.S. See Part IV, lines 15 and 16.	38,356.	38,356.		
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	277,992.	233,954.	34,103.	9,935.
6 Compensation not included above, to disqualified persons (as defined under section 4958(f)(1) and persons described in section 4958(c)(3)(B).	0.	0.	0.	0.
7 Other salaries and wages				
8 Pension plan contributions (include section 401(k) and section 403(b) employer contributions)				
9 Other employee benefits	23,072.	19,417.	2,830.	825.
10 Payroll taxes	21,580.	18,161.	2,648.	771.
11 Fees for services (non-employees)				
a Management				
b Legal				
c Accounting				
d Lobbying				
e Prof fundraising svcs. See Part IV, ln 17.				
f Investment management fees				
g Other	211,964.	145,259.	66,705.	
12 Advertising and promotion				
13 Office expenses	67,863.	49,445.	18,367.	51.
14 Information technology				
15 Royalties				
16 Occupancy				
17 Travel	140,866.	124,402.	16,464.	
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				
24 Other expenses. Itemize expenses not covered above. (Expenses grouped together and labeled miscellaneous may not exceed 5% of total expenses shown on line 25 below.)				
a <u>Audio Visual expense</u>	32,434.	32,434.		
b <u>Printing and Publications</u>	14,099.	12,734.	1,365.	
c <u>Telephone</u>	7,919.	2,413.	5,506.	
d <u>Dues & conferences</u>	5,627.	376.	5,251.	
e <u>Insurance</u>	4,965.		4,965.	
f All other expenses	4,350.	2,415.	1,935.	
25 Total functional expenses. Add lines 1 through 24f.	1,066,625.	894,904.	160,139.	11,582.
26 Joint Costs. Check here <input type="checkbox"/> if following SOP 98-2. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation.				

Part X Balance Sheet

		(A) Beginning of year		(B) End of year
ASSETS	1 Cash – non-interest-bearing		1	
	2 Savings and temporary cash investments	2,317,189.	2	2,242,382.
	3 Pledges and grants receivable, net	973.	3	125,000.
	4 Accounts receivable, net	1,477.	4	7,235.
	5 Receivables from current and former officers, directors, trustees, key employees, or other related parties. Complete Part II of Schedule L		5	
	6 Receivables from other disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B). Complete Part II of Schedule L		6	
	7 Notes and loans receivable, net		7	
	8 Inventories for sale or use		8	
	9 Prepaid expenses and deferred charges	7,297.	9	712.
	10a Land, buildings, and equipment: cost basis	10a 3,225.		
	b Less: accumulated depreciation. Complete Part VI of Schedule D	10b 3,225.	10c	
	11 Investments – publicly-traded securities	286,833.	11	
	12 Investments – other securities. See Part IV, line 11		12	
	13 Investments – program-related. See Part IV, line 11		13	
	14 Intangible assets		14	
	15 Other assets. See Part IV, line 11		15	
16 Total assets. Add lines 1 through 15 (must equal line 34)	2,613,769.	16	2,375,329.	
LIABILITIES	17 Accounts payable and accrued expenses	15,684.	17	15,581.
	18 Grants payable	168,300.	18	134,843.
	19 Deferred revenue		19	
	20 Tax-exempt bond liabilities		20	
	21 Escrow account liability. Complete Part IV of Schedule D		21	
	22 Payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons. Complete Part II of Schedule L		22	
	23 Secured mortgages and notes payable to unrelated third parties		23	
	24 Unsecured notes and loans payable		24	
	25 Other liabilities. Complete Part X of Schedule D		25	
	26 Total liabilities. Add lines 17 through 25	183,984.	26	150,424.
RESTRICTED ASSETS OR FUNDS	Organizations that follow SFAS 117, check here <input checked="" type="checkbox"/> and complete lines 27 through 29 and lines 33 and 34.			
	27 Unrestricted net assets	1,993,659.	27	1,486,721.
	28 Temporarily restricted net assets	436,126.	28	738,184.
	29 Permanently restricted net assets		29	
	Organizations that do not follow SFAS 117, check here <input type="checkbox"/> and complete lines 30 through 34.			
	30 Capital stock or trust principal, or current funds		30	
	31 Paid-in or capital surplus, or land, building, and equipment fund		31	
	32 Retained earnings, endowment, accumulated income, or other funds		32	
	33 Total net assets or fund balances.	2,429,785.	33	2,224,905.
34 Total liabilities and net assets/fund balances.	2,613,769.	34	2,375,329.	

Part XI Financial Statements and Reporting

1 Accounting method used to prepare the Form 990: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other	Yes	No
2a Were the organization's financial statements compiled or reviewed by an independent accountant?		X
b Were the organization's financial statements audited by an independent accountant?	X	
c If 'Yes' to 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant?	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?		

BAA

SCHEDULE A
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support

To be completed by all section 501 (c)(3) organizations and section 4947(a)(1) nonexempt charitable trusts.

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

OMB No. 1545-0047

2008

Open to Public Inspection

Name of the organization

The Barth Syndrome Foundation, Inc.

Employer identification number

22-3755704

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: (Please check only **one** organization.)

- 1 A church, convention of churches or association of churches described in **section 170(b)(1)(A)(i)**.
- 2 A school described in **section 170(b)(1)(A)(ii)**. (Attach Schedule E.)
- 3 A hospital or cooperative hospital service organization described in **section 170(b)(1)(A)(iii)**. (Attach Schedule H.)
- 4 A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii)**. Enter the hospital's name, city, and state: _____
- 5 An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv)**. (Complete Part II.)
- 6 A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v)**.
- 7 An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi)**. (Complete Part II.)
- 8 A community trust described in **section 170(b)(1)(A)(vi)**. (Complete Part II.)
- 9 An organization that normally receives: (1) more than 33-1/3 % of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions – subject to certain exceptions, and (2) no more than 33-1/3 % of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See **section 509(a)(2)**. (Complete Part III.)
- 10 An organization organized and operated exclusively to test for public safety. See **section 509(a)(4)**. (see instructions)
- 11 An organization organized and operated exclusively for the benefit of, to perform the functions of, or carry out the purposes of one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2). See **section 509(a)(3)**. Check the box that describes the type of supporting organization and complete lines 11e through 11h.
 - a Type I
 - b Type II
 - c Type III – Functionally integrated
 - d Type III – Other
- e By checking this box, I certify that the organization is not controlled directly or indirectly by one or more disqualified persons other than foundation managers and other than one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2).
- f If the organization received a written determination from the IRS that is a Type I, Type II or Type III supporting organization, check this box
- g Since August 17, 2006, has the organization accepted any gift or contribution from any of the following persons?

	Yes	No
(i) a person who directly or indirectly controls, either alone or together with persons described in (ii) and (iii) below, the governing body of the supported organization?		
(ii) a family member of a person described in (i) above?		
(iii) a 35% controlled entity of a person described in (i) or (ii) above?		

h Provide the following information about the organizations the organization supports.

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

Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)

(Complete only if you checked the box on line 5, 7, or 8 of Part I.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ▶	(a) 2004	(b) 2005	(c) 2006	(d) 2007	(e) 2008	(f) Total
1 Gifts, grants, contributions and membership fees received. (Do not include 'unusual grants'.)	338,932.	1,144,539.	1,018,888.	674,457.	727,957.	3,904,773.
2 Tax revenues levied for the organization's benefit and either paid to it or expended on its behalf.						0.
3 The value of services or facilities furnished to the organization by a governmental unit without charge. Do not include the value of services or facilities generally furnished to the public without charge.						0.
4 Total. Add lines 1-3.	338,932.	1,144,539.	1,018,888.	674,457.	727,957.	3,904,773.
5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f).						1,230,018.
6 Public support. Subtract line 5 from line 4.						2,674,755.

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2004	(b) 2005	(c) 2006	(d) 2007	(e) 2008	(f) Total
7 Amounts from line 4.	338,932.	1,144,539.	1,018,888.	674,457.	727,957.	3,904,773.
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources.	17,350.	21,802.	66,816.	116,505.	113,788.	336,261.
9 Net income from unrelated business activities, whether or not the business is regularly carried on.						0.
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)						0.
11 Total support. Add lines 7 through 10.						4,241,034.
12 Gross receipts from related activities, etc. (see instructions)					12	0.
13 First five 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. ▶ <input type="checkbox"/>						

Section C. Computation of Public Support Percentage

14 Public support percentage for 2008 (line 6, column (f) divided by line 11, column (f)).	14	63.1 %
15 Public support percentage for 2007 Schedule A, Part IV-A, line 26f.	15	58.8 %
16a 33-1/3 support test – 2008. If the organization did not check the box on line 13, and the line 14 is 33-1/3 % or more, check this box and stop here. The organization qualifies as a publicly supported organization. ▶ <input checked="" type="checkbox"/>		
b 33-1/3 support test – 2007. If the organization did not check a box on line 13, or 16a, and line 15 is 33-1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization. ▶ <input type="checkbox"/>		
17a 10%-facts-and-circumstances test – 2008. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the 'facts-and-circumstances' test, check this box and stop here. Explain in Part IV how the organization meets the 'facts-and-circumstances' test. The organization qualifies as a publicly supported organization. ▶ <input type="checkbox"/>		
b 10%-facts-and-circumstances test – 2007. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the 'facts-and-circumstances' test, check this box and stop here. Explain in Part IV how the organization meets the 'facts-and-circumstances' test. The organization qualifies as a publicly supported organization. ▶ <input type="checkbox"/>		
18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions. ▶ <input type="checkbox"/>		

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

(Complete only if you checked the box on line 9 of Part I.)

Section A. Public Support

Calendar year (or fiscal yr beginning in) ▶	(a) 2004	(b) 2005	(c) 2006	(d) 2007	(e) 2008	(f) Total
1 Gifts, grants, contributions and membership fees received. (Do not include 'unusual grants.') ...						
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in a activity that is related to the organization's tax-exempt purpose						
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1-5						
7a Amounts included on lines 1, 2, 3 received from disqualified persons						
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of 1% of the total of lines 9, 10c, 11, and 12 for the year or \$5,000 ..						
c Add lines 7a and 7b						
8 Public support (Subtract line 7c from line 6.)						

Section B. Total Support

Calendar year (or fiscal yr beginning in) ▶	(a) 2004	(b) 2005	(c) 2006	(d) 2007	(e) 2008	(f) Total
9 Amounts from line 6						
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975 ..						
c Add lines 10a and 10b						
11 Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)						
13 Total support. (Add lines 9, 10c, 11, and 12.)						

14 **First five years.** If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here.

Section C. Computation of Public Support Percentage

15 Public support percentage for 2008 (line 8, column (f) divided by line 13, column (f))	15	%
16 Public support percentage from 2007 Schedule A, Part IV-A, line 27g	16	%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2008 (line 10c, column (f) divided by line 13, column (f))	17	%
18 Investment income percentage from 2007 Schedule A, Part IV-A, line 27h	18	%

19a **33-1/3 support tests - 2008.** 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 - 2007.** If the organization did not check a box on line 14 or 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.

SCHEDULE D (Form 990)

Department of the Treasury Internal Revenue Service

Supplemental Financial Statements

Attach to Form 990. To be completed by organizations that answered 'Yes,' to Form 990, Part IV, lines 6, 7, 8, 9, 10, 11, or 12.

OMB No. 1545-0047

2008

Open to Public Inspection

Name of the organization

The Barth Syndrome Foundation, Inc.

Employer identification number

22-3755704

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

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

5 Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control? Yes No

6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds may be used only for charitable purposes and not for the benefit of the donor or donor advisor or other impermissible private benefit? Yes No

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

1 Purpose(s) of conservation easements held by the organization (check all that apply).

- Preservation of land for public use (e.g., recreation or pleasure)
Protection of natural habitat
Preservation of open space
Preservation of an historically important land area
Preservation of certified historic structure

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

Table with 2 columns: Description, Held at the End of the Year. Rows 2a-2d for total number, acreage, and structure counts.

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

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

5 Does the organization have a written policy regarding the periodic monitoring, inspection, violations, and enforcement of the conservation easement it holds? Yes No

6 Staff or volunteer hours devoted to monitoring, inspecting, and enforcing easements during the year

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

8 Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and 170(h)(4)(B)(ii)? Yes No

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

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

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

b If the organization elected, as permitted under SFAS 116, 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 the following amounts relating to these items:

- (i) Revenues included in Form 990, Part VIII, line 1
(ii) Assets included in Form 990, Part X

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

- a Revenues included in Form 990, Part VIII, line 1
b Assets included in Form 990, Part X

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

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

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

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

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

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

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

b If 'Yes,' explain the arrangement in Part XIV and complete the following table:

	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? Yes No

b If 'Yes,' explain the arrangement in Part XIV.

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

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1a Beginning of year balance					
b Contributions					
c Investment earnings or losses					
d Grants or scholarships					
e Other expenditures for facilities and programs					
f Administrative expenses					
g End of year balance					

2 Provide the estimated percentage of the year end balance held as:

- a Board designated or quasi-endowment _____ %
- b Permanent endowment _____ %
- c Term endowment _____ %

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

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

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

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

Description of investment	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Depreciation	(d) Book Value
1a Land				
b Buildings				
c Leasehold improvements				
d Equipment		3,225.	3,225.	0.
e Other				
Total. Add lines 1a-1e (Column (d) should equal Form 990, Part X, column (B), line 10(c).)				0.

BAA

**Schedule F
(Form 990)**

Department of the Treasury
Internal Revenue Service

Statement of Activities Outside the United States

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

OMB No. 1545-0047

2008

Open to Public Inspection

Name of the organization

The Barth Syndrome Foundation, Inc.

Employer identification number

22-3755704

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

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

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

3 Activities per Region. (Use Schedule F-1 (Form 990) if additional space is needed.)

(a) Region	(b) Number of offices in the region	(c) Number of employees or agents in region	(d) Activities conducted in region (by type) (i.e., fundraising, program services, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in region	(f) Total expenditures in region
Europe	0	0	Grant to recipient located in this region		40,000.
North America	0	0	\$77,256 of grants awarded were funded by another charitable organization.		-77,256.
North America	0	0	Grant to recipient located in this region		75,612.
Totals	0	0			38,356.

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

Schedule F (Form 990) (2008)

Part IV Supplemental Information

Complete this part to provide the information required in Part I, line 2, and any other additional information.

Part I, Line 2 - Grantmakers Explanation For Grants Outside US

Prospective Grant recipients must submit detailed research proposals and biographies and be associated with an established and recognized research institution known to our Scientific and Medical Advisory Board. The Grant Review Process includes assessments of the proposal as to its 1) importance and impact, 2) feasibility and 3) prospect for long term funding. 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 recipient. 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 BSF as well as any published findings.

Additional Supplemental Information

During 2008, the Barth Syndrome Foundation Board approved three grants to entities outside of the United States totaling \$115,612. \$77,256 of these grants was funded by other charitable organizations independent of the Barth Syndrome Foundation. Total grant expense to entities outside of the United States was \$38,356.

**SCHEDULE I
(Form 990)**

**Grants and Other Assistance to Organizations,
Governments and Individuals in the U.S.**

OMB No. 1545-0047

2008

**Open to Public
Inspection**

Department of the Treasury
Internal Revenue Service

▶ **Complete if the organization answered 'Yes,' on Form 990, Part IV, lines 21 or 22.
▶ Attach to Form 990.**

Name of the organization

The Barth Syndrome Foundation, Inc.

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. See Part VI

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

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 non-cash assistance	(h) Purpose of grant or assistance
<u>Henry Ford Health System 2799 W. Grand Blvd, Room 7 Detroit, MI 48202</u>	<u>38-1357020</u>	<u>501 (c) 3</u>	<u>39,996.</u>	<u>0.</u>			<u>Research</u>
<u>Medical College of Wisconsin 8701 Watertown Plank Road Milwaukee, WI 53226</u>	<u>39-0806261</u>	<u>501 (c) 3</u>	<u>40,000.</u>	<u>0.</u>			<u>Research</u>
<u>Nemours Children's Clinic 1600 Rockland Road Wilmington, DE 19803</u>	<u>59-0634433</u>	<u>501 (c) 3</u>	<u>24,145.</u>	<u>0.</u>			<u>Research</u>
<u>University of Colorado 12635 East Montview Blvd, Aurora, CO 80045</u>	<u>84-6000555</u>	<u>501 (c) 3</u>	<u>33,701.</u>	<u>0.</u>			<u>Research</u>
<u>University of Washington 1959 NE Pacific Street, Bo Seattle, WA 98195</u>	<u>91-6001537</u>	<u>n/a</u>	<u>40,000.</u>	<u>0.</u>			<u>Research</u>
<u>Wayne State University 5047 Gullen Mall Detroit, MI 48202</u>	<u>38-6028429</u>	<u>501 (c) 3</u>	<u>40,000.</u>	<u>0.</u>			<u>Research</u>

2 Enter total number of section 501(c)(3) and government organizations. ▶ 6

3 Enter total number of other organizations. ▶ 0

Part III Grants and Other Assistance to Individuals in the United States. Complete if the organization answered 'Yes' on Form 990, Part IV, line 22.
Use Schedule I-1 (Form 990) if additional space is needed.

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

Part IV Supplemental Information. Complete this part to provide the information required in Part I, line 2, and any other additional information.

Part I, Line 2 - Grantmaker's Description of How Grants are Used

Prospective Grant recipients must submit detailed research proposals and biographies and be associated with an established and recognized research institution known to our Scientific and Medical Advisory Board. The Grant Review Process includes assessments of the proposal as to its 1) importance and impact, 2) feasibility and 3) prospect for long term funding. 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 recipient. 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

Client BARTH

The Barth Syndrome Foundation, Inc.

22-3755704

3/17/09

02:09PM

Part I, Line 2 - Grantmaker's Description of How Grants are Used (continued)

proposal. Following completion of the work, a summary of the research results is required to be sent to BSF as well as any published findings.

Part IV - Additional Supplemental Information

During 2008, the Barth Syndrome Foundation Board approved six grants to organizations inside the United States totaling \$217,842. \$2,304 of unused grant funds were returned to the Barth Syndrome Foundation. Total grant expense to organizations inside the United States was \$215,538.

SCHEDULE O
(Form 990)

Supplemental Information to Form 990

OMB No. 1545-0047

2008

**Open to Public
Inspection**

Department of the Treasury
Internal Revenue Service

▶ **Attach to Form 990. To be completed by organizations to provide additional information for responses to specific questions for the Form 990 or to provide any additional information.**

Name of the organization

The Barth Syndrome Foundation, Inc.

Employer identification number

22-3755704

Form 990, Part III, Line 1 - Organization Mission

The Barth Syndrome Foundation is a not-for-profit organization dedicated to: 1) promote awareness of Barth syndrome; 2) assist in the support of families with children suffering from Barth syndrome; 3) assist in the support of research centers and organizations addressing the causes, diagnosis, treatment and cure of Barth syndrome; and 4) such other charitable, scientific and educational purposes within the meaning of Section 501(c)(3) of the Code as may be determined by the Board of Directors of the Barth Syndrome Foundation.

Form 990, Part III, Line 4a - Program Service Accomplishments

Scientific Research Program

2008 marked the seventh year of the Barth Syndrome Foundation's (BSF) Research program. In 2008, following announcement of the program via internet and several scientific journals, BSF's Scientific and Medical Review Board and several independent reviewers assessed the scientific merit of the proposals, the qualifications of the researcher, the likely success of the research in attracting future funding, and the impact of the research on advancing understanding of Barth syndrome, and made approval recommendations to the Board of BSF which made the final decisions. The BSF Board approved nine out of 14 proposals submitted for a total of \$333,454, \$77,256 of which were funded by other charitable organizations in Canada and the UK. Approved proposals were submitted from 9 academic and research institutions in 3 countries and ran for periods of up to 2 years. In total, BSF has now approved a total of almost \$1.5M in 40 seed grants to researchers on three continents through the same rigorous peer reviewed advisory process.

Form 990, Part III, Line 4b - Program Service Accomplishments

International Scientific, Medical and Family Conference

Every two years, BSF runs an International Scientific, Medical and Family Conference

Name of the organization

The Barth Syndrome Foundation, Inc.

Employer identification number

22-3755704

Form 990, Part III, Line 4b - Program Service Accomplishments (continued)

with the most recent one in 2008. This unique and acclaimed format brings together the world's top Barth syndrome researchers, clinicians attending affected families and the families themselves to share their data, their research and their observations. The Conference begins with a clinic at which extensive data and samples are gathered from the affected boys and their families for the Barth Syndrome Registry and Repository (see below) and clinicians have the chance to examine and take histories from the largest gathering of people affected by this rare disorder in the world. Then researchers present the results of their work and extensive discussion ensues. Families benefit from access to the world's experts on Barth syndrome in all of the many disciplines affected by this multi-system disorder, and from scientists reviewing results of their latest research. Over the years, a strong sense of trust and mutually beneficial cooperation has grown among the various groups in attendance which continues to facilitate and encourage further discovery.

Form 990, Part III, Line 4d - Other Program Services Description

Other program services include newsletters and publications as well as other support for families with children suffering from Barth syndrome.

Form 990, Part VI, Line 10 - Form 990 Review Process

The Form 990 was sent to the full board of directors via e mail prior to being filed with the IRS. All directors were afforded the opportunity to ask questions and offer edits. The decision of whether to make edits was made by the staff person in charge of finances within the organization in conjunction with consultation with our tax preparer.

Name of the organization

The Barth Syndrome Foundation, Inc.

Employer identification number

22-3755704

Form 990, Part VI, Line 12c - Explanation of Monitoring and Enforcement of Conflicts

The organization has a conflicts of interest policy. Each board member must fill out an annual declaration stating that they had no conflicts or identifying the nature of their interested party transactions.

Form 990, Part VI, Line 15b - Compensation Review & Approval Process for Officers & Key Employees

Each year, the executive committee reviews comparable salaries based on a recognized study and reviews the performance of 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 which this Return is Filed

MA NY CT NJ IL TN PA DE CA FL MD UT GA



IRAT L. SCHALL, CPA
DAVID C. ASHENFARB, CPA

THE BARTH SYNDROME FOUNDATION, INC.

Audited Financial Statements

December 31, 2008 and 2007

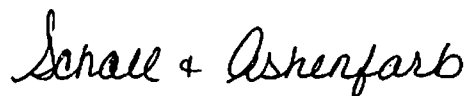
INDEPENDENT AUDITORS' REPORT

To the Board of Directors of
The Barth Syndrome Foundation, Inc.

We have audited the accompanying statement of financial position of The Barth Syndrome Foundation, Inc. (the "Foundation") as of December 31, 2008 and 2007 and the related statements of activities, functional expenses, and cash flows for the years then ended. These financial statements are the responsibility of the Foundation's management. Our responsibility is to express an opinion on these financial statements based on our audits.

We conducted our audits in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audits to obtain reasonable assurance about whether the financial statements are free of material misstatements. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation. We believe that our audits provide a reasonable basis for our opinion.

In our opinion, based on our audits, the financial statements referred to above present fairly, in all material respects, the financial position of The Barth Syndrome Foundation, Inc. as of December 31, 2008 and 2007, and the changes in its net assets and its cash flows for the years then ended in conformity with accounting principles generally accepted in the United States of America.



Schall & Ashenfarb
Certified Public Accountants, LLC

March 16, 2009

THE BARTH SYNDROME FOUNDATION, INC.
STATEMENT OF FINANCIAL POSITION
AT DECEMBER 31, 2008 AND 2007

	<u>12/31/08</u>	<u>12/31/07</u>
Assets		
Cash and cash equivalents (Notes 2g and 2h)	\$2,242,382	\$2,317,189
Investments (Note 5)	0	286,833
Accounts receivable	7,235	1,477
Unconditional promises to give (Note 2c and 2e)	125,000	973
Prepaid expenses	<u>712</u>	<u>7,297</u>
 Total assets	 <u><u>\$2,375,329</u></u>	 <u><u>\$2,613,769</u></u>
 Liabilities and Net Assets		
Liabilities:		
Accounts payable and accrued expenses	\$15,581	\$15,684
Grants payable (Note 4)	<u>134,843</u>	<u>168,300</u>
 Total liabilities	 <u>150,424</u>	 <u>183,984</u>
 Net Assets: (Note 2b)		
Unrestricted	1,486,721	1,993,659
Temporarily restricted (Note 3)	<u>738,184</u>	<u>436,126</u>
 Total net assets	 <u>2,224,905</u>	 <u>2,429,785</u>
 Total liabilities and net assets	 <u><u>\$2,375,329</u></u>	 <u><u>\$2,613,769</u></u>

*The attached notes and auditors' report
are an integral part of these financial statements.*

THE BARTH SYNDROME FOUNDATION, INC.
STATEMENT OF ACTIVITIES
FOR THE YEARS ENDED DECEMBER 31, 2008 AND 2007

	<u>12/31/08</u>			<u>12/31/07</u>		
	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Total</u>	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Total</u>
Public Support and Revenue:						
Contributions (Notes 2c and 3)	\$361,165	\$366,792	\$727,957	\$291,849	\$382,608	\$674,457
Interest income	133,788		133,788	116,505		116,505
Net assets released from restrictions:						
Satisfaction of program restrictions (Note 3)	64,734	(64,734)	0	335,697	(335,697)	0
Total public support and revenue	559,687	302,058	861,745	744,051	46,911	790,962
Expenses:						
Program services	894,904		894,904	596,095		596,095
Management and general	160,139		160,139	81,864		81,864
Fundraising	11,582		11,582	12,372		12,372
Total expenses	1,066,625	0	1,066,625	690,331	0	690,331
Change in net assets	(506,938)	302,058	(204,880)	53,720	46,911	100,631
Net assets - beginning of year	1,993,659	436,126	2,429,785	1,939,939	389,215	2,329,154
Net assets - end of year	<u>\$1,486,721</u>	<u>\$738,184</u>	<u>\$2,224,905</u>	<u>\$1,993,659</u>	<u>\$436,126</u>	<u>\$2,429,785</u>

*The attached notes and auditors' report
are an integral part of these financial statements.*

**THE BARTH SYNDROME FOUNDATION, INC.
STATEMENT OF FUNCTIONAL EXPENSES
FOR THE YEAR ENDED DECEMBER 31, 2008**

	<u>Program Services</u>	<u>Management and General</u>	<u>Fundraising</u>	<u>Total 12/31/08</u>	<u>Total 12/31/07</u>
Salaries	\$233,954	\$34,103	\$9,935	\$277,992	\$216,749
Payroll taxes and benefits	37,578	5,478	1,596	44,652	15,723
Total personnel services	<u>271,532</u>	<u>39,581</u>	<u>11,531</u>	<u>322,644</u>	<u>232,472</u>
Research grants	253,894			253,894	309,200
Professional	145,259	66,705		211,964	48,616
Telephone	2,413	5,506		7,919	5,508
Office expense	49,445	18,367	51	67,863	25,908
Printing and publications	12,734	1,365		14,099	12,480
Dues and conferences	376	5,251		5,627	8,759
Transportation	124,402	16,464		140,866	30,572
Insurance		4,965		4,965	2,043
Meals	492	1,935		2,427	8,388
Audio visual expense	32,434			32,434	0
Exhibits	1,923			1,923	6,385
	<u> </u>	<u> </u>	<u> </u>	<u> </u>	<u> </u>
Total expenses	<u><u>\$894,904</u></u>	<u><u>\$160,139</u></u>	<u><u>\$11,582</u></u>	<u><u>\$1,066,625</u></u>	<u><u>\$690,331</u></u>

*The attached notes and auditors' report
are an integral part of these financial statements.*

THE BARTH SYNDROME FOUNDATION, INC.
STATEMENT OF FUNCTIONAL EXPENSES
FOR THE YEAR ENDED DECEMBER 31, 2007

	<u>Program Services</u>	<u>Management and General</u>	<u>Fundraising</u>	<u>Total 12/31/07</u>
Salaries	\$191,188	\$25,561		\$216,749
Payroll taxes and benefits	13,869	1,854		15,723
Total personnel services	<u>205,057</u>	<u>27,415</u>	0	<u>232,472</u>
Research grants	309,200			309,200
Professional	20,774	27,842		48,616
Telephone	2,453	3,055		5,508
Office expense	7,691	9,451	8,766	25,908
Printing and publications	8,271	2,683	1,526	12,480
Dues and conferences	4,241	4,518		8,759
Transportation	26,036	4,536		30,572
Insurance		2,043		2,043
Meals	5,987	321	2,080	8,388
Audio visual expense				0
Exhibits	<u>6,385</u>			<u>6,385</u>
Total expenses	<u><u>\$596,095</u></u>	<u><u>\$81,864</u></u>	<u><u>\$12,372</u></u>	<u><u>\$690,331</u></u>

*The attached notes and auditors' report
are an integral part of these financial statements.*

THE BARTH SYNDROME FOUNDATION, INC.
STATEMENT OF CASH FLOWS
FOR THE YEARS ENDED DECEMBER 31, 2008 AND 2007

	<u>12/31/08</u>	<u>12/31/07</u>
Cash Flows from Operating Activities:		
Change in net assets	(\$204,880)	\$100,631
Adjustments to reconcile change in net assets to net cash provided by/(used for) operating activities:		
Donated stock	0	(10,395)
Realized gain on sale of investments	(1,762)	0
(Increase)/decrease in assets:		
Accounts receivable	(5,758)	(929)
Unconditional promises to give	(124,027)	335,332
Prepaid expenses	6,585	(5,998)
Increase/(decrease) in liabilities:		
Accounts payable and accrued expenses	(103)	3,531
Grants payable	(33,457)	49,276
	<u>(158,522)</u>	<u>370,817</u>
Total adjustments		
Net cash (used for)/provided by operating activities	<u>(363,402)</u>	<u>471,448</u>
Cash Flows from Investing Activities:		
Proceeds from sales of investments and donated stock	288,595	21,596
Purchase of investments	0	(286,990)
	<u>288,595</u>	<u>(265,394)</u>
Net cash provided by/(used for) investing activities		
Net (decrease)/increase in cash and cash equivalents	(74,807)	206,054
Cash and cash equivalents - beginning of year	<u>2,317,189</u>	<u>2,111,135</u>
Cash and cash equivalents - end of year	<u><u>\$2,242,382</u></u>	<u><u>\$2,317,189</u></u>
Supplemental data:		
Interest & income taxes paid	<u>\$0</u>	<u>\$0</u>

*The attached notes and auditors' report
are an integral part of these financial statements.*

**THE BARTH SYNDROME FOUNDATION, INC.
NOTES TO FINANCIAL STATEMENTS
DECEMBER 31, 2008 AND 2007**

Note 1. Organization

The Barth Syndrome Foundation, Inc. (the "Foundation") is a not-for-profit organization incorporated under the laws of the state of Delaware on September 8, 2000 to act as a public foundation, operated for the following purposes: a) to promote awareness of Barth Syndrome; b) to educate and support physicians, research centers and organizations addressing the causes, diagnosis, treatment and cure of Barth Syndrome, and c) to assist in the support of families with children suffering from Barth Syndrome.

The Foundation is a tax-exempt organization under Section 501(c)(3) of the Internal Revenue Code. They have not been designated as a private foundation.

Note 2. Summary of Significant Accounting Policies

a. **Basis of Accounting**

The financial statements have been prepared on the accrual basis of accounting and accordingly reflect all significant receivables, payables, and other liabilities.

b. **Basis of Presentation**

The Foundation follows Statement of Financial Accounting Standards (SFAS) No.'s 116 and 117, *Accounting for Contributions Received and Contributions Made*, and *Financial Statements of Not-for-Profit Organizations*. Under SFAS No. 117, organizations are required to report information regarding their financial position and activities according to the following classes of net assets:

- *Unrestricted* – represents all activity without donor imposed restrictions.
- *Temporarily restricted* – relates to contributions of cash and other assets with donor stipulations that make clear the assets restriction, either due to a program nature or by passage of time.
- *Permanently restricted* – relates to contributions of cash and other assets whereby the assets must remain intact due to restrictions placed by the donor. The Foundation had no permanently restricted net assets at December 31, 2008 and 2007.

c. **Contributions**

Contributions received are recorded as unrestricted or temporarily restricted support depending on the existence and/or nature of any donor restrictions.

Support that is restricted by the donor is reported as an increase in unrestricted net assets if the restriction expires in the reporting period in which the support is recognized. All other donor-restricted support is reported as an increase in temporarily restricted net assets, depending on the nature of the restriction. When a restriction expires (that is, when a stipulated time restriction ends or purpose

restriction is accomplished), temporarily restricted net assets are reclassified to unrestricted net assets and reported in the statement of activities as net assets released from restriction.

d. Donated Assets

Donated marketable securities and other non-cash donations are recorded as contributions at their estimated fair values at the date of donation.

e. Unconditional Promises to Give

Unconditional promises to give are recognized as revenues or gains in the period received and as assets or decreases of liabilities, depending on the form of the benefits received. Conditional promises to give are recognized when the conditions on which they depend are substantially met. At year end, the full amount is due within one year. These receivables have been evaluated for collectability and no allowance for doubtful accounts is deemed necessary.

f. In-Kind Contributions

Under SFAS No. 116, organizations are required to recognize contributions of services that enhance non-financial assets and require specialized skills. Many individuals volunteer their time and perform a variety of tasks that assist the Association with specific programs, campaign solicitation, and various committee assignments. These volunteer services do not meet the criteria stated above and have not been recognized in the financial statements.

g. Cash and Cash Equivalents

For purposes of financial reporting, cash and cash equivalents include cash held in banks, certificates of deposits and money market funds. There were no interest or taxes paid during the year.

h. Concentration of Credit Risk

The Foundation maintains its cash balances at institutions they consider to be credit worthy. The cash balances are insured by the Federal Deposit Insurance Corporation (FDIC) for amounts up to \$250,000. From time to time, balances may exceed insured limits and at December 31, 2008, the Foundation had uninsured cash balances of \$141,635.

i. Capitalization Policies

Items of property and equipment with an individual cost in excess of \$5,000 are capitalized at cost. Routine maintenance and repair costs and leasehold improvements, which do not materially extend the estimated useful lives of property and equipment, are expensed as incurred.

j. Expense Allocation

The costs of providing various programs and other activities have been summarized on a functional basis in the statement of activities and in the statement of functional expenses. Accordingly, certain costs have been allocated among the programs and supporting services benefited. Management and general expenses include those expenses that are not directly identifiable with any other specific function but provide for the overall support and direction of the Foundation.

k. **Management Estimates**

The preparation of financial statements in accordance with accounting principles generally accepted in the United States of America requires management to make estimates and assumptions that affect certain reported amounts and disclosures. Accordingly, results could differ from those estimates.

Note 3. Temporarily Restricted Net assets

At December 31, 2008, temporarily restricted net assets consist of the following:

	Balance <u>1/1/08</u>	Contributions	Released from Restrictions	Balance <u>12/31/08</u>
Program Restrictions:				
Paula & Woody Varner				
Science and Medicine Fund	\$188,918	\$24,607	(\$45,431)	\$168,094
Barth Syndrome Trust	19,303	0	(19,303)	0
Science and Medicine Fund	<u>227,905</u>	<u>217,185</u>	<u>0</u>	<u>445,090</u>
Total Program Restrictions	436,126	241,792	(64,734)	613,184
Time Restrictions	<u>0</u>	<u>125,000</u>	<u>0</u>	<u>125,000</u>
Total	<u>\$436,126</u>	<u>\$366,792</u>	<u>(\$64,734)</u>	<u>\$738,184</u>

At December 31, 2007, temporarily restricted net assets consist of the following:

	Balance <u>1/1/07</u>	Contributions	Released from Restrictions	Balance <u>12/31/07</u>
Program Restrictions:				
Paula & Woody Varner				
Science and Medicine Fund	\$89,215	\$99,703	\$0	\$188,918
Barth Syndrome Trust	0	55,000	(35,697)	19,303
Science and Medicine Fund	<u>0</u>	<u>227,905</u>	<u>0</u>	<u>227,905</u>
Total Program Restrictions	89,215	382,608	(35,697)	436,126
Time Restrictions	<u>300,000</u>	<u>0</u>	<u>(300,000)</u>	<u>0</u>
Total	<u>\$389,215</u>	<u>\$382,608</u>	<u>(\$335,697)</u>	<u>\$436,126</u>

Note 4. Commitments

Grants payable accrued of \$134,843 are all due to be paid within twelve months.

Although the Foundation does not have any long-term leases, they are committed to research grants awarded subsequent to year end, up to the amount of \$119,998, that are payable in 2009 and 2010.

Note 5. Investments

Securities are carried at fair market value in accordance with SFAS No. 124. At December 31, 2007, investments consisted of a United States Treasury Bill. At December 31, 2008, the Foundation did not carry any investments. At year end, the quoted market price was used as the basis of determining fair value, which also approximates the original cost.