Form **990**

Department of the Treasury
Internal Revenue Service

Return of Organization Exempt From Income Tax

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)

▶ Do not enter Social Security numbers on this form as it may be made public.

▶ Information about Form 990 and its instructions is at *www.irs.gov/form990.*

OMB No. 1545-0047

2013

Open to Public Inspection

A For the 2013 calendar year, or tax year beginning OCT 1, 2013 and ending SEP 30, 2014

B Check if applicable:
☐ Address change
☐ Name change
☐ Initial return
☐ Termin-ated
☐ Amended return
☐ Applica-tion 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 or town, state or province, country, and ZIP or foreign postal 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 $ 2,274,823.

H(a) Is this a group return for subordinates? ☐ Yes ☒ No

H(b) Are all subordinates included? ☐ Yes ☐ No
If "No," attach a list. (see instructions)

H(c) Group exemption number ▶

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

J Website: ▶ WWW.FIRSTSKINFOUNDATION.ORG

K Form of organization: ☒ Corporation ☐ Trust ☐ Association ☐ Other ▶

L Year of formation: 1981 **M** State of legal domicile: CA

Part I Summary

Activities & Governance	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 ▶ ☐ if the organization discontinued its operations or disposed of more than 25% of its net assets.	
	3	Number of voting members of the governing body (Part VI, line 1a)	15
	4	Number of independent voting members of the governing body (Part VI, line 1b)	15
	5	Total number of individuals employed in calendar year 2013 (Part V, line 2a)	6
	6	Total number of volunteers (estimate if necessary)	400
	7a	Total unrelated business revenue from Part VIII, column (C), line 12	4,458.
	b	Net unrelated business taxable income from Form 990-T, line 34	2,901.

			Prior Year	Current Year
Revenue	8	Contributions and grants (Part VIII, line 1h)	749,381.	798,176.
	9	Program service revenue (Part VIII, line 2g)	165.	100,089.
	10	Investment income (Part VIII, column (A), lines 3, 4, and 7d)	372,798.	50,391.
	11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	4,428.	8,309.
	12	Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	1,126,772.	956,965.
Expenses	13	Grants and similar amounts paid (Part IX, column (A), lines 1-3)	86,250.	156,219.
	14	Benefits paid to or for members (Part IX, column (A), line 4)	0.	0.
	15	Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	243,705.	321,563.
	16a	Professional fundraising fees (Part IX, column (A), line 11e)	0.	0.
	b	Total fundraising expenses (Part IX, column (D), line 25) ▶ 87,045.		
	17	Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	257,776.	343,842.
	18	Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	587,731.	821,624.
	19	Revenue less expenses. Subtract line 18 from line 12	539,041.	135,341.

			Beginning of Current Year	End of Year
Net Assets or Fund Balances	20	Total assets (Part X, line 16)	1,906,929.	2,089,093.
	21	Total liabilities (Part X, line 26)	21,216.	28,143.
	22	Net assets or fund balances. Subtract line 21 from line 20	1,885,713.	2,060,950.

Part II Signature Block

Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete. Declaration of preparer (other than officer) is based on all information of which preparer has any knowledge.

Sign Here

▶ Signature of officer — Date 3/2/15

▶ JEAN R. PICKFORD, EXECUTIVE DIRECTOR
Type or print name and title

Paid Preparer Use Only

Print/Type preparer's name: ISAAC M. MARTIN
Preparer's signature
Date: 02/21/15
Check ☐ 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

SEE SCHEDULE O FOR ORGANIZATION MISSION STATEMENT CONTINUATION

Part III Statement of Program Service Accomplishments

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

1 Briefly describe the organization's mission:
TO EDUCATE, INSPIRE AND CONNECT THOSE TOUCHED BY ICHTHYOSIS AND RELATED DISORDERS THROUGH EMOTIONAL SUPPORT, EDUCATION, 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 ☒ No
If "Yes," describe these new services on Schedule O.

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services? ..... ☐ Yes ☒ No
If "Yes," describe these changes on Schedule O.

4 Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses. Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.

4a (Code:) (Expenses $ 50,000. including grants of $ 50,000.) (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. 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 $ 138,771. including grants of $) (Revenue $ 100,089.)
THE FOUNDATION FOR ICHTHYOSIS HOSTS A 3 DAY NATIONAL FAMILY CONFERENCE EVERY TWO YEARS. THE CONFERENCE IS A FANTASTIC OPPORTUNITY FOR AFFECTED INDIVIDUALS AND THEIR FAMILIES TO MEET AND NETWORK WITH OTHER AFFECTED INDIVIDUALS. THEY CONNECT THOSE SEARCHING FOR INFORMATION AND SUPPORT IN LIVING WITH ICHTHYOSIS AND RELATED SKIN TYPES. THIS YEAR'S CONFERENCE HAD MORE THAN 400 PEOPLE REPRESENTING 140 FAMILIES.

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

4d Other program services (Describe in Schedule O.)
(Expenses $ 473,693. including grants of $ 106,219.) (Revenue $ 3,851.)

4e Total program service expenses ▶ 662,464.

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*	1	X	
2	Is the organization required to complete *Schedule B, Schedule of Contributors*?	2	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*	3		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? *If "Yes," complete Schedule C, Part II*	4		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? *If "Yes," complete Schedule C, Part III*	5		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? *If "Yes," complete Schedule D, Part I*	6		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*	7		X
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? *If "Yes," complete Schedule D, Part III*	8		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? *If "Yes," complete Schedule D, Part IV*	9		X
10	Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi-endowments? *If "Yes," complete Schedule D, Part V*	10	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? *If "Yes," complete Schedule D, Part VI*	11a	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? *If "Yes," complete Schedule D, Part VII*	11b		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? *If "Yes," complete Schedule D, Part VIII*	11c		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? *If "Yes," complete Schedule D, Part IX*	11d		X
e	Did the organization report an amount for other liabilities in Part X, line 25? *If "Yes," complete Schedule D, Part X*	11e		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)? *If "Yes," complete Schedule D, Part X*	11f	X	
12a	Did the organization obtain separate, independent audited financial statements for the tax year? *If "Yes," complete Schedule D, Parts XI and XII*	12a	X	
b	Was the organization included in consolidated, independent audited financial statements for the tax year? *If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional*	12b		X
13	Is the organization a school described in section 170(b)(1)(A)(ii)? *If "Yes," complete Schedule E*	13		X
14a	Did the organization maintain an office, employees, or agents outside of the United States?	14a		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? *If "Yes," complete Schedule F, Parts I and IV*	14b		X
15	Did the organization report on Part IX, column (A), line 3, more than $5,000 of grants or other assistance to or for any foreign organization? *If "Yes," complete Schedule F, Parts II and IV*	15	X	
16	Did the organization report on Part IX, column (A), line 3, more than $5,000 of aggregate grants or other assistance to or for foreign individuals? *If "Yes," complete Schedule F, Parts III and IV*	16		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? *If "Yes," complete Schedule G, Part I*	17		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? *If "Yes," complete Schedule G, Part II*	18	X	
19	Did the organization report more than $15,000 of gross income from gaming activities on Part VIII, line 9a? *If "Yes," complete Schedule G, Part III*	19		X
20a	Did the organization operate one or more hospital facilities? *If "Yes," complete Schedule H*	20a		X
b	If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?	20b		

Part IV Checklist of Required Schedules *(continued)*

			Yes	No
21	Did the organization report more than $5,000 of grants or other assistance to any domestic organization or government on Part IX, column (A), line 1? *If "Yes," complete Schedule I, Parts I and II*	21	X	
22	Did the organization report more than $5,000 of grants or other assistance to individuals in the United States on Part IX, column (A), line 2? *If "Yes," complete Schedule I, Parts I and III*	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? *If "Yes," complete Schedule J*	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? *If "Yes," answer lines 24b through 24d and complete Schedule K. If "No", go to line 25a*	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? *If "Yes," complete Schedule L, Part 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? *If "Yes," complete Schedule L, Part I*	25b		X
26	Did the organization report any amount on Part X, line 5, 6, or 22 for receivables from or payables to any current or former officers, directors, trustees, key employees, highest compensated employees, or disqualified persons? If so, complete Schedule L, Part II	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? *If "Yes," complete Schedule L, Part III*	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? *If "Yes," complete Schedule L, Part IV*	28a		X
b	A family member of a current or former officer, director, trustee, or key employee? *If "Yes," complete Schedule L, Part IV*	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? *If "Yes," complete Schedule L, Part IV*	28c		X
29	Did the organization receive more than $25,000 in non-cash contributions? *If "Yes," complete Schedule M*	29		X
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? *If "Yes," complete Schedule M*	30		X
31	Did the organization liquidate, terminate, or dissolve and cease operations? *If "Yes," complete Schedule N, Part I*	31		X
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? *If "Yes," complete Schedule N, Part II*	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? *If "Yes," complete Schedule R, Part I*	33		X
34	Was the organization related to any tax-exempt or taxable entity? *If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1*	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)? *If "Yes," complete Schedule R, Part V, line 2*	35b		
36	**Section 501(c)(3) organizations.** Did the organization make any transfers to an exempt non-charitable related organization? *If "Yes," complete Schedule R, Part V, line 2*	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? *If "Yes," complete Schedule R, Part VI*	37		X
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? **Note.** All Form 990 filers are required to complete Schedule O	38	X	

Part V Statements Regarding Other IRS Filings and Tax Compliance

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

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

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 or note to any line in this Part VI X

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	1a	15		
	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.				
b	Enter the number of voting members included in line 1a, above, who are independent	1b	15		
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.

X Own website ☐ Another's website X 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

SEE SCHEDULE O FOR FULL LIST OF STATES

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

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

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

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

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
- List all of the organization's **current** key employees, if any. See instructions for definition of "key employee."
- List the organization's five **current** highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than $100,000 from the organization and any related organizations.
- List all of the organization's **former** officers, key employees, and highest compensated employees who received more than $100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than $10,000 of reportable compensation from the organization and any related organizations.

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) GREG LICALZI, JR. 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) JONATHAN DYER, MD BOARD MEMBER	2.00	X						0.	0.	0.
(7) TRACIE PRETAK BOARD MEMBER	2.00	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) ROBERT SILVERMAN, MD BOARD MEMBER	2.00	X						0.	0.	0.
(13) JEFF HOERLE SECRETARY PRESIDENT-ELECT	2.00	X		X				0.	0.	0.
(14) RACHEL SEE BOARD MEMBER	2.00	X						0.	0.	0.
(15) KIMBERLY COLE BOARD MEMBER	2.00	X						0.	0.	0.
(16) JEAN R. PICKFORD EXECUTIVE DIRECTOR	40.00			X				94,357.	0.	0.

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below 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			
1b Sub-total ▶								94,357.	0.	0.
c Total from continuation sheets to Part VII, Section A ▶								0.	0.	0.
d Total (add lines 1b and 1c) ▶								94,357.	0.	0.

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

		Yes	No
3	Did the organization list any **former** officer, director, or trustee, key employee, or highest compensated employee on line 1a? *If "Yes," complete Schedule J for such individual*		X
4	For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than $150,000? *If "Yes," complete Schedule J for such individual*		X
5	Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? *If "Yes," complete Schedule J for such person*		X

Section B. Independent Contractors

1 Complete this table for your five highest compensated independent contractors that received more than $100,000 of compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax year.

(A) Name and business address	(B) Description of services	(C) Compensation
NONE		

2 Total number of independent contractors (including but not limited to those listed above) who received more than $100,000 of compensation from the organization ▶ 0

Part VIII Statement of Revenue

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

				(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512-514
Contributions, Gifts, Grants and Other Similar Amounts	1a Federated campaigns	1a	13,649.				
	b Membership dues	1b					
	c Fundraising events	1c	24,776.				
	d Related organizations	1d					
	e Government grants (contributions)	1e					
	f All other contributions, gifts, grants, and similar amounts not included above	1f	759,751.				
	g Noncash contributions included in lines 1a-1f: $						
	h **Total.** Add lines 1a-1f			798,176.			
Program Service Revenue		Business Code					
	2a NATIONAL CONFERENCE	900099		100,089.	100,089.		
	b						
	c						
	d						
	e						
	f All other program service revenue						
	g **Total.** Add lines 2a-2f			100,089.			
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)			41,510.			41,510.
	4 Income from investment of tax-exempt bond proceeds						
	5 Royalties						
		(i) Real	(ii) Personal				
	6a Gross rents						
	b Less: rental expenses						
	c Rental income or (loss)						
	d Net rental income or (loss)						
		(i) Securities	(ii) Other				
	7a Gross amount from sales of assets other than inventory	1,320,715.					
	b Less: cost or other basis and sales expenses	1,311,834.					
	c Gain or (loss)	8,881.					
	d Net gain or (loss)			8,881.			8,881.
	8a Gross income from fundraising events (not including $ 24,776. of contributions reported on line 1c). See Part IV, line 18	a	6,024.				
	b Less: direct expenses	b	6,024.				
	c Net income or (loss) from fundraising events			0.			
	9a Gross income from gaming activities. See Part IV, line 19	a					
	b Less: direct expenses	b					
	c Net income or (loss) from gaming activities						
	10a 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					
	11a ADVERTISING	541800		4,458.		4,458.	
	b MISCELLANEOUS	900099		3,851.	3,851.		
	c						
	d All other revenue						
	e **Total.** Add lines 11a-11d			8,309.			
	12 **Total revenue.** See instructions.			956,965.	103,940.	4,458.	50,391.

Part IX Statement of Functional Expenses

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

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

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to governments and organizations in the United States. See Part IV, line 21	90,000.	90,000.		
2 Grants and other assistance to individuals in the United States. See Part IV, line 22	16,219.	16,219.		
3 Grants and other assistance to governments, organizations, and individuals outside the United States. See Part IV, lines 15 and 16	50,000.	50,000.		
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	112,472.	89,977.	16,871.	5,624.
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	185,098.	138,266.	11,505.	35,327.
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
9 Other employee benefits	945.	851.	66.	28.
10 Payroll taxes	23,048.	17,691.	2,175.	3,182.
11 Fees for services (non-employees):				
a Management				
b Legal				
c Accounting	9,350.		9,350.	
d Lobbying				
e Professional fundraising services. See Part IV, line 17				
f Investment management fees	11,795.		11,795.	
g Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Sch O.)	1,842.		1,842.	
12 Advertising and promotion				
13 Office expenses	49,742.	31,975.	9,835.	7,932.
14 Information technology	1,280.	1,242.		38.
15 Royalties				
16 Occupancy	22,483.	20,235.	1,574.	674.
17 Travel				
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	152,837.	151,645.	835.	357.
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	3,672.	3,305.	257.	110.
23 Insurance	4,017.		4,017.	
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	26.		26.	
b GRASS ROOTS	55,354.	30,689.		24,665.
c STRATEGIC INITIATIVES	21,534.	13,637.	1,014.	6,883.
d MEMBERSHIP ASSISTANCE F	3,400.	3,400.		
e All other expenses	6,510.	3,332.	953.	2,225.
25 Total functional expenses. Add lines 1 through 24e	821,624.	662,464.	72,115.	87,045.
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here ▶ ☐ if following SOP 98-2 (ASC 958-720)				

Part X Balance Sheet

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

				(A) Beginning of year		(B) End of year
Assets	1	Cash - non-interest-bearing		20,619.	1	0.
	2	Savings and temporary cash investments		277,185.	2	230,591.
	3	Pledges and grants receivable, net			3	75,000.
	4	Accounts receivable, net		25,866.	4	20,527.
	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		3,115.	9	3,115.
	10a	Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a 28,584.			
	b	Less: accumulated depreciation	10b 19,504.	5,472.	10c	9,080.
	11	Investments - publicly traded securities		1,571,672.	11	1,747,780.
	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		3,000.	15	3,000.
	16	**Total assets.** Add lines 1 through 15 (must equal line 34)		1,906,929.	16	2,089,093.
Liabilities	17	Accounts payable and accrued expenses		21,216.	17	28,143.
	18	Grants payable			18	
	19	Deferred revenue			19	
	20	Tax-exempt bond liabilities			20	
	21	Escrow or custodial account liability. Complete Part IV of Schedule D			21	
	22	Loans and other payables to 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 to unrelated third parties			24	
	25	Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24). Complete Part X of Schedule D		0.	25	0.
	26	**Total liabilities.** Add lines 17 through 25		21,216.	26	28,143.
Net Assets or Fund Balances		**Organizations that follow SFAS 117 (ASC 958), check here ▶ [X] and complete lines 27 through 29, and lines 33 and 34.**				
	27	Unrestricted net assets		1,248,347.	27	1,377,915.
	28	Temporarily restricted net assets		527,353.	28	573,022.
	29	Permanently restricted net assets		110,013.	29	110,013.
		Organizations that do not follow SFAS 117 (ASC 958), check here ▶ ☐ 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, or equipment fund			31	
	32	Retained earnings, endowment, accumulated income, or other funds			32	
	33	Total net assets or fund balances		1,885,713.	33	2,060,950.
	34	Total liabilities and net assets/fund balances		1,906,929.	34	2,089,093.

Part XI Reconciliation of Net Assets

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	956,965.
2	Total expenses (must equal Part IX, column (A), line 25)	2	821,624.
3	Revenue less expenses. Subtract line 2 from line 1	3	135,341.
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	1,885,713.
5	Net unrealized gains (losses) on investments	5	39,896.
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	2,060,950.

Part XII Financial Statements and Reporting

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

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

SCHEDULE A (Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support

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

▶ **Attach to Form 990 or Form 990-EZ.**

▶ **Information about Schedule A (Form 990 or 990-EZ) and its instructions is at *www.irs.gov/form990.***

OMB No. 1545-0047

2013

Open to Public Inspection

Name of the organization	**Employer identification number**
FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES	94-2738019

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

The organization is not a private foundation because it is: (For lines 1 through 11, check only one box.)

1 ☐ A church, convention of churches, or association of churches described in **section 170(b)(1)(A)(i).**

2 ☐ A school described in **section 170(b)(1)(A)(ii).** (Attach Schedule E.)

3 ☐ A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii).**

4 ☐ A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii).** Enter the hospital's name, city, and state: _____

5 ☐ An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv).** (Complete Part II.)

6 ☐ A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v).**

7 ☒ An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi).** (Complete Part II.)

8 ☐ A community trust described in **section 170(b)(1)(A)(vi).** (Complete Part II.)

9 ☐ An 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).**

11 ☐ An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2). See **section 509(a)(3).** Check the box 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 - Non-functionally integrated

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 it 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?	11g(i)	
(ii)	A family member of a person described in (i) above?	11g(ii)	
(iii)	A 35% controlled entity of a person described in (i) or (ii) above?	11g(iii)	

h Provide the following information about the supported organization(s).

(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 monetary 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 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) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	730,575.	470,096.	571,858.	749,381.	798,176.	3320086.
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	730,575.	470,096.	571,858.	749,381.	798,176.	3320086.
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)						456,565.
6 **Public support.** Subtract line 5 from line 4.						2863521.

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
7 Amounts from line 4	730,575.	470,096.	571,858.	749,381.	798,176.	3320086.
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	20,526.	18,169.	16,651.	35,050.	41,510.	131,906.
9 Net income from unrelated business activities, whether or not the business is regularly carried on		1,224.	1,200.	1,176.	4,458.	8,058.
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)	3,917.	3,436.	4,289.	2,828.	3,851.	18,321.
11 **Total support.** Add lines 7 through 10						3478371.

12 Gross receipts from related activities, etc. (see instructions) ..... 12 199,383.

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** ..... ▶ ☐

Section C. Computation of Public Support Percentage

14 Public support percentage for 2013 (line 6, column (f) divided by line 11, column (f)) ..... 14 82.32 %

15 Public support percentage from 2012 Schedule A, Part II, line 14 ..... 15 83.29 %

16a **33 1/3% support test - 2013.** If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and **stop here.** The organization qualifies as a publicly supported organization ..... ▶ ☒

b **33 1/3% support test - 2012.** If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and **stop here.** The organization qualifies as a publicly supported organization ..... ▶ ☐

17a **10% -facts-and-circumstances test - 2013.** 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 ..... ▶ ☐

b **10% -facts-and-circumstances test - 2012.** 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 ..... ▶ ☐

18 **Private foundation.** If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions ..... ▶ ☐

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

(Complete only if you checked the box on line 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

Calendar year (or fiscal year beginning in) ▶	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")						
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 **Total.** Add lines 1 through 5						
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of $5,000 or 1% of the amount on line 13 for the year						
c Add lines 7a and 7b						
8 **Public support** (Subtract line 7c from line 6.)						

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(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 2013 (line 8, column (f) divided by line 13, column (f))	15	%
16 Public support percentage from 2012 Schedule A, Part III, line 15	16	%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for **2013** (line 10c, column (f) divided by line 13, column (f))	17	%
18 Investment income percentage from **2012** Schedule A, Part III, line 17	18	%

19a 33 1/3% support tests - 2013. 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 - 2012. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3%, and line 18 is not more than 33 1/3%, check this box and **stop here.** The organization qualifies as a publicly supported organization ▶ ☐

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

Part IV **Supplemental Information.** Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; and Part III, line 12. Also complete this part for any additional information. (See instructions).

SCHEDULE A, PART II, LINE 10, EXPLANATION FOR OTHER INCOME:

MISCELLANEOUS INCOME

2009 AMOUNT: $ 3,917.

2010 AMOUNT: $ 3,436.

2011 AMOUNT: $ 4,289.

2012 AMOUNT: $ 2,828.

2013 AMOUNT: $ 3,851.

Schedule A — Identification of Excess Contributions Included on Part II, Line 5 — 2013

** Do Not File **
*** Not Open to Public Inspection ***

Contributor's Name	Total Contributions	Excess Contributions
MICHAEL BRIGGS	119,400.	49,833.
LENNOX FOUNDATION	425,000.	355,433.
JEFF HOERLE	85,000.	15,433.
ANONYMOUS	100,000.	30,433.
GALDERMA	75,000.	5,433.

Total Excess Contributions to Schedule A, Part II, Line 5 .... 456,565.

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

Schedule of Contributors

▶ Attach to Form 990, Form 990-EZ, or Form 990-PF.
▶ Information about Schedule B (Form 990, 990-EZ, or 990-PF) and its instructions is at *www.irs.gov/form990*

OMB No. 1545-0047

2013

Name of the organization
FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES

Employer identification number
94-2738019

Organization type (check one):

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

Check if your organization is covered by the **General Rule** or a **Special Rule.**
Note. Only a section 501(c)(7), (8), or (10) organization can check boxes for both the General Rule and a Special Rule. See instructions.

General Rule

[ ] For an organization filing Form 990, 990-EZ, or 990-PF that received, during the year, $5,000 or more (in money or property) from any one contributor. Complete Parts I and II.

Special Rules

[X] For a section 501(c)(3) organization filing Form 990 or 990-EZ that met the 33 1/3% support test of the regulations under sections 509(a)(1) and 170(b)(1)(A)(vi) and received from any one contributor, during the year, a contribution of the greater of **(1)** $5,000 or **(2)** 2% of the amount on (i) Form 990, Part VIII, line 1h, or (ii) Form 990-EZ, line 1. Complete Parts I and II.

[ ] For a section 501(c)(7), (8), or (10) organization filing Form 990 or 990-EZ that received from any one contributor, during the year, total contributions of more than $1,000 for use *exclusively* for religious, charitable, scientific, literary, or educational purposes, or the prevention of cruelty to children or animals. Complete Parts I, II, and III.

[ ] For a section 501(c)(7), (8), or (10) organization filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions for use *exclusively* for religious, charitable, etc., purposes, but these contributions did not total to more than $1,000. If this box is checked, enter here the total contributions that were received during the year for an *exclusively* religious, charitable, etc., purpose. Do not complete any of the parts unless the **General Rule** applies to this organization because it received *nonexclusively* religious, charitable, etc., contributions of $5,000 or more during the year ..... ▶ $ _____

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

Name of organization	Employer identification number
FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES	94-2738019

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

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
1	LENNOX FOUNDATION 501 SILVERSIDE ROAD, SUITE 123 WILMINGTON, DE 19809-1377	$ 100,000.	Person [X] Payroll [ ] Noncash [ ] (Complete Part II for noncash contributions.)
2	ANONYMOUS 2616 N. BROAD ST COLMAR, PA 18915	$ 100,000.	Person [X] Payroll [ ] Noncash [ ] (Complete Part II for noncash contributions.)
3	GALDERMA INTERNATIONAL SAS TOUR EUROPLAZA, 20, AVENUE ANDRE PROTHIN LA DEFENSE CEDEX, FRANCE 92927	$ 75,000.	Person [X] Payroll [ ] Noncash [ ] (Complete Part II for noncash contributions.)
4	JEFF HOERLE AND ALLISON DRAPER 367 SUGAR MILL DRIVE OSPREY, FL 34229	$ 35,000.	Person [X] Payroll [ ] Noncash [ ] (Complete Part II for noncash contributions.)
5	SELECT EQUITY GROUP, INC. 380 LAFAYETTE STREET NEW YORK, NY 10003	$ 20,000.	Person [X] Payroll [ ] Noncash [ ] (Complete Part II for noncash contributions.)
6	DAVID AND VALERIE SCHOLL 4805 MAXWELL DRIVE MASON, OH 45040	$ 25,000.	Person [X] Payroll [ ] Noncash [ ] (Complete Part II for noncash contributions.)

Name of organization	Employer identification number
FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES	94-2738019

Part II **Noncash Property** (see instructions). Use duplicate copies of Part II if additional space is needed.

(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (see instructions)	(d) Date received
		$	
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (see instructions)	(d) Date received
		$	
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (see instructions)	(d) Date received
		$	
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (see instructions)	(d) Date received
		$	
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (see instructions)	(d) Date received
		$	
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (see instructions)	(d) Date received
		$	

Name of organization
FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES

Employer identification number
94-2738019

Part III *Exclusively* religious, charitable, etc., individual contributions to section 501(c)(7), (8), or (10) organizations that total more than $1,000 for the year. Complete columns (a) through (e) and the following line entry. For organizations completing Part III, enter the total of *exclusively* religious, charitable, etc., contributions of $1,000 or less for the year. (Enter this information once.) ▶ $

Use duplicate copies of Part III if additional space is needed.

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held

(e) Transfer of gift

Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held

(e) Transfer of gift

Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held

(e) Transfer of gift

Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held

(e) Transfer of gift

Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee

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.
▶ Information about Schedule D (Form 990) and its instructions is at *www.irs.gov/form990.*

OMB No. 1545-0047
2013
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.

		(a) Donor advised funds	(b) Funds and other accounts
1	Total number at end of year		
2	Aggregate contributions to (during year)		
3	Aggregate grants from (during year)		
4	Aggregate value at end of year		

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

6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit? ☐ 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 education)
☐ Protection of natural habitat
☐ Preservation of open space
☐ Preservation of an historically important land area
☐ Preservation of a certified historic structure

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

			Held at the End of the Tax Year
a	Total number of conservation easements	2a	
b	Total acreage restricted by conservation easements	2b	
c	Number of conservation easements on a certified historic structure included in (a)	2c	
d	Number of conservation easements included in (c) acquired after 8/17/06, and not on a historic structure listed in the National Register	2d	

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

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

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

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

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

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

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

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

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

1a If the organization elected, as permitted under SFAS 116 (ASC 958), not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIII, the text of the footnote to its financial statements that describes these items.

b If the organization elected, as permitted under SFAS 116 (ASC 958), to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items:

(i) 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 (ASC 958) 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 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	124,365.	124,592.	85,242.	83,567.	81,780.
b Contributions	550.	950.	39,810.		
c Net investment earnings, gains, and losses	3,819.	1,623.	1,040.	3,675.	2,587.
d Grants or scholarships					
e Other expenditures for facilities and programs	3,400.	2,800.	1,500.	2,000.	800.
f Administrative expenses					
g End of year balance	125,334.	124,365.	124,592.	85,242.	83,567.

2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:

a Board designated or quasi-endowment ▶ .00 %
b Permanent endowment ▶ 87.78 %
c Temporarily restricted endowment ▶ 12.22 %

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	3a(i)		X
(ii) related organizations	3a(ii)		X
b If "Yes" to 3a(ii), are the related organizations listed as required on Schedule R?	3b		

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

Part VI Land, Buildings, and Equipment.

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

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements				
d Equipment		28,584.	19,504.	9,080.
e Other				
Total. Add lines 1a through 1e. *(Column (d) must equal Form 990, Part X, column (B), line 10(c).)* ▶				9,080.

Part VII Investments - Other Securities.

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

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

Part VIII Investments - Program Related.

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

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

Part IX Other Assets.

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

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

Part X Other Liabilities.

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

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

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

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

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

1	Total revenue, gains, and other support per audited financial statements			1	1,018,642.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:				
a	Net unrealized gains on investments	2a	39,896.		
b	Donated services and use of facilities	2b	15,757.		
c	Recoveries of prior year grants	2c			
d	Other (Describe in Part XIII.)	2d	6,024.		
e	Add lines 2a through 2d			2e	61,677.
3	Subtract line 2e from line 1			3	956,965.
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	956,965.

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

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

1	Total expenses and losses per audited financial statements			1	843,405.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:				
a	Donated services and use of facilities	2a	15,757.		
b	Prior year adjustments	2b			
c	Other losses	2c			
d	Other (Describe in Part XIII.)	2d	6,024.		
e	Add lines 2a through 2d			2e	21,781.
3	Subtract line 2e from line 1			3	821,624.
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	821,624.

Part XIII Supplemental Information.

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

PART V, LINE 4:

EXPLANATION: 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 FIRST'S BOARD OF DIRECTORS DETERMINES THAT THE EARNINGS ARE ACCUMULATED TO A LEVEL THAT WILL ENABLE THEM TO PROVIDE RESEARCH GRANTS. EARNINGS ON THE JANE BUKATY MEMBERSHIP ASSISTANCE FUND 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 XIII Supplemental Information *(continued)*

PART X, LINE 2:

EXPLANATION: 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 2011.

PART XI, LINE 2D - OTHER ADJUSTMENTS:

REDUCTION OF SPECIAL EVENTS FOR DIRECT EXPENSES	6,024.

PART XII, LINE 2D - OTHER ADJUSTMENTS:

REDUCTION OF SPECIAL EVENTS FOR DIRECT EXPENSES	6,024.

SCHEDULE F (Form 990)

Department of the Treasury
Internal Revenue Service

Statement of Activities Outside the United States

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

▶ Attach to Form 990. ▶ See separate instructions.

▶ Information about Schedule F (Form 990) and its instructions is at *www.irs.gov/form990.*

OMB No. 1545-0047

2013

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

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

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

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

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in region	(d) Activities conducted in region (by type) (e.g., fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in region	(f) Total expenditures for and investments in region
3 a Sub-total	0	0			0.
b Total from continuation sheets to Part I	0	0			0.
c **Totals** (add lines 3a and 3b)	0	0			0.

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

1 (a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of non-cash assistance	(h) Description of non-cash assistance	(i) Method of valuation (book, FMV, appraisal, other)
		EUROPE (INCLUDING ICELAND & GREENLAND)	RESEARCH PROJECTS	50,000.	BANK WIRE TRANSFER	0.		

2 Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as tax-exempt by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter ▶ 1

3 Enter total number of other organizations or entities ▶

Part III **Grants and Other Assistance to Individuals Outside the United States.** Complete if the organization answered "Yes" on Form 990, Part IV, line 16.
Part III can be duplicated if additional space is needed.

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

Part IV Foreign Forms

1	Was the organization a U.S. transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926)*	☐ Yes	☒ No
2	Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to file Form 3520, Annual Return to Report Transactions with Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see Instructions for Forms 3520 and 3520-A)*	☐ Yes	☒ No
3	Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons With Respect To Certain Foreign Corporations. (see Instructions for Form 5471)*	☐ Yes	☒ No
4	Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund. (see Instructions for Form 8621)*	☐ Yes	☒ No
5	Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons With Respect To Certain Foreign Partnerships. (see Instructions for Form 8865)*	☐ Yes	☒ No
6	Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to file Form 5713, International Boycott Report. (see Instructions for Form 5713)*	☐ Yes	☒ No

Part V Supplemental Information

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

PART I, LINE 2:

EXPLANATION: 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 G (Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Supplemental Information Regarding Fundraising or Gaming Activities

Complete if the organization answered "Yes" to Form 990, Part IV, lines 17, 18, or 19, or if the organization entered more than $15,000 on Form 990-EZ, line 6a.

▶ **Attach to Form 990 or Form 990-EZ.**

▶ Information about Schedule G (Form 990 or 990-EZ) and its instructions is at *www.irs.gov/form990.*

OMB No. 1545-0047

2013

Open To Public Inspection

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

Employer identification number: 94-2738019

Part I **Fundraising Activities.** Complete if the organization answered "Yes" to Form 990, Part IV, line 17. Form 990-EZ filers are not required to complete this part.

1 Indicate whether the organization raised funds through any of the following activities. Check all that apply.

- **a** ☐ Mail solicitations
- **b** ☐ Internet and email solicitations
- **c** ☐ Phone solicitations
- **d** ☐ In-person solicitations
- **e** ☐ Solicitation of non-government grants
- **f** ☐ Solicitation of government grants
- **g** ☐ Special fundraising events

2 a Did the organization have a written or oral agreement with any individual (including officers, directors, trustees or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services? ☐ **Yes** ☐ **No**

b If "Yes," list the ten highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least $5,000 by the organization.

(i) Name and address of individual or entity (fundraiser)	(ii) Activity	(iii) Did fundraiser have custody or control of contributions? Yes	(iii) No	(iv) Gross receipts from activity	(v) Amount paid to (or retained by) fundraiser listed in col. (i)	(vi) Amount paid to (or retained by) organization
Total ▶						

3 List all states in which the organization is registered or licensed to solicit contributions or has been notified it is exempt from registration or licensing.

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 TESTIMONIAL DINNER (event type)	(b) Event #2 (event type)	(c) Other events NONE (total number)	(d) Total events (add col. (a) through col. (c))
Revenue	1 Gross receipts	30,800.			30,800.
	2 Less: Contributions	24,776.			24,776.
	3 Gross income (line 1 minus line 2)	6,024.			6,024.
Direct Expenses	4 Cash prizes				
	5 Noncash prizes				
	6 Rent/facility costs				
	7 Food and beverages	6,024.			6,024.
	8 Entertainment				
	9 Other direct expenses				
	10 Direct expense summary. Add lines 4 through 9 in column (d) ▶				6,024.
	11 Net income summary. Subtract line 10 from line 3, column (d) ▶				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))
Revenue	1 Gross revenue				
Direct Expenses	2 Cash prizes				
	3 Noncash prizes				
	4 Rent/facility costs				
	5 Other direct expenses				
	6 Volunteer labor	☐ Yes ____ % ☐ No	☐ Yes ____ % ☐ No	☐ Yes ____ % ☐ No	
	7 Direct expense summary. Add lines 2 through 5 in column (d) ▶				
	8 Net gaming income summary. Subtract line 7 from line 1, column (d) ▶				

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: _____

11 Does the organization operate gaming activities with nonmembers? ☐ Yes ☐ No

12 Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity formed to administer charitable gaming? ☐ Yes ☐ No

13 Indicate the percentage of gaming activity operated in:

a The organization's facility	13a	%
b An outside facility	13b	%

14 Enter the name and address of the person who prepares the organization's gaming/special events books and records:

Name ▶ _____

Address ▶ _____

15a Does the organization have a contract with a third party from whom the organization receives gaming revenue? ☐ Yes ☐ No

b If "Yes," enter the amount of gaming revenue received by the organization ▶ $ _____ and the amount of gaming revenue retained by the third party ▶ $ _____ .

c If "Yes," enter name and address of the third party:

Name ▶ _____

Address ▶ _____

16 Gaming manager information:

Name ▶ _____

Gaming manager compensation ▶ $ _____

Description of services provided ▶ _____

☐ Director/officer ☐ Employee ☐ Independent contractor

17 Mandatory distributions:

a Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license? ☐ Yes ☐ No

b Enter the amount of distributions required under state law to be distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year ▶ $

Part IV **Supplemental Information.** Provide the explanations required by Part I, line 2b, columns (iii) and (v), and Part III, lines 9, 9b, 10b, 15b, 15c, 16, and 17b, as applicable. Also complete this part to provide any additional information (see instructions).

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.

▶ Information about Schedule I (Form 990) and its instructions is at *www.irs.gov/form990.*

OMB No. 1545-0047

2013

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? ..... [X] 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
YALE UNIVERSITY YALE UNIVERSITY OFFICE OF DEVELOPMENT, PO BOX 2038 - NEW HAVEN, CT 06521-203	10-6064973	501(C)(3)	90,000.	0.			TO SUPPORT DR. KEITH CHOATE'S WORK IN DISORDERS OF KERATINIZATION RESEARCH

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 ..... ▶

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.	10	16,219.	0.		

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

SCHEDULE O (Form 990 or 990-EZ)	Supplemental Information to Form 990 or 990-EZ	OMB No. 1545-0047
Department of the Treasury Internal Revenue Service	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. ▶ Information about Schedule O (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.	2013 Open to Public Inspection

Name of the organization	Employer identification number
FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES	94-2738019

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

SUPPORT, EDUCATION, ADVOCACY AND RESEARCH FUNDING FOR BETTER TREATMENTS AND EVENTUAL CURES. HOST NATIONAL AND REGIONAL CONFERENCES FOR AFFECTED FAMILIES TO MEET OTHERS AND EXPERT PHYSICIANS.

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

Name of the organization FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES

Employer identification number 94-2738019

TRAVEL SHORT DISTANCES TO MEET OTHERS WHO SHARE THE SAME ISSUES.

EXPENSES $ 473,693. INCLUDING GRANTS OF $ 106,219. REVENUE $ 3,851.

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

EXPLANATION: 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:

EXPLANATION: 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:

EXPLANATION: 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:

EXPLANATION: GOVERNING DOCUMENTS AND CONFLICT OF INTEREST POLICY ARE

Name of the organization FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES

Employer identification number 94-2738019

AVAILABLE UPON REQUEST. FINANCIAL STATEMENTS ARE PUBLISHED ON OUR WEBSITE AND AVAILABLE THROUGH OTHER WEBSITES SUCH AS GUIDESTAR AND CHARITY NAVIGATOR.

Form **8879-EO**

Department of the Treasury
Internal Revenue Service

IRS e-file Signature Authorization for an Exempt Organization

For calendar year 2013, or fiscal year beginning OCT 1 , 2013, and ending SEP 30 ,20 14

▶ **Do not send to the IRS. Keep for your records.**

▶ **Information about Form 8879-EO and its instructions is at *www.irs.gov/form8879eo.***

OMB No. 1545-1878

2013

Name of exempt organization
FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES

Employer identification number
94-2738019

Name and title of officer
JEAN R. PICKFORD
EXECUTIVE DIRECTOR

Part I Type of Return and Return Information (Whole Dollars Only)

Check the box for the return for which you are using this Form 8879-EO and enter the applicable amount, if any, from the return. If you check the box on line **1a, 2a, 3a, 4a,** or **5a,** below, and the amount on that line for the return being filed with this form was blank, then leave line **1b, 2b, 3b, 4b,** or **5b,** whichever is applicable, blank (do not enter -0-). But, if you entered -0- on the return, then enter -0- on the applicable line below. **Do not** complete more than 1 line in Part I.

1a	Form 990 check here ▶ [X]	**b**	**Total revenue,** if any (Form 990, Part VIII, column (A), line 12)	**1b**	956,965.
2a	Form 990-EZ check here ▶ [ ]	**b**	**Total revenue,** if any (Form 990-EZ, line 9)	**2b**	
3a	Form 1120-POL check here ▶ [ ]	**b**	**Total tax** (Form 1120-POL, line 22)	**3b**	
4a	Form 990-PF check here ▶ [ ]	**b**	**Tax based on investment income** (Form 990-PF, Part VI, line 5)	**4b**	
5a	Form 8868 check here ▶ [ ]	**b**	**Balance Due** (Form 8868, Part I, line 3c or Part II, line 8c)	**5b**	

Part II Declaration and Signature Authorization of Officer

Under penalties of perjury, I declare that I am an officer of the above organization and that I have examined a copy of the organization's 2013 electronic return and accompanying schedules and statements and to the best of my knowledge and belief, they are true, correct, and complete. I further declare that the amount in Part I above is the amount shown on the copy of the organization's electronic return. I consent to allow my intermediate service provider, transmitter, or electronic return originator (ERO) to send the organization's return to the IRS and to receive from the IRS **(a)** an acknowledgement of receipt or reason for rejection of the transmission, **(b)** the reason for any delay in processing the return or refund, and **(c)** the date of any refund. If applicable, I authorize the U.S. Treasury and its designated Financial Agent to initiate an electronic funds withdrawal (direct debit) entry to the financial institution account indicated in the tax preparation software for payment of the organization's federal taxes owed on this return, and the financial institution to debit the entry to this account. To revoke a payment, I must contact the U.S. Treasury Financial Agent at 1-888-353-4537 no later than 2 business days prior to the payment (settlement) date. I also authorize the financial institutions involved in the processing of the electronic payment of taxes to receive confidential information necessary to answer inquiries and resolve issues related to the payment. I have selected a personal identification number (PIN) as my signature for the organization's electronic return and, if applicable, the organization's consent to electronic funds withdrawal.

Officer's PIN: check one box only

[X] I authorize BAUM, SMITH & CLEMENS, LLP to enter my PIN 38019

ERO firm name

Enter five numbers, but do not enter all zeros

as my signature on the organization's tax year 2013 electronically filed return. If I have indicated within this return that a copy of the return is being filed with a state agency(ies) regulating charities as part of the IRS Fed/State program, I also authorize the aforementioned ERO to enter my PIN on the return's disclosure consent screen.

[ ] As an officer of the organization, I will enter my PIN as my signature on the organization's tax year 2013 electronically filed return. If I have indicated within this return that a copy of the return is being filed with a state agency(ies) regulating charities as part of the IRS Fed/State program, I will enter my PIN on the return's disclosure consent screen.

Officer's signature ▶ _____ Date ▶ _____

Part III Certification and Authentication

ERO's EFIN/PIN. Enter your six-digit electronic filing identification number (EFIN) followed by your five-digit self-selected PIN. 23020300187

do not enter all zeros

I certify that the above numeric entry is my PIN, which is my signature on the 2013 electronically filed return for the organization indicated above. I confirm that I am submitting this return in accordance with the requirements of **Pub. 4163,** Modernized e-File (MeF) Information for Authorized IRS *e-file* Providers for Business Returns.

ERO's signature ▶ _____ Date ▶ 02/21/15

ERO Must Retain This Form - See Instructions
Do Not Submit This Form To the IRS Unless Requested To Do So