

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

2012

Department of the Treasury
Internal Revenue Service

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

Open to Public Inspection

A For the 2012 calendar year, or tax year beginning OCT 1, 2012 and ending SEP 30, 2013

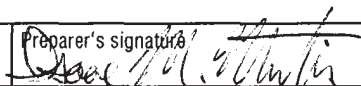
B Check if applicable: <input type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial return <input type="checkbox"/> Terminated <input type="checkbox"/> Amended return <input type="checkbox"/> Application pending	C Name of organization FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES Doing Business As FIRST Number and street (or P.O. box if mail is not delivered to street address) Room/suite 2616 N. BROAD ST. City, town, or post office, state, and ZIP code COLMAR, PA 18915-9423 F Name and address of principal officer: JEAN R. PICKFORD SAME AS C ABOVE	D Employer identification number 94-2738019 E Telephone number (215) 977-9400 G Gross receipts \$ 4,030,060. H(a) Is this a group return for affiliates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No H(b) Are all affiliates included? <input type="checkbox"/> Yes <input type="checkbox"/> No If "No," attach a list. (see instructions) H(c) Group exemption number ▶
I Tax-exempt status: <input checked="" type="checkbox"/> 501(c)(3) <input type="checkbox"/> 501(c) () ◀ (insert no.) <input type="checkbox"/> 4947(a)(1) or <input type="checkbox"/> 527		L Year of formation: 1981 M State of legal domicile: CA
J Website: ▶ WWW.FIRSTSKINFOUNDATION.ORG		
K Form of organization: <input checked="" type="checkbox"/> Corporation <input type="checkbox"/> Trust <input type="checkbox"/> Association <input type="checkbox"/> Other ▶		

Part I Summary

	1	Briefly describe the organization's mission or most significant activities: TO EDUCATE, INSPIRE, AND CONNECT THOSE TOUCHED BY ICHTHYOSIS AND RELATED DISORDERS THROUGH EMOTIONAL		
	2	Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.		
Activities & Governance	3	Number of voting members of the governing body (Part VI, line 1a)	14	
	4	Number of independent voting members of the governing body (Part VI, line 1b)	14	
	5	Total number of individuals employed in calendar year 2012 (Part V, line 2a)	5	
	6	Total number of volunteers (estimate if necessary)	200	
	7a	Total unrelated business revenue from Part VIII, column (C), line 12	1,600.	
	7b	Net unrelated business taxable income from Form 990-T, line 34	176.	
	Revenue	8	Contributions and grants (Part VIII, line 1h)	749,381.
9		Program service revenue (Part VIII, line 2g)	165.	
10		Investment income (Part VIII, column (A), lines 3, 4, and 7d)	372,798.	
11		Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	4,428.	
12		Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	1,126,772.	
Expenses		13	Grants and similar amounts paid (Part IX, column (A), lines 1-3)	86,250.
		14	Benefits paid to or for members (Part IX, column (A), line 4)	0.
		15	Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	243,705.
		16a	Professional fundraising fees (Part IX, column (A), line 11e)	0.
		b	Total fundraising expenses (Part IX, column (D), line 25) ▶ 65,362.	
		17	Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	257,776.
		18	Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	587,731.
19	Revenue less expenses. Subtract line 18 from line 12	539,041.		
Net Assets or Fund Balances	20	Total assets (Part X, line 16)	1,906,929.	
	21	Total liabilities (Part X, line 26)	21,216.	
	22	Net assets or fund balances. Subtract line 21 from line 20	1,885,713.	

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 JEAN R. PICKFORD, EXECUTIVE DIRECTOR Type or print name and title	Date		
Paid Preparer Use Only	Print/Type preparer's name ISAAC M. MARTIN	Preparer's signature 	Date 01/28/14	Check <input type="checkbox"/> if self-employed PTIN P01628745
	Firm's name ▶ BAUM, SMITH & CLEMENS, LLP	Firm's EIN ▶ 23-2315910		
	Firm's address ▶ 2128 N. BROAD STREET LANSDALE, PA 19446		Phone no. (215) 368-5755	

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

FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES

Part III Statement of Program Service Accomplishments

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

1 Briefly describe the organization's mission: TO EDUCATE, INSPIRE, AND CONNECT THOSE TOUCHED BY ICHTHYOSIS AND RELATED DISORDERS THROUGH EMOTIONAL SUPPORT, INFORMATION, ADVOCACY, AND RESEARCH FUNDING FOR BETTER TREATMENTS AND EVENTUAL CURES.

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.

4a (Code:) (Expenses \$ 75,000. including grants of \$ 75,000.) (Revenue \$) RESEARCH PROGRAM: THE FOUNDATION'S COMMITMENT TO RESEARCH IS A MAJOR COMPONENT IN OUR MISSION. FIRST, OFFICIALLY LAUNCHED ITS OWN IN-HOUSE RESEARCH GRANT PROGRAM IN EARLY 2006, WHICH HAS STIMULATED INTEREST INTO THE ICHTHYOSIS AND RELATED SKIN TYPES. THE PROGRAM IS MANAGED BY A RESEARCH REVIEW COMMITTEE COMPRISED OF PROMINENT, KNOWLEDGEABLE, PHYSICIANS AND SCIENTISTS AND FOUNDATION LEADERS. SINCE ITS INCEPTION, FIRST HAS RECEIVED MANY WORTHY GRANT APPLICATIONS AND WILL CONTINUE TO FUND THE MOST PROMISING PROJECTS, BASED UPON AVAILABLE FUNDING.

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

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

4d Other program services (Describe in Schedule O.) (Expenses \$ 382,619. including grants of \$ 11,250.) (Revenue \$ 165.)

4e Total program service expenses 457,619.

**FOUNDATION FOR ICHTHYOSIS AND RELATED
SKIN TYPES**

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 temporarily restricted endowments, permanent endowments, or 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 assistance to any organization or entity located outside the United States? <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 assistance to individuals located outside the United States? <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?		

**FOUNDATION FOR ICHTHYOSIS AND RELATED
SKIN TYPES**

Part IV Checklist of Required Schedules *(continued)*

		Yes	No
21 Did the organization report more than \$5,000 of grants and other assistance to any government or organization in the United States on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>	21	X	
22 Did the organization report more than \$5,000 of grants and other assistance to individuals in the United States on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>	22	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>	23		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 25</i>	24a		X
b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		
c Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?	24c		
d Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d		
25a Section 501(c)(3) and 501(c)(4) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i>	25a		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>	25b		X
26 Was a loan to or by a current or former officer, director, trustee, key employee, highest compensated employee, or disqualified person outstanding as of the end of the organization's tax year? <i>If "Yes," complete Schedule L, Part II</i>	26		X
27 Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i>	27		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, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>	28a		X
b A family member of a current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>	28b		X
c An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer, director, trustee, or direct or indirect owner? <i>If "Yes," complete Schedule L, Part IV</i>	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, Part II, III, or IV, and Part V, line 1</i>	34		X
35a Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a		X
b If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i>	35b		
36 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
38 Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19?	38	X	

FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES

Part V Statements Regarding Other IRS Filings and Tax Compliance

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

		Yes	No
1a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable		
1b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable		
1c	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	X	
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return		
2b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns? Note. If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)	X	
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?	X	
3b	If "Yes," has it filed a Form 990-T for this year? If "No," provide an explanation in Schedule O	X	
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
4b	If "Yes," enter the name of the foreign country: See instructions for filing requirements for Form TD F 90-22.1, Report of Foreign Bank and Financial Accounts.		
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?		X
5b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?		X
5c	If "Yes," to line 5a or 5b, did the organization file Form 8886-T?		
6a	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions?		X
6b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?		
7	Organizations that may receive deductible contributions under section 170(c).		
7a	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?	X	
7b	If "Yes," did the organization notify the donor of the value of the goods or services provided?	X	
7c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?		X
7d	If "Yes," indicate the number of Forms 8282 filed during the year		
7e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?		
7f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?		
7g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?		
7h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?		
8	Sponsoring organizations maintaining donor advised funds and section 509(a)(3) supporting organizations. Did the supporting organization, or a donor advised fund maintained by a sponsoring organization, have excess business holdings at any time during the year?		
9	Sponsoring organizations maintaining donor advised funds.		
9a	Did the organization make any taxable distributions under section 4966?		
9b	Did the organization make a distribution to a donor, donor advisor, or related person?		
10	Section 501(c)(7) organizations. Enter:		
10a	Initiation fees and capital contributions included on Part VIII, line 12		
10b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities		
11	Section 501(c)(12) organizations. Enter:		
11a	Gross income from members or shareholders		
11b	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them.)		
12a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?		
12b	If "Yes," enter the amount of tax-exempt interest received or accrued during the year		
13	Section 501(c)(29) qualified nonprofit health insurance issuers.		
13a	Is the organization licensed to issue qualified health plans in more than one state? Note. See the instructions for additional information the organization must report on Schedule O.		
13b	Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans		
13c	Enter the amount of reserves on hand		
14a	Did the organization receive any payments for indoor tanning services during the tax year?		X
14b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O		

FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES

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 in Schedule O. See instructions.

Check if Schedule O contains a response to any question 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 in Schedule O.	1a	14		
b Enter the number of voting members included in line 1a, above, who are independent	1b	14		
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?	2			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?	3			X
4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?	4			X
5 Did the organization become aware during the year of a significant diversion of the organization's assets?	5			X
6 Did the organization have members or stockholders?	6			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?	7a			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?	7b			X
8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:				
a The governing body?	8a		X	
b Each committee with authority to act on behalf of the governing body?	8b		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 in Schedule O	9			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?	10a			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?	11a		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	12a		X	
b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	12b		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	12c		X	
13 Did the organization have a written whistleblower policy?	13		X	
14 Did the organization have a written document retention and destruction policy?	14		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	15a		X	
b Other officers or key employees of the organization	15b			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?	16a			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 **▶ AK, AL, AR, AZ, CA, CT, DC, FL, GA, IL, KS, KY**
- 18** Section 6104 requires an organization to make its Forms 1023 (or 1024 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 in Schedule O)
- 19** Describe in Schedule O whether (and if so, how), the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.
- 20** State the name, physical address, and telephone number of the person who possesses the books and records of the organization: **▶** _____
JEAN PICKFORD (EXECUTIVE DIRECTOR) - (215) 997-9400
2616 N. BROAD ST., COLMAR, PA 18915

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

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

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

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

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
- List all of the organization's **current** key employees, if any. See instructions for definition of "key employee."
- List the organization's five **current** highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations.
- List all of the organization's **former** officers, key employees, 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.

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

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

(A) Name and Title	(B) Average hours per week (list any hours for related organizations below 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) DAVID SCHOLL, PHD BOARD MEMBER	2.00	X						0.	0.	0.
(2) JOHN J. SCHOENDORF BOARD MEMBER	2.00	X						0.	0.	0.
(3) MIKE BRIGGS PRESIDENT	3.00	X		X				0.	0.	0.
(4) LARRY SILVERMAN CHIEF FINANCIAL OFFICER	3.00	X		X				0.	0.	0.
(5) DENISE BENEDETTO BOARD MEMBER	2.00	X						0.	0.	0.
(6) JOHNATHAN DYER, MD BOARD MEMBER	2.00	X						0.	0.	0.
(7) JENNIFER HILLMAN SECRETARY	2.00	X		X				0.	0.	0.
(8) GABRIELE RICHARD, MD BOARD MEMBER	2.00	X						0.	0.	0.
(9) MOISE LEVY, MD VICE PRESIDENT	2.00	X		X				0.	0.	0.
(10) WILLIAM B. RIZZO, MD BOARD MEMBER	2.00	X						0.	0.	0.
(11) ERIC SCHWEIGHOFFER BOARD MEMBER	2.00	X						0.	0.	0.
(12) TERRY TORMEY BOARD MEMBER	2.00	X						0.	0.	0.
(13) JEFF HOERLE BOARD MEMBER	2.00	X						0.	0.	0.
(14) RACHEL SEE BOARD MEMBER	2.00	X						0.	0.	0.
(15) JEAN R. PICKFORD EXECUTIVE DIRECTOR	40.00			X				89,864.	0.	0.

FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES

Part VIII Statement of Revenue

Check if Schedule O contains a response to any question 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, 513, or 514		
Contributions, Gifts, Grants and Other Similar Amounts	1 a	Federated campaigns	1a	15,613.				
	b	Membership dues	1b					
	c	Fundraising events	1c	42,160.				
	d	Related organizations	1d					
	e	Government grants (contributions)	1e					
	f	All other contributions, gifts, grants, and similar amounts not included above	1f	691,608.				
	g	Noncash contributions included in lines 1a-1f: \$						
	h	Total. Add lines 1a-1f		749,381.				
Program Service Revenue	2 a	NATIONAL CONFERENCE	Business Code	165.	165.			
			900099					
	b							
	c							
	d							
	e							
	f	All other program service revenue						
g	Total. Add lines 2a-2f		165.					
Other Revenue	3	Investment income (including dividends, interest, and other similar amounts)		35,050.			35,050.	
	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				
			3,233,311.					
	b	Less: cost or other basis and sales expenses						
c	Gain or (loss)							
d	Net gain or (loss)			337,748.		337,748.		
8 a	Gross income from fundraising events (not including \$ 42,160. of contributions reported on line 1c). See Part IV, line 18	a		7,725.				
		b		7,725.				
				0.				
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						
		c						
Miscellaneous Revenue			Business Code					
11 a	MISCELLANEOUS	900099	2,828.	2,828.				
b	ADVERTISING	541800	1,600.		1,600.			
c								
d	All other revenue							
e	Total. Add lines 11a-11d		4,428.					
12	Total revenue. See instructions.		1,126,772.	2,993.	1,600.	372,798.		

FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES

Part IX Statement of Functional Expenses

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

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

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to governments and organizations in the United States. See Part IV, line 21	75,000.	75,000.		
2 Grants and other assistance to individuals in the United States. See Part IV, line 22	11,250.	11,250.		
3 Grants and other assistance to governments, organizations, and individuals outside the United States. See Part IV, lines 15 and 16				
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	94,537.	75,630.	14,181.	4,726.
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	130,590.	90,098.	11,075.	29,417.
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
9 Other employee benefits				
10 Payroll taxes	18,578.	13,566.	2,229.	2,783.
11 Fees for services (non-employees):				
a Management				
b Legal				
c Accounting	9,249.		9,249.	
d Lobbying				
e Professional fundraising services. See Part IV, line 17				
f Investment management fees	13,160.		13,160.	
g Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Sch O.)	1,791.		1,791.	
12 Advertising and promotion				
13 Office expenses	41,559.	29,214.	5,306.	7,039.
14 Information technology	3,945.	3,826.		119.
15 Royalties				
16 Occupancy	21,769.	19,592.	1,524.	653.
17 Travel				
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	6,558.	6,143.	291.	124.
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	3,057.	2,751.	214.	92.
23 Insurance	3,595.		3,595.	
24 Other expenses. Itemize expenses not covered above. (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
a UNRELATED BUSINESS INCO	180.		180.	
b STRATEGIC INITIATIVES	53,396.	47,556.	750.	5,090.
c GRASS ROOTS	40,505.	27,654.		12,851.
d SCIENTIFIC MEETING	32,000.	32,000.		
e All other expenses	27,012.	23,339.	1,205.	2,468.
25 Total functional expenses. Add lines 1 through 24e	587,731.	457,619.	64,750.	65,362.
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)

**FOUNDATION FOR ICHTHYOSIS AND RELATED
SKIN TYPES**

Form 990 (2012)

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Part X Balance Sheet

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

		(A) Beginning of year		(B) End of year	
Assets	1 Cash - non-interest-bearing	32,186.	1	20,619.	
	2 Savings and temporary cash investments	1,301,829.	2	277,185.	
	3 Pledges and grants receivable, net		3		
	4 Accounts receivable, net		4	25,866.	
	5 Loans and other receivables from current and former officers, directors, trustees, key employees, and highest compensated employees. Complete Part II of Schedule L		5		
	6 Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing employers and sponsoring organizations of section 501(c)(9) voluntary employees' beneficiary organizations (see instr). Complete Part II of Sch L		6		
	7 Notes and loans receivable, net		7		
	8 Inventories for sale or use		8		
	9 Prepaid expenses and deferred charges	1,735.	9	3,115.	
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	21,304.			
	b Less: accumulated depreciation	15,832.			
	11 Investments - publicly traded securities	4,833.	10c	5,472.	
	12 Investments - other securities. See Part IV, line 11	324,043.	11	1,571,672.	
	13 Investments - program-related. See Part IV, line 11		12		
	14 Intangible assets		13		
	15 Other assets. See Part IV, line 11	3,000.	14	3,000.	
16 Total assets. Add lines 1 through 15 (must equal line 34)	1,667,626.	15	1,906,929.		
Liabilities	17 Accounts payable and accrued expenses	3,708.	16	1,906,929.	
	18 Grants payable		17	21,216.	
	19 Deferred revenue		18		
	20 Tax-exempt bond liabilities		19		
	21 Escrow or custodial account liability. Complete Part IV of Schedule D		20		
	22 Loans and other payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons. Complete Part II of Schedule L		21		
	23 Secured mortgages and notes payable to unrelated third parties		22		
	24 Unsecured notes and loans payable to unrelated third parties		23		
	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		24		
	26 Total liabilities. Add lines 17 through 25	3,708.	25	21,216.	
Net Assets or Fund Balances	Organizations that follow SFAS 117 (ASC 958), check here <input checked="" type="checkbox"/> and complete lines 27 through 29, and lines 33 and 34.				
	27 Unrestricted net assets	1,124,805.	26	21,216.	
	28 Temporarily restricted net assets	429,100.	27	1,248,347.	
	29 Permanently restricted net assets	110,013.	28	527,353.	
	Organizations that do not follow SFAS 117 (ASC 958), check here <input type="checkbox"/> and complete lines 30 through 34.				
	30 Capital stock or trust principal, or current funds		29	110,013.	
	31 Paid-in or capital surplus, or land, building, or equipment fund		30		
	32 Retained earnings, endowment, accumulated income, or other funds		31		
33 Total net assets or fund balances	1,663,918.	32	1,885,713.		
34 Total liabilities and net assets/fund balances	1,667,626.	33	1,906,929.		

Form **990** (2012)

Part XI Reconciliation of Net Assets

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	1,126,772.
2	Total expenses (must equal Part IX, column (A), line 25)	2	587,731.
3	Revenue less expenses. Subtract line 2 from line 1	3	539,041.
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	1,663,918.
5	Net unrealized gains (losses) on investments	5	-317,246.
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain in Schedule O)	9	0.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 33, column (B))	10	1,885,713.

Part XII Financial Statements and Reporting

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

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

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

(Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ▶	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	617,682.	730,575.	470,096.	571,858.	749,381.	3139592.
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
3 The value of services or facilities furnished by a governmental unit to the organization without charge						
4 Total. Add lines 1 through 3	617,682.	730,575.	470,096.	571,858.	749,381.	3139592.
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)						397,730.
6 Public support. Subtract line 5 from line 4.						2741862.

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
7 Amounts from line 4	617,682.	730,575.	470,096.	571,858.	749,381.	3139592.
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	36,254.	20,526.	18,169.	16,651.	35,050.	126,650.
9 Net income from unrelated business activities, whether or not the business is regularly carried on			1,224.	1,200.	1,176.	3,600.
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)	7,443.	3,917.	3,436.	4,289.	2,828.	21,913.
11 Total support. Add lines 7 through 10						3291755.
12 Gross receipts from related activities, etc. (see instructions)					12	99,294.
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 2012 (line 6, column (f) divided by line 11, column (f))	14	83.29 %
15 Public support percentage from 2011 Schedule A, Part II, line 14	15	83.82 %
16a 33 1/3% support test - 2012. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization	<input checked="" type="checkbox"/>	
b 33 1/3% support test - 2011. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization	<input type="checkbox"/>	
17a 10% -facts-and-circumstances test - 2012. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization	<input type="checkbox"/>	
b 10% -facts-and-circumstances test - 2011. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization	<input type="checkbox"/>	
18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions	<input type="checkbox"/>	

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

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

Section A. Public Support

Table with 7 columns: Calendar year (or fiscal year beginning in), (a) 2008, (b) 2009, (c) 2010, (d) 2011, (e) 2012, (f) Total. Rows include: 1 Gifts, grants, contributions, and membership fees received; 2 Gross receipts from admissions, merchandise sold or services performed; 3 Gross receipts from activities that are not an unrelated trade or business; 4 Tax revenues levied for the organization's benefit; 5 The value of services or facilities furnished by a governmental unit; 6 Total. Add lines 1 through 5; 7a Amounts included on lines 1, 2, and 3 received from disqualified persons; 7b Amounts included on lines 2 and 3 received from other than disqualified persons; 8 Public support (Subtract line 7c from line 6).

Section B. Total Support

Table with 7 columns: Calendar year (or fiscal year beginning in), (a) 2008, (b) 2009, (c) 2010, (d) 2011, (e) 2012, (f) Total. Rows include: 9 Amounts from line 6; 10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources; 10b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975; 11 Net income from unrelated business activities not included in line 10b; 12 Other income. Do not include gain or loss from the sale of capital assets; 13 Total support. (Add lines 9, 10c, 11, and 12).

14 First 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

Table with 3 columns: Description, Line number, Percentage. Row 15: Public support percentage for 2012 (line 8, column (f) divided by line 13, column (f)) 15 %; Row 16: Public support percentage from 2011 Schedule A, Part III, line 15 16 %

Section D. Computation of Investment Income Percentage

Table with 3 columns: Description, Line number, Percentage. Row 17: Investment income percentage for 2012 (line 10c, column (f) divided by line 13, column (f)) 17 %; Row 18: Investment income percentage from 2011 Schedule A, Part III, line 17 18 %

19a 33 1/3% support tests - 2012. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization

b 33 1/3% support tests - 2011. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3%, and line 18 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization

20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions

SCHEDULE D (Form 990)

Department of the Treasury Internal Revenue Service

Supplemental Financial Statements

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

Attach to Form 990. See separate instructions.

OMB No. 1545-0047

2012

Open to Public Inspection

Name of the organization FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES

Employer identification number 94-2738019

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: Question, (a) Donor advised funds, (b) Funds and other accounts. Rows include total number at end of year, aggregate contributions, aggregate grants, aggregate value, and questions about property control and grant fund usage.

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

Form for Part II Conservation Easements. Includes questions about purpose of easements, total number and acreage, and monitoring details. Includes a table for 'Held at the End of the Tax Year' with rows 2a, 2b, 2c, and 2d.

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.

Form for Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets. Includes questions about reporting requirements and amounts for revenues and assets.

FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES

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

- 3** Using the organization's acquisition, accession, and other records, check any of the following that are a significant use of its collection items (check all that apply):
- a** Public exhibition
 - b** Scholarly research
 - c** Preservation for future generations
 - d** Loan or exchange programs
 - e** Other _____
- 4** Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII.
- 5** During the year, did the organization solicit or receive donations of art, historical treasures, or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection? Yes No

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

- 1a** Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X? Yes No
- b** If "Yes," explain the arrangement in Part XIII and complete the following table:
- | | Amount |
|--|-----------|
| 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 XIII. Check here if the explanation has been provided in Part XIII

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

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1a Beginning of year balance	124,592.	85,242.	83,567.	81,780.	80,157.
b Contributions	950.	39,810.			
c Net investment earnings, gains, and losses	1,623.	1,040.	3,675.	2,587.	1,823.
d Grants or scholarships					
e Other expenditures for facilities and programs	2,800.	1,500.	2,000.	800.	200.
f Administrative expenses					
g End of year balance	124,365.	124,592.	85,242.	83,567.	81,780.

- 2** Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
- a** Board designated or quasi-endowment 0.00 %
 - b** Permanent endowment 88.46 %
 - c** Temporarily restricted endowment 11.54 %
- The percentages in lines 2a, 2b, and 2c should equal 100%.
- 3a** Are there endowment funds not in the possession of the organization that are held and administered for the organization by:
- | | Yes | No |
|------------------------------------|--------------------------|-------------------------------------|
| (i) unrelated organizations | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
| (ii) related organizations | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
- b** If "Yes" to 3a(ii), are the related organizations listed as required on Schedule R?

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

Part VI Land, Buildings, and Equipment. 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		21,304.	15,832.	5,472.
e Other				
Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c).)				5,472.

FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES

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

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

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

(a) Description of investment type	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1)		
(2)		
(3)		
(4)		
(5)		
(6)		
(7)		
(8)		
(9)		
(10)		
Total. (Col. (b) must equal Form 990, Part X, col. (B) line 13.) ▶		

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

(a) Description	(b) Book value
(1)	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
(10)	
Total. (Column (b) must equal Form 990, Part X, col. (B) line 15.) ▶	

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

1. (a) Description of liability	(b) Book value
(1) Federal income taxes	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
(10)	
(11)	
Total. (Column (b) must equal Form 990, Part X, col. (B) line 25.) ▶	

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

FOUNDATION FOR ICHTHYOSIS AND RELATED
SKIN TYPES

Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per Return			
1	Total revenue, gains, and other support per audited financial statements		867,384.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:		
a	Net unrealized gains on investments	2a	-317,246.
b	Donated services and use of facilities	2b	43,056.
c	Recoveries of prior year grants	2c	
d	Other (Describe in Part XIII.)	2d	14,802.
e	Add lines 2a through 2d	2e	-259,388.
3	Subtract line 2e from line 1	3	1,126,772.
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIII.)	4b	
c	Add lines 4a and 4b	4c	0.
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)	5	1,126,772.

Part XII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return			
1	Total expenses and losses per audited financial statements		645,589.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:		
a	Donated services and use of facilities	2a	43,056.
b	Prior year adjustments	2b	
c	Other losses	2c	
d	Other (Describe in Part XIII.)	2d	14,802.
e	Add lines 2a through 2d	2e	57,858.
3	Subtract line 2e from line 1	3	587,731.
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	587,731.

Part XIII Supplemental Information

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

PART V, LINE 4: CORPUS OF THE ENDOWMENT ASSET IS HELD IN PERPETUITY

FOR THE EDNA AND MYRON CURL ENDOWMENT AND THE JANE BUKATY MEMBERSHIP

ASSISTANCE FUND BASED ON DONOR-RESTRICTION. THE ENDOWMENT ASSET IS

INVESTED IN A MIX OF EQUITY AND FIXED INCOME SECURITIES. INVESTMENT

EARNINGS ON THE EDNA AND MYRON CURL ENDOWMENT IS APPROPRIATED TO RESEARCH

AND WILL BE SPENT WHEN F.I.R.S.T.'S BOARD OF DIRECTORS DETERMINE THAT THE

EARNINGS HAVE ACCUMULATED TO A LEVEL THAT WILL ENABLE THEM TO PROVIDE

RESEARCH GRANTS. EARNINGS ON THE JANE BUKATY MEMBERSHIP ASSISTANCE FUND

Part XIII Supplemental Information (continued)

IS USED TO PROVIDE FINANCIAL ASSISTANCE TO FAMILIES WITH ONE OR MORE AFFECTED INDIVIDUALS WHOSE FINANCIAL AND REIMBURSEMENT CIRCUMSTANCES MAKE OBTAINING ADEQUATE CARE AND TREATMENT DIFFICULT OR IMPOSSIBLE.

PART X, LINE 2: THE ORGANIZATION IS REQUIRED TO RECOGNIZE, MEASURE, CLASSIFY, AND DISCLOSE IN THE FINANCIAL STATEMENTS UNCERTAIN TAX POSITIONS TAKEN OR EXPECTED TO BE TAKEN IN THE ORGANIZATION'S TAX RETURNS.

MANAGEMENT HAS DETERMINED THAT THE ORGANIZATION DOES NOT HAVE ANY UNCERTAIN TAX POSITIONS AND ASSOCIATED UNRECOGNIZED BENEFITS THAT MATERIALLY IMPACT THE FINANCIAL STATEMENTS OR RELATED DISCLOSURES.

GENERALLY THE ORGANIZATION IS NO LONGER SUBJECT TO TAX EXAMINATIONS BY TAX AUTHORITIES FOR FISCAL YEARS PRIOR TO 2010.

PART XI, LINE 2D - OTHER ADJUSTMENTS:
REDUCTION OF SPECIAL EVENTS FOR DIRECT EXPENSES

PART XII, LINE 2D - OTHER ADJUSTMENTS:
REDUCTION OF SPECIAL EVENTS FOR DIRECT EXPENSES

SCHEDULE D, PART XII, LINE 2D
REDUCTION OF SPECIAL EVENTS FOR DIRECT EXPENSES: \$14,802

SCHEDULE D, PART XII, LINE 4B
REDUCTION OF SPECIAL EVENTS FOR DIRECT EXPENSES: \$14,802

FOUNDATION FOR ICHTHYOSIS AND RELATED

Part II Fundraising Events. Complete if the organization answered "Yes" to Form 990, Part IV, line 18, or reported more than \$15,000 of fundraising event contributions and gross income on Form 990-EZ, lines 1 and 6b. List events with gross receipts greater than \$5,000.

		(a) Event #1	(b) Event #2	(c) Other events	(d) Total events (add col. (a) through col. (c))	
		TESTIMONIAL DINNER		NONE		
		(event type)	(event type)	(total number)		
Revenue	1	Gross receipts	49,885.			49,885.
	2	Less: Contributions	42,160.			42,160.
	3	Gross income (line 1 minus line 2)	7,725.			7,725.
Direct Expenses	4	Cash prizes				
	5	Noncash prizes				
	6	Rent/facility costs				
	7	Food and beverages	7,725.			7,725.
	8	Entertainment				
	9	Other direct expenses				
	10	Direct expense summary. Add lines 4 through 9 in column (d)				(7,725)
	11	Net income summary. Combine line 3, column (d), and line 10				0.

Part III Gaming. Complete if the organization answered "Yes" to Form 990, Part IV, line 19, or reported more than \$15,000 on Form 990-EZ, line 6a.

		(a) Bingo	(b) Pull tabs/instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col. (a) through col. (c))
		1	Gross revenue		
Direct Expenses	2	Cash prizes			
	3	Noncash prizes			
	4	Rent/facility costs			
	5	Other direct expenses			
	6	Volunteer labor	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No
7	Direct expense summary. Add lines 2 through 5 in column (d)				()
8	Net gaming income summary. Combine line 1, column d, and line 7				

9 Enter the state(s) in which the organization operates gaming activities: _____
 a Is the organization licensed to operate gaming activities in each of these states? Yes No
 b If "No," explain: _____

10a Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year? Yes No
 b If "Yes," explain: _____

**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" to Form 990, Part IV, line 21 or 22.

▶ Attach to Form 990.

OMB No. 1545-0047

2012

Open to Public
Inspection

Name of the organization **FOUNDATION FOR ICHTHYOSIS AND RELATED
SKIN TYPES**

Employer identification number
94-2738019

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 Governments and Organizations in the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 21, for any recipient that received more than \$5,000. 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 non-cash assistance	(h) Purpose of grant or assistance
NORTHWESTERN UNIVERSITY 750 N. LAKE SHORE DR. CHICAGO, IL 60611	36-2167817	501(C)(3)	75,000.	0.	CASH		RESEARCH PROJECTS

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

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) (2012)

FOUNDATION FOR ICHTHYOSIS AND RELATED

SKIN TYPES

Part III **Grants and Other Assistance to Individuals in the United States.** Complete if the organization answered "Yes" to Form 990, Part IV, line 22.
Part III can be duplicated if additional space is needed.

(a) Type of grant or assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of non-cash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of non-cash assistance
SCHOLARSHIPS FOR POST-SECONDARY EDUCATION FOR AFFECTED STUDENTS IN COLLEGE.	9	11,250.	0.		

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

SCHEDULE I, PART I, LINE 2: FIRST REQUESTS A FINANCIAL AND PROGRESS REPORT

FROM THE UNIVERSITY AT SIX MONTHS AND AT ONE YEAR. A FINAL FINANCIAL

REPORT AND SUMMARY REPORT IS DUE ONE MONTH AFTER THE CONTRACT EXPIRES.

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.

OMB No. 1545-0047

2012

Open to Public
Inspection

Name of the organization

FOUNDATION FOR ICHTHYOSIS AND RELATED
SKIN TYPES

Employer identification number
94-2738019

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

SUPPORT, INFORMATION, ADVOCACY, AND RESEARCH FUNDING FOR BETTER
TREATMENTS AND EVENTUAL CURES.

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

OTHER PROGRAM EXPENDITURES INCLUDE:

UFIRST SCHOLARS PROGRAM - THE UFIRST SCHOLARS PROGRAM WAS ESTABLISHED
IN 2010 TO PROVIDE AN OPPORTUNITY FOR AFFECTED STUDENTS TO ADVANCE
THEIR POST-SECONDARY EDUCATION IN PARTNERSHIP WITH FIRST BY RECEIVING
COLLEGE SCHOLARSHIPS. THE SEED MONEY FOR THIS PROGRAM WAS PROVIDED BY
VALERIE AND DAVE SCHOLL, WHOSE INSPIRATION IS TO PROVIDE THE
OPPORTUNITY FOR STUDENTS AFFECTED WITH A FORM OF ICHTHYOSIS OR RELATED
SKIN TYPE TO ACHIEVE THEIR HIGHEST EDUCATIONAL POTENTIAL.

REGIONAL SUPPORT NETWORK - THE RSN IS A COMMUNITY OF PEOPLE WHO COME
TOGETHER AND SUPPORT EACH OTHER THROUGH THE SHARING OF KNOWLEDGE,
EXPERIENCE, AND ADVICE. IT IS OUR HOPE FOR ALL WHO JOIN THIS CARING
COMMUNITY THAT THEY WILL FIND COMFORT IN KNOWING THEY ARE NOT ALONE ON
THEIR JOURNEY. THE GOALS OF THE RSN ARE TO PROVIDE MORAL SUPPORT,
INFORMATION, PRACTICAL ADVICE, GUIDANCE, EDUCATION AND RESOURCE
INFORMATION, AND INCREASE AWARENESS AND GRASSROOTS FUND RAISING EVENTS.
INDIVIDUALS AND PARENTS OF CHILDREN WITH ICHTHYOSIS, OFTEN HAVE NEVER
MET ANOTHER PERSON WHO SHARES THE DISEASE. THIS CAN LEAD TO FEELINGS OF
ISOLATION. THE REGIONAL MEETINGS PROVIDE AN OPPORTUNITY FOR FAMILIES TO
TRAVEL SHORT DISTANCES TO MEET OTHERS WHO SHARE THE SAME ISSUES.

Name of the organization	FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES	Employer identification number	94-2738019
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EXPENSES \$ 382,619. INCLUDING GRANTS OF \$ 11,250. REVENUE \$ 165.

FORM 990, PART VI, SECTION B, LINE 11: AFTER WE RECEIVED THE 990 FROM OUR INDEPENDENT PREPARER, THE FORM IS INITIALLY REVIEWED BY THE FINANCE COMMITTEE AND THE UPDATED 990 IS ELECTRONICALLY SUBMITTED TO EACH MEMBER OF THE BOARD OF DIRECTORS FOR THEIR REVIEW. THE BOARD THEN HAS THE OPPORTUNITY TO ASK QUESTIONS BEFORE IT IS SUBMITTED TO THE INTERNAL REVENUE SERVICE.

FORM 990, PART VI, SECTION B, LINE 12C: THE CONFLICT OF INTEREST POLICY IS REVIEWED ANNUALLY BY EACH BOARD MEMBER. IF THERE IS A CONFLICT, THE BOARD MEMBER IS ASKED TO REMOVE THEMSELVES FROM THE DISCUSSION AND VOTING.

FORM 990, PART VI, SECTION B, LINE 15A: THE PRESIDENT AND CFO POLLED LOCAL ORGANIZATIONS, SEARCH FIRMS, AND EMPLOYMENT AGENCIES TO OBTAIN A SENSE OF APPROPRIATE COMPENSATION. FROM YEAR-TO-YEAR, A MORE DETAILED ANALYSIS OF MARKET RATES HAS BEEN PERFORMED TO ESTABLISH THAT COMPENSATION IS COMMENSURATE WITH RESPONSIBILITIES AND PERFORMANCE.

FORM 990, PART VI, LINE 17, LIST OF STATES RECEIVING COPY OF FORM 990:
AK, AL, AR, AZ, CA, CT, DC, FL, GA, IL, KS, KY, LA, MA, MD, MI, MN, MS, NC, NH, NJ, NM, NY, OH, OK
OR, PA, RI, SC, TN, UT, VA, WA, WI, WV

FORM 990, PART VI, SECTION C, LINE 19: GOVERNING DOCUMENTS, CONFLICT OF INTEREST POLICY, AND FINANCIAL STATEMENTS AVAILABLE UPON REQUEST THROUGH THE OFFICE.