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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

2014

Open to Public Inspection

A For the 2014 calendar year, or tax year beginning 01-01-2014 , and ending 12-31-2014

B Check if applicable ☐ Address change ☐ Name change ☐ Initial return ☐ Final return/terminated ☐ Amended return ☐ Application pending	C Name of organization Everylife Foundation for Rare Diseases		D Employer identification number 26-4614274
	Doing business as		
	Number and street (or P O box if mail is not delivered to street address) Room/suite 77 Digital Drive		E Telephone number (415) 884-0223
	City or town, state or province, country, and ZIP or foreign postal code Novato, CA 94949		G Gross receipts \$ 1,351,627
	F Name and address of principal officer Emil D Kakkis MD 77 Digital Drive 210 Novato, CA 94949		
I Tax-exempt status ☒ 501(c)(3) ☐ 501(c) () ☐ (insert no) ☐ 4947(a)(1) or ☐ 527		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 ▶	
J Website: ▶ www.everylifefoundation.org			
K Form of organization ☒ Corporation ☐ Trust ☐ Association ☐ Other ▶			L Year of formation 2009
			M State of legal domicile CA

Part I	Summary																																																											
Activities & Governance	1 Briefly describe the organization’s mission or most significant activities EveryLife Foundation for Rare Dis- eases is dedicated to accelerating biotech innovation for rare disease treatments through science-driven public policy We do more with the existitng science and bring life-saving treatments to millions of people suffering from rare diseases																																																											
	2 Check this box ☐ if the organization discontinued its operations or disposed of more than 25% of its net assets																																																											
Revenue	<table><tr><td>3 Number of voting members of the governing body (Part VI, line 1a)</td><td>3</td><td>8</td></tr><tr><td>4 Number of independent voting members of the governing body (Part VI, line 1b)</td><td>4</td><td>7</td></tr><tr><td>5 Total number of individuals employed in calendar year 2014 (Part V, line 2a)</td><td>5</td><td>7</td></tr><tr><td>6 Total number of volunteers (estimate if necessary)</td><td>6</td><td></td></tr><tr><td>7a Total unrelated business revenue from Part VIII, column (C), line 12</td><td>7a</td><td>0</td></tr><tr><td>b Net unrelated business taxable income from Form 990-T, line 34</td><td>7b</td><td></td></tr></table>	3 Number of voting members of the governing body (Part VI, line 1a)	3	8	4 Number of independent voting members of the governing body (Part VI, line 1b)	4	7	5 Total number of individuals employed in calendar year 2014 (Part V, line 2a)	5	7	6 Total number of volunteers (estimate if necessary)	6		7a Total unrelated business revenue from Part VIII, column (C), line 12	7a	0	b Net unrelated business taxable income from Form 990-T, line 34	7b																																										
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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	2015-08-11 Date			
	Emil D Kakkis MD President Type or print name and title				
Paid Preparer Use Only	Print/Type preparer's name Douglas W Regalia	Preparer's signature Douglas W Regalia	Date	Check ☐ if self-employed	PTIN P00186389
	Firm's name ▶ Regalia & Associates CPAs				Firm's EIN ▶
	Firm's address ▶ 103 Town Country Dr Ste K Danville, CA 94526				Phone no (925) 314-0390

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

For Paperwork Reduction Act Notice, see the separate instructions. Cat No 11282Y Form 990 (2014)

Part III

Statement of Program Service Accomplishments

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

☐ Yes ☒ No

1

Briefly describe the organization's mission

Information regarding The Foundation's programs can be obtained at www.everylifefoundation.org

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 \$ 428,161 including grants of \$) (Revenue \$)

Rare Disease Legislative AdvocatesRare Disease Legislative Advocates (RDLA) is a collaborative organization designed to support the advocacy of all rare disease groups. RDLA works to empower the individual to become an advocate by providing informational meetings, legislative resources, advocacy tools, and special events that support organizations and advocates working to promote rare disease legislation. RDLA's goal is to bring the rare disease community together, grow the patient advocacy community and work collectively to ensure that the many voices of patients with rare diseases have an opportunity to be heard in State Government and on Capitol Hill.

4b

(Code) (Expenses \$ 424,560 including grants of \$ 111,859) (Revenue \$)

Everylife FoundationThe EveryLife Foundation for Rare Diseases is a 501(c)(3) nonprofit dedicated to accelerating biotech innovation for rare disease treatments through science-driven public policy. We can do more with the science we already have and bring life-saving treatments to millions of people suffering from rare diseases. Currently, there are fewer than 400 approved treatments for 7000 rare diseases affecting more than 30 million Americans. The science exists for many of these diseases to be treated, however, treatments may never be developed because of roadblocks in the development process, such as a lack of investment and a challenging regulatory environment. The Foundation works with Patient Organizations, Industry, Academic Scientists, the Food and Drug (continued on Schedule O)

4c

(Code) (Expenses \$ 111,316 including grants of \$) (Revenue \$ 52,069)

Italian Street Painting MarinItalian Street Painting Marin (ISPM), the Foundation's community outreach program, showcases the fine art of street painting and supports quality arts-based programs in our community, Marin County, California. ISPM holds an annual event spotlighting Madonnari (street painters) from around the world in downtown San Rafael and provides creative opportunities for community members to feature this popular performance art. The Foundation believes the arts enhance, inspire, and change lives.

4d

Other program services (Describe in Schedule O)

(Expenses \$ including grants of \$) (Revenue \$)

4e

Total program service expenses

964,037

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 Yes	
2 Is the organization required to complete Schedule B, Schedule of Contributors (see instructions)? 	2 Yes	
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	No
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 Yes	
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	No
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	No
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	No
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III 	8	No
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	No
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	No
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 Yes	
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	No
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	No
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	No
e Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X 	11e Yes	
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 Yes	
12a Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI and XII 	12a Yes	
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	No
13 Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E	13	No
14a Did the organization maintain an office, employees, or agents outside of the United States?	14a Yes	
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 Yes	
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	No
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	No
17 Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? If "Yes," complete Schedule G, Part I (see instructions)	17	No
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	No
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	No
20a Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H	20a	No
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)

21	Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>	21		No
22	Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>	22	Yes	
23	Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J</i>	23		No
24a	Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a</i>	24a		No
b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		No
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		No
d	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d		No
25a	Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i>	25a		No
b	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I</i>	25b		No
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? <i>If "Yes," complete Schedule L, Part II</i>	26		No
27	Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i>	27		No
28	Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions)			
a	A current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>	28a		No
b	A family member of a current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>	28b		No
c	An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer, director, trustee, or direct or indirect owner? <i>If "Yes," complete Schedule L, Part IV</i>	28c		No
29	Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i>	29		No
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i>	30		No
31	Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>	31		No
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II</i>	32		No
33	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If "Yes," complete Schedule R, Part I</i>	33		No
34	Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1</i>	34		No
35a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a		No
b	If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i>	35b		No
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i>	36		No
37	Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? <i>If "Yes," complete Schedule R, Part VI</i>	37		No
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	Yes	

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.		
1b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable.		
1c	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	Yes	
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return.		
2b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns? Note. If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions).	Yes	
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?		No
3b	If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation in Schedule O.		No
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)?		No
b	If "Yes," enter the name of the foreign country: See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).		
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?		No
5b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?		No
5c	If "Yes," to line 5a or 5b, did the organization file Form 8886-T?		
6a	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions?		No
6b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?		
7	Organizations that may receive deductible contributions under section 170(c).		
7a	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?		No
7b	If "Yes," did the organization notify the donor of the value of the goods or services provided?		
7c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?		No
7d	If "Yes," indicate the number of Forms 8282 filed during the year.		0
7e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?		No
7f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?		No
7g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?		No
7h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?		No
8	Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?		No
9a	Did the sponsoring organization make any taxable distributions under section 4966?		No
9b	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?		No
10	Section 501(c)(7) organizations. Enter		
10a	Initiation fees and capital contributions included on Part VIII, line 12.		
10b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities.		
11	Section 501(c)(12) organizations. Enter		
11a	Gross income from members or shareholders.		
11b	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them).		
12a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?		No
12b	If "Yes," enter the amount of tax-exempt interest received or accrued during the year.		
13	Section 501(c)(29) qualified nonprofit health insurance issuers.		
13a	Is the organization licensed to issue qualified health plans in more than one state? Note. See the instructions for additional information the organization must report on Schedule O.		No
13b	Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans.		
13c	Enter the amount of reserves on hand.		
14a	Did the organization receive any payments for indoor tanning services during the tax year?		No
14b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O.		

Part VI

Governance, Management, and Disclosure

For each "Yes" response to lines 2 through 7b below, and for a "No" response to lines 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

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	8	
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	7	
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	Yes
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	No
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?	4	No
5	Did the organization become aware during the year of a significant diversion of the organization's assets?	5	No
6	Did the organization have members or stockholders?	6	No
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	No
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	No
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following		
a	The governing body?	8a	Yes
b	Each committee with authority to act on behalf of the governing body?	8b	Yes
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	No

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	No
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	Yes
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	Yes
b	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	12b	Yes
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	Yes
13	Did the organization have a written whistleblower policy?	13	Yes
14	Did the organization have a written document retention and destruction policy?	14	Yes
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	Yes
b	Other officers or key employees of the organization	15b	Yes
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	No
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	CA
18	Section 6104 requires an organization to make its Form 1023 (or 1024 if applicable), 990, and 990-T (501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply. ☐ Own website ☒ Another's website ☒ Upon request ☐ Other (explain in Schedule O)	
19	Describe in Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year	
20	State the name, address, and telephone number of the person who possesses the organization's books and records Deborah Walter Finance Mgr 77 Digital Drive 210 Novato, CA 94949 (415) 884-0223	

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, or 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 dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W- 2/1099-MISC)	(E) Reportable compensation from related organizations (W- 2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
(1) Emil D Kakkis MD President	4 00 0 00	X		X				0	0	0
(2) Julia Jenkins Secretary & E D	40 00 0 00	X		X				141,750	0	5,418
(3) John Klock MD Treasurer	4 00 0 00	X		X				0	0	0
(4) Ritu Baral Director	2 00 0 00	X						0	0	0
(5) Mark Dant Director	2 00 0 00	X						0	0	0
(6) David Rowitch MD Director	2 00 0 00	X						0	0	0
(7) Jenny Soriano MD Director	2 00 0 00	X						0	0	0
(8) Matt Wilsey Director	2 00 0 00	X						0	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 dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			

1b	Sub-Total	▶			
c	Total from continuation sheets to Part VII, Section A	▶			
d	Total (add lines 1b and 1c)	▶	141,750		5,418

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▶1

		Yes	No
3	Did the organization list any former officer, director or trustee, key employee, or highest compensated employee on line 1a? <i>If "Yes," complete Schedule J for such individual</i>	3	No
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? <i>If "Yes," complete Schedule J for such individual</i>	4	No
5	Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? <i>If "Yes," complete Schedule J for such person</i>	5	No

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

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				
	b	Membership dues	1b				
	c	Fundraising events	1c				
	d	Related organizations	1d				
	e	Government grants (contributions)	1e				
	f	All other contributions, gifts, grants, and similar amounts not included above	1f	1,299,018			
	g	Noncash contributions included in lines 1a-1f \$					
	h	Total. Add lines 1a-1f		1,299,018			
Program Service Revenue	2a	Earned income from ISP	Business Code	18,164	18,164		
	b	Ticket Sales		34,445	34,445		
	c						
	d						
	e						
	f	All other program service revenue					
	g	Total. Add lines 2a-2f		52,609			
	Other Revenue	3	Investment income (including dividends, interest, and other similar amounts)		0		
4		Income from investment of tax-exempt bond proceeds		0			
5		Royalties		0			
6a		Gross rents	(i) Real	(ii) Personal			
		b	Less rental expenses				
		c	Rental income or (loss)				
		d	Net rental income or (loss)		0		
7a		Gross amount from sales of assets other than inventory	(i) Securities	(ii) Other			
		b	Less cost or other basis and sales expenses				
		c	Gain or (loss)				
		d	Net gain or (loss)		0		
8a		Gross income from fundraising events (not including \$ _____ of contributions reported on line 1c) See Part IV, line 18	a				
		b	Less direct expenses	b			
		c	Net income or (loss) from fundraising events		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		0		
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		0		
Miscellaneous Revenue		Business Code					
11a							
b							
c							
d	All other revenue						
e	Total. Add lines 11a-11d		0				
12	Total revenue. See Instructions		1,351,627	52,609			

Part IX

Statement of Functional Expenses

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

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

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.		(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1	Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21.	36,656	36,656		
2	Grants and other assistance to domestic individuals. See Part IV, line 22.	55,889	55,889		
3	Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16.	19,314	19,314		
4	Benefits paid to or for members.	0			
5	Compensation of current officers, directors, trustees, and key employees.	147,168	97,473	16,256	33,439
6	Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B).	0			
7	Other salaries and wages.	305,405	202,279	33,735	69,391
8	Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions).	0			
9	Other employee benefits.	39,359	26,068	4,348	8,943
10	Payroll taxes.	27,521	18,228	3,040	6,253
11	Fees for services (non-employees):				
a	Management.	0			
b	Legal.	3,600	3,600		
c	Accounting.	2,250	75	2,175	
d	Lobbying.	0			
e	Professional fundraising services. See Part IV, line 17.	0			
f	Investment management fees.	0			
g	Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O).	137,940	136,759		1,181
12	Advertising and promotion.	23,441	23,441		
13	Office expenses.	24,371	18,564	4,798	1,009
14	Information technology.	36,624	25,534	3,553	7,537
15	Royalties.	0			
16	Occupancy.	68,102	45,164	10,099	12,839
17	Travel.	48,408	48,408		
18	Payments of travel or entertainment expenses for any federal, state, or local public officials.	0			
19	Conferences, conventions, and meetings.	0			
20	Interest.	0			
21	Payments to affiliates.	0			
22	Depreciation, depletion, and amortization.	25,886	3,214	22,672	
23	Insurance.	4,386	2,762	1,624	
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	Program Events	174,357	174,357		
b	Printing and Publications	15,126	14,593	290	243
c	Telephone and internet	9,734	5,633	1,843	2,258
d	Miscellaneous	6,339	5,256	982	101
e	All other expenses	2,486	770	1,436	280
25	Total functional expenses. Add lines 1 through 24e.	1,214,362	964,037	106,851	143,474
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)		(B)
				Beginning of year		End of year
Assets	1	Cash—non-interest-bearing		179,425	1	336,111
	2	Savings and temporary cash investments			2	0
	3	Pledges and grants receivable, net			3	65,000
	4	Accounts receivable, net		36,386	4	0
	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	0
	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 instructions) Complete Part II of Schedule L			6	0
	7	Notes and loans receivable, net			7	0
	8	Inventories for sale or use			8	0
	9	Prepaid expenses and deferred charges		4,223	9	10,647
	10a	Land, buildings, and equipment cost or other basis Complete Part VI of Schedule D	10a97,114			
	b	Less accumulated depreciation	10b78,122	41,573	10c	18,992
	11	Investments—publicly traded securities			11	0
	12	Investments—other securities See Part IV, line 11			12	0
	13	Investments—program-related See Part IV, line 11			13	0
	14	Intangible assets			14	0
	15	Other assets See Part IV, line 11		32,486	15	6,228
	16	Total assets. Add lines 1 through 15 (must equal line 34)		294,093	16	436,978
Liabilities	17	Accounts payable and accrued expenses		11,165	17	19,576
	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			25	39,853
	26	Total liabilities. Add lines 17 through 25		11,165	26	59,429
Net Assets or Fund Balances	Organizations that follow SFAS 117 (ASC 958), check here ☒ and complete lines 27 through 29, and lines 33 and 34.					
	27	Unrestricted net assets		282,928	27	332,549
	28	Temporarily restricted net assets			28	45,000
	29	Permanently restricted net assets			29	
	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		282,928	33	377,549
	34	Total liabilities and net assets/fund balances		294,093	34	436,978

Part XI Reconciliation of Net Assets

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	1,351,627
2	Total expenses (must equal Part IX, column (A), line 25)	2	1,214,362
3	Revenue less expenses Subtract line 2 from line 1	3	137,265
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	282,928
5	Net unrealized gains (losses) on investments	5	
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	-42,644
10	Net assets or fund balances at end of year Combine lines 3 through 9 (must equal Part X, line 33, column (B))	10	377,549

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

SCHEDULE A
(Form 990 or 990EZ)

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

2014

Open to Public Inspection

Name of the organization Everylife Foundation for Rare Diseases	Employer identification number 26-4614274
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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 in lines 11a through 11d that describes the type of supporting organization and complete lines 11e, 11f, and 11g

a

☐

Type I. A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization **You must complete Part IV, Sections A and B.**

b

☐

Type II. A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s) **You must complete Part IV, Sections A and C.**

c

☐

Type III functionally integrated. A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions) **You must complete Part IV, Sections A, D, and E.**

d

☐

Type III non-functionally integrated. A supporting organization operated in connection with its supported organization(s) that is not functionally integrated The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions) **You must complete Part IV, Sections A and D, and Part V.**

e

☐

Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization

f

Enter the number of supported organizations _____

g

Provide the following information about the supported organization(s)

(i)Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1- 9 above or IRC section (see instructions))	(iv) Is the organization listed in your governing document?		(v) Amount of monetary support (see instructions)	(vi) Amount of other support (see instructions)
			Yes	No		
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) 2010	(b) 2011	(c) 2012	(d) 2013	(e) 2014	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")	556,934	736,576	791,676	872,694	1,299,018	4,256,898
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						0
3 The value of services or facilities furnished by a governmental unit to the organization without charge						0
4 Total. Add lines 1 through 3	556,934	736,576	791,676	872,694	1,299,018	4,256,898
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)						2,976,666
6 Public support. Subtract line 5 from line 4						1,280,232

Section B. Total Support						
Calendar year (or fiscal year beginning in) ▶	(a) 2010	(b) 2011	(c) 2012	(d) 2013	(e) 2014	(f) Total
7 Amounts from line 4	556,934	736,576	791,676	872,694	1,299,018	4,256,898
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						0
9 Net income from unrelated business activities, whether or not the business is regularly carried on						0
10 Other income Do not include gain or loss from the sale of capital assets (Explain in Part VI)						0
11 Total support Add lines 7 through 10						4,256,898
12 Gross receipts from related activities, etc (see instructions)					12	
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 2014 (line 6, column (f) divided by line 11, column (f))	14	30 070 %
15 Public support percentage for 2013 Schedule A, Part II, line 14	15	37 230 %
16a 33 1/3% support test—2014. 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—2013. 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—2014. 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 VI how the organization meets the "facts-and-circumstances" test The organization qualifies as a publicly supported organization	▶	
b 10%-facts-and-circumstances test—2013. 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 VI 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 IIISupport 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) 2010	(b) 2011	(c) 2012	(d) 2013	(e) 2014	(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) 2010	(b) 2011	(c) 2012	(d) 2013	(e) 2014	(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 VI.)						
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 2014 (line 8, column (f) divided by line 13, column (f))	15	
16 Public support percentage from 2013 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage		
17 Investment income percentage for 2014 (line 10c, column (f) divided by line 13, column (f))	17	
18 Investment income percentage from 2013 Schedule A, Part III, line 17	18	
19a 33 1/3% support tests—2014. 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—2013. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3% and line 18 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization ▶		
20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions ▶		

Part IV Supporting Organizations

(Complete only if you checked a box on line 11 of Part I. If you checked 11a of Part I, complete Sections A and B. If you checked 11b of Part I, complete Sections A and C. If you checked 11c of Part I, complete Sections A, D, and E. If you checked 11d of Part I, complete Sections A and D, and complete Part V.)

Section A. All Supporting Organizations

	Yes	No
1 Are all of the organization's supported organizations listed by name in the organization's governing documents? If "No," describe in Part VI how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.	1	
2 Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? If "Yes," explain in Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).	2	
3a Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? If "Yes," answer (b) and (c) below.	3a	
b Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? If "Yes," describe in Part VI when and how the organization made the determination.	3b	
c Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? If "Yes," explain in Part VI what controls the organization put in place to ensure such use.	3c	
4a Was any supported organization not organized in the United States ("foreign supported organization")? If "Yes" and if you checked 11a or 11b in Part I, answer (b) and (c) below.	4a	
b Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? If "Yes," describe in Part VI how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.	4b	
c Did the organization support any foreign supported organization that does not have an IRS determination under sections 501(c)(3) and 509(a)(1) or (2)? If "Yes," explain in Part VI what controls the organization used to ensure that all support to the foreign supported organization was used exclusively for section 170(c)(2)(B) purposes.	4c	
5a Did the organization add, substitute, or remove any supported organizations during the tax year? If "Yes," answer (b) and (c) below (if applicable). Also, provide detail in Part VI, including (i) the names and EIN numbers of the supported organizations added, substituted, or removed, (ii) the reasons for each such action, (iii) the authority under the organization's organizing document authorizing such action, and (iv) how the action was accomplished (such as by amendment to the organizing document).	5a	
b Type I or Type II only. Was any added or substituted supported organization part of a class already designated in the organization's organizing document?	5b	
c Substitutions only. Was the substitution the result of an event beyond the organization's control?	5c	
6 Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (a) its supported organizations, (b) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (c) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? If "Yes," provide detail in Part VI .	6	
7 Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (defined in IRC 4958(c)(3)(C)), a family member of a substantial contributor, or a 35-percent controlled entity with regard to a substantial contributor? If "Yes," complete Part I of Schedule L (Form 990).	7	
8 Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? If "Yes," complete Part II of Schedule L (Form 990).	8	
9a Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? If "Yes," provide detail in Part VI .	9a	
b Did one or more disqualified persons (as defined in line 9(a)) hold a controlling interest in any entity in which the supporting organization had an interest? If "Yes," provide detail in Part VI .	9b	
c Did a disqualified person (as defined in line 9(a)) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? If "Yes," provide detail in Part VI .	9c	
10a Was the organization subject to the excess business holdings rules of IRC 4943 because of IRC 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? If "Yes," answer b below.	10a	
b Did the organization have any excess business holdings in the tax year? (Use Schedule C, Form 4720, to determine whether the organization had excess business holdings).	10b	
11 Has the organization accepted a gift or contribution from any of the following persons?		
a A person who directly or indirectly controls, either alone or together with persons described in (b) and (c) below, the governing body of a supported organization?	11a	
b A family member of a person described in (a) above?	11b	
c A 35% controlled entity of a person described in (a) or (b) above? If "Yes" to a, b, or c, provide detail in Part VI.	11c	

Part IV

Supporting Organizations (continued)

Section B. Type I Supporting Organizations

	Yes	No
1 Did the directors, trustees, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the tax year? If "No," describe in Part VI how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove directors or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.		
2 Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised or controlled the supporting organization.		

Section C. Type II Supporting Organizations

	Yes	No
1 Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)? If "No," describe in Part VI how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s).		

Section D. All Type III Supporting Organizations

	Yes	No
1 Did the organization provide to each of its supported organizations, by the last day of the fifth month of the organization's tax year, (1) a written notice describing the type and amount of support provided during the prior tax year, (2) a copy of the Form 990 that was most recently filed as of the date of notification, and (3) copies of the organization's governing documents in effect on the date of notification, to the extent not previously provided?		
2 Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported organization(s) or (ii) serving on the governing body of a supported organization? If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).		
3 By reason of the relationship described in (2), did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year? If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.		

Section E. Type III Functionally-Integrated Supporting Organizations

1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions)			
a ☐ The organization satisfied the Activities Test. Complete line 2 below.			
b ☐ The organization is the parent of each of its supported organizations. Complete line 3 below.			
c ☐ The organization supported a governmental entity. Describe in Part VI how you supported a government entity (see instructions).			
2 <u>Activities Test</u> Answer (a) and (b) below.			
a Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.			
b Did the activities described in (a) constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.			
3 <u>Parent of Supported Organizations</u> Answer (a) and (b) below.			
a Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? Provide details in Part VI.			
b Did the organization exercise a substantial degree of direction over the policies, programs and activities of each of its supported organizations? If "Yes," describe in Part VI the role played by the organization in this regard.			

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

1 ☐ Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov 20, 1970 **See instructions.** All other Type III non-functionally integrated supporting organizations must complete Sections A through E

Section A - Adjusted Net Income		(A) Prior Year	(B) Current Year (optional)
1	Net short-term capital gain	1	
2	Recoveries of prior-year distributions	2	
3	Other gross income (see instructions)	3	
4	Add lines 1 through 3	4	
5	Depreciation and depletion	5	
6	Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions)	6	
7	Other expenses (see instructions)	7	
8	Adjusted Net Income (subtract lines 5, 6 and 7 from line 4)	8	

Section B - Minimum Asset Amount		(A) Prior Year	(B) Current Year (optional)
1	Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year)	1	
a	Average monthly value of securities	1a	
b	Average monthly cash balances	1b	
c	Fair market value of other non-exempt-use assets	1c	
d	Total (add lines 1a, 1b, and 1c)	1d	
e	Discount claimed for blockage or other factors (explain in detail in Part VI) _____		
2	Acquisition indebtedness applicable to non-exempt use assets	2	
3	Subtract line 2 from line 1d	3	
4	Cash deemed held for exempt use Enter 1-1/2% of line 3 (for greater amount, see instructions)	4	
5	Net value of non-exempt-use assets (subtract line 4 from line 3)	5	
6	Multiply line 5 by .035	6	
7	Recoveries of prior-year distributions	7	
8	Minimum Asset Amount (add line 7 to line 6)	8	

Section C - Distributable Amount			Current Year
1	Adjusted net income for prior year (from Section A, line 8, Column A)	1	
2	Enter 85% of line 1	2	
3	Minimum asset amount for prior year (from Section B, line 8, Column A)	3	
4	Enter greater of line 2 or line 3	4	
5	Income tax imposed in prior year	5	
6	Distributable Amount. Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions)	6	
7	☐ Check here if the current year is the organization's first as a non-functionally-integrated Type III supporting organization (see instructions)		

Section D - Distributions	Current Year
1 Amounts paid to supported organizations to accomplish exempt purposes	
2 Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	
3 Administrative expenses paid to accomplish exempt purposes of supported organizations	
4 Amounts paid to acquire exempt-use assets	
5 Qualified set-aside amounts (prior IRS approval required)	
6 Other distributions (describe in Part VI) See instructions	
7 Total annual distributions. Add lines 1 through 6	
8 Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI) See instructions	
9 Distributable amount for 2014 from Section C, line 6	
10 Line 8 amount divided by Line 9 amount	

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2014	(iii) Distributable Amount for 2014
1 Distributable amount for 2014 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2014 (reasonable cause required--see instructions)			
3 Excess distributions carryover, if any, to 2014			
a From 2009.			
b From 2010.			
c From 2011.			
d From 2012.			
e From 2013.			
f Total of lines 3a through e			
g Applied to underdistributions of prior years			
h Applied to 2014 distributable amount			
i Carryover from 2009 not applied (see instructions)			
j Remainder Subtract lines 3g, 3h, and 3i from 3f			
4 Distributions for 2014 from Section D, line 7 \$			
a Applied to underdistributions of prior years			
b Applied to 2014 distributable amount			
c Remainder Subtract lines 4a and 4b from 4			
5 Remaining underdistributions for years prior to 2014, if any Subtract lines 3g and 4a from line 2 (if amount greater than zero, see instructions)			
6 Remaining underdistributions for 2014 Subtract lines 3h and 4b from line 1 (if amount greater than zero, see instructions)			
7 Excess distributions carryover to 2015. Add lines 3j and 4c			
8 Breakdown of line 7			
a From 2010.			
b From 2011.			
c From 2012.			
d From 2013.			
e From 2014.			

Part VI **Supplemental Information.** Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; Part III, line 12; Part IV, Section A, lines 1, 2, 3b, 3c, 4b, 4c, 5a, 6, 9a, 9b, 9c, 11a, 11b, and 11c; Part IV, Section B, lines 1 and 2; Part IV, Section C, line 1; Part IV, Section D, lines 2 and 3; Part IV, Section E, lines 1c, 2a, 2b, 3a and 3b; Part V, line 1; Part V, Section B, line 1e; Part V Section D, lines 5, 6, and 8; and Part V, Section E, lines 2, 5, and 6. Also complete this part for any additional information. (See instructions).

Facts And Circumstances Test

Return Reference

Explanation

SCHEDULE C

(Form 990 or 990-EZ)

Department of the Treasury

Internal Revenue Service

Political Campaign and Lobbying Activities

For Organizations Exempt From Income Tax Under section 501(c) and section 527

▶ Complete if the organization is described below. ▶ Attach to Form 990 or Form 990-EZ.

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

OMB No 1545-0047

2014

Open to Public Inspection

If the organization answered "Yes" to Form 990, Part IV, Line 3, or Form 990-EZ, Part V, line 46 (Political Campaign Activities), then

- Section 501(c)(3) organizations Complete Parts I-A and B Do not complete Part I-C
- Section 501(c) (other than section 501(c)(3)) organizations Complete Parts I-A and C below Do not complete Part I-B
- Section 527 organizations Complete Part I-A only

If the organization answered "Yes" to Form 990, Part IV, Line 4, or Form 990-EZ, Part VI, line 47 (Lobbying Activities), then

- Section 501(c)(3) organizations that have filed Form 5768 (election under section 501(h)) Complete Part II-A Do not complete Part II-B
- Section 501(c)(3) organizations that have NOT filed Form 5768 (election under section 501(h)) Complete Part II-B Do not complete Part II-A

If the organization answered "Yes" to Form 990, Part IV, Line 5 (Proxy Tax) (see separate instructions) or Form 990-EZ, Part V, line 35c (Proxy Tax) (see separate instructions), then

- Section 501(c)(4), (5), or (6) organizations Complete Part III

Name of the organization Everylife Foundation for Rare Diseases	Employer identification number 26-4614274
--	--

Part I-A Complete if the organization is exempt under section 501(c) or is a section 527 organization.

1	Provide a description of the organization's direct and indirect political campaign activities in Part IV	
2	Political expenditures	▶ \$ 698
3	Volunteer hours	

Part I-B Complete if the organization is exempt under section 501(c)(3).

1	Enter the amount of any excise tax incurred by the organization under section 4955	▶ \$	
2	Enter the amount of any excise tax incurred by organization managers under section 4955	▶ \$	
3	If the organization incurred a section 4955 tax, did it file Form 4720 for this year?		☐ Yes ☒ No
4a	Was a correction made?		☐ Yes ☒ No
b	If "Yes," describe in Part IV		

Part I-C Complete if the organization is exempt under section 501(c), except section 501(c)(3).

1	Enter the amount directly expended by the filing organization for section 527 exempt function activities	▶ \$	
2	Enter the amount of the filing organization's funds contributed to other organizations for section 527 exempt function activities	▶ \$	
3	Total exempt function expenditures Add lines 1 and 2 Enter here and on Form 1120-POL, line 17b	▶ \$	
4	Did the filing organization file Form 1120-POL for this year?		☐ Yes ☐ No
5	Enter the names, addresses and employer identification number (EIN) of all section 527 political organizations to which the filing organization made payments For each organization listed, enter the amount paid from the filing organization's funds Also enter the amount of political contributions received that were promptly and directly delivered to a separate political organization, such as a separate segregated fund or a political action committee (PAC) If additional space is needed, provide information in Part IV		

(a) Name	(b) Address	(c) EIN	(d) Amount paid from filing organization's funds If none, enter -0-	(e) Amount of political contributions received and promptly and directly delivered to a separate political organization If none, enter -0-

Part II-A

Complete if the organization is exempt under section 501(c)(3) and filed Form 5768 (election under section 501(h)).

- A
- Check ☐ if the filing organization belongs to an affiliated group (and list in Part IV each affiliated group member's name, address, EIN, expenses, and share of excess lobbying expenditures)
- B
- Check ☐ if the filing organization checked box A and "limited control" provisions apply

Limits on Lobbying Expenditures (The term "expenditures" means amounts paid or incurred.)		(a) Filing organization's totals	(b) Affiliated group totals												
1a Total lobbying expenditures to influence public opinion (grass roots lobbying)		698													
b Total lobbying expenditures to influence a legislative body (direct lobbying)															
c Total lobbying expenditures (add lines 1a and 1b)		698													
d Other exempt purpose expenditures		1,213,664													
e Total exempt purpose expenditures (add lines 1c and 1d)		1,214,362													
f Lobbying nontaxable amount Enter the amount from the following table in both columns		196,436													
<table><tr><th>If the amount on line 1e, column (a) or (b) is:</th><th>The lobbying nontaxable amount is:</th></tr><tr><td>Not over \$500,000</td><td>20% of the amount on line 1e</td></tr><tr><td>Over \$500,000 but not over \$1,000,000</td><td>\$100,000 plus 15% of the excess over \$500,000</td></tr><tr><td>Over \$1,000,000 but not over \$1,500,000</td><td>\$175,000 plus 10% of the excess over \$1,000,000</td></tr><tr><td>Over \$1,500,000 but not over \$17,000,000</td><td>\$225,000 plus 5% of the excess over \$1,500,000</td></tr><tr><td>Over \$17,000,000</td><td>\$1,000,000</td></tr></table>		If the amount on line 1e, column (a) or (b) is:	The lobbying nontaxable amount is:	Not over \$500,000	20% of the amount on line 1e	Over \$500,000 but not over \$1,000,000	\$100,000 plus 15% of the excess over \$500,000	Over \$1,000,000 but not over \$1,500,000	\$175,000 plus 10% of the excess over \$1,000,000	Over \$1,500,000 but not over \$17,000,000	\$225,000 plus 5% of the excess over \$1,500,000	Over \$17,000,000	\$1,000,000		
If the amount on line 1e, column (a) or (b) is:	The lobbying nontaxable amount is:														
Not over \$500,000	20% of the amount on line 1e														
Over \$500,000 but not over \$1,000,000	\$100,000 plus 15% of the excess over \$500,000														
Over \$1,000,000 but not over \$1,500,000	\$175,000 plus 10% of the excess over \$1,000,000														
Over \$1,500,000 but not over \$17,000,000	\$225,000 plus 5% of the excess over \$1,500,000														
Over \$17,000,000	\$1,000,000														
g Grassroots nontaxable amount (enter 25% of line 1f)		49,109													
h Subtract line 1g from line 1a If zero or less, enter -0-															
i Subtract line 1f from line 1c If zero or less, enter -0-															
j If there is an amount other than zero on either line 1h or line 1i, did the organization file Form 4720 reporting section 4911 tax for this year?		☐ Yes ☒ No													

4-Year Averaging Period Under section 501(h)
(Some organizations that made a section 501(h) election do not have to complete all of the five columns below. See the separate instructions for lines 2a through 2f.)

Lobbying Expenditures During 4-Year Averaging Period					
Calendar year (or fiscal year beginning in)	(a) 2011	(b) 2012	(c) 2013	(d) 2014	(e) Total
2a Lobbying nontaxable amount	139,950	169,679	150,444	196,436	656,509
b Lobbying ceiling amount (150% of line 2a, column(e))					984,764
c Total lobbying expenditures	47,946	100,774	5,000	698	154,418
d Grassroots nontaxable amount	34,988	42,420	37,611	49,109	164,128
e Grassroots ceiling amount (150% of line 2d, column (e))					246,192
f Grassroots lobbying expenditures				698	698

Part II-B

Complete if the organization is exempt under section 501(c)(3) and has NOT filed Form 5768 (election under section 501(h)).

For each "Yes" response to lines 1a through 1i below, provide in Part IV a detailed description of the lobbying activity.		(a)		(b)
		Yes	No	Amount
1	During the year, did the filing organization attempt to influence foreign, national, state or local legislation, including any attempt to influence public opinion on a legislative matter or referendum, through the use of			
a	Volunteers?			
b	Paid staff or management (include compensation in expenses reported on lines 1c through 1i)?			
c	Media advertisements?			
d	Mailings to members, legislators, or the public?			
e	Publications, or published or broadcast statements?			
f	Grants to other organizations for lobbying purposes?			
g	Direct contact with legislators, their staffs, government officials, or a legislative body?			
h	Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means?			
i	Other activities?			
j	Total. Add lines 1c through 1i.			
2a	Did the activities in line 1 cause the organization to be not described in section 501(c)(3)?			
b	If "Yes," enter the amount of any tax incurred under section 4912.			
c	If "Yes," enter the amount of any tax incurred by organization managers under section 4912.			
d	If the filing organization incurred a section 4912 tax, did it file Form 4720 for this year?			

Part III-A

Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6).

1	Were substantially all (90% or more) dues received nondeductible by members?	1	Yes	No
2	Did the organization make only in-house lobbying expenditures of \$2,000 or less?	2		
3	Did the organization agree to carry over lobbying and political expenditures from the prior year?	3		

Part III-B

Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered "No" OR (b) Part III-A, line 3, is answered "Yes."

1	Dues, assessments and similar amounts from members	1	
2	Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid).		
a	Current year	2a	
b	Carryover from last year	2b	
c	Total	2c	
3	Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues	3	
4	If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditure next year?	4	
5	Taxable amount of lobbying and political expenditures (see instructions)	5	

Part IV

Supplemental Information

Provide the descriptions required for Part I-A, line 1, Part I-B, line 4, Part I-C, line 5, Part II-A (affiliated group list), Part II-A, lines 1 and 2 (see instructions), and Part II-B, line 1. Also, complete this part for any additional information.

Return Reference	Explanation

[illegible]

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

2014

Open to Public Inspection

Name of the organization Everylife Foundation for Rare Diseases	Employer identification number 26-4614274
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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 value of contributions to (during year)	
3	Aggregate value of grants from (during year)	
4	Aggregate value at end of year	
5	Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control? ☐ 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) ☐ Preservation of an historically important land area
☐ Protection of natural habitat ☐ Preservation of a certified historic structure
☐ Preservation of open space

2

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

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

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) Revenue 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

Revenue included in Form 990, Part VIII, line 1

► \$ _____

b

Assets included in Form 990, Part X

► \$ _____

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

Cat No 52283D

Schedule D (Form 990) 2014

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 |
| 1c | |
| 1d | |
| 1e | |
| 1f | |

c

Beginning balance

d

Additions during the year

e

Distributions during the year

f

Ending balance
- 2a

Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability?

☐ Yes

☐ No
- b

If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided 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	b (c)Two years back	(d)Three years back	(e)Four years back
1a	Beginning of year balance				
b	Contributions				
c	Net investment earnings, gains, and losses				
d	Grants or scholarships				
e	Other expenditures for facilities and programs				
f	Administrative expenses				
g	End of year balance				

2

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

a

Board designated or quasi-endowment

b

Permanent endowment

c

Temporarily restricted endowment

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

(i) unrelated organizations

3a(i)

(ii) related organizations

3a(ii)

b

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

3b

4

Describe in Part 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	30,921		20,387	10,534
d Equipment	66,193		57,735	8,458
e Other				
Total. Add lines 1a through 1e (Column (d) must equal Form 990, Part X, column (B), line 10(c).)				18,992

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	1,306,627
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12	2e	
a	Net unrealized gains (losses) on investments	2a	
b	Donated services and use of facilities	2b	
c	Recoveries of prior year grants	2c	
d	Other (Describe in Part XIII)	2d	
e	Add lines 2a through 2d	2e	
3	Subtract line 2e from line 1	3	1,306,627
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1	4c	45,000
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIII)	4b	45,000
c	Add lines 4a and 4b	4c	
5	Total revenue Add lines 3 and 4c. (This must equal Form 990, Part I, line 12)	5	1,351,627

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	1,214,362
2	Amounts included on line 1 but not on Form 990, Part IX, line 25	2e	
a	Donated services and use of facilities	2a	
b	Prior year adjustments	2b	
c	Other losses	2c	
d	Other (Describe in Part XIII)	2d	
e	Add lines 2a through 2d	2e	
3	Subtract line 2e from line 1	3	1,214,362
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:	4c	
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	
5	Total expenses Add lines 3 and 4c. (This must equal Form 990, Part I, line 18)	5	1,214,362

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.

Return Reference	Explanation
Part X FIN48 Footnote	Income TaxesFinancial statement presentation follows the recommendations of ASC 740, Income Taxes. Under ASC 740, the Foundation is required to report information regarding its exposure to various tax positions taken by the Foundation and requires a two-step process that separates recognition from measurement. The first step is determining whether a tax position has met the recognition threshold, the second step is measuring a tax position that meets the recognition threshold. Management believes that the Foundation has adequately evaluated its current tax positions and has concluded that as of December 31, 2014, the Foundation does not have any uncertain tax positions for which a reserve or an accrual for a tax liability would be necessary. The Foundation has received notification from the Internal Revenue Service and the State of California that it qualifies for tax-exempt status under Section 501(c)(3) of the Internal Revenue Code and Section 23701d of the California Revenue and Taxation Code. The exemptions are subject to periodic review by the federal and state taxing authorities and management is confident that the Foundation continues to satisfy all federal and state statutes in order to qualify for continued tax exemption status. The Foundation may periodically receive unrelated business income (such as sublease rental income) requiring the Foundation to file separate tax returns under federal and state statutes. Under such conditions, the Foundation calculates and accrues the applicable taxes.
Part XI, Line 4b Other revenue amounts included on 990 but not included in F/S	Temp Restricted Contributions \$45000

[illegible]

SCHEDULE F
(Form 990)

Department of the Treasury
Internal Revenue Service

Statement of Activities Outside the United States

► Complete if the organization answered "Yes" to Form 990,
Part IV, line 14b, 15, or 16.
► Attach to Form 990.
► Information about Schedule F (Form 990) and its instructions is at www.irs.gov/form990.

OMB No 1545-0047

2014

Open to Public Inspection

Name of the organization
Everylife Foundation for Rare Diseases

Employer identification number
26-4614274

Part I

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

- 1 For grantmakers. Does the organization maintain records to substantiate the amount of its grants and other assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? ☒ Yes ☐ No
- 2 For grantmakers. Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.
- 3 Activites 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
(1) Canada	0	0	Disease Research	Grant Award	6,000
(2) France	0	0	Disease Research	Grant Award	13,314
(3)					
(4)					
(5)					
3a Sub-total					19,314
b Total from continuation sheets to Part I					
c Totals (add lines 3a and 3b)					19,314

Part II

Grants and Other Assistance to Organizations or Entities Outside the United States. Complete if the organization answered "Yes" to 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)
(1)									
(2)									
(3)									
(4)									

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 ▶

2

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" to 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)
(1)							
(2)							
(3)							
(4)							
(5)							
(6)							
(7)							
(8)							
(9)							
(10)							
(11)							
(12)							
(13)							
(14)							
(15)							
(16)							
(17)							
(18)							

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; do not file with Form 990)*

☐ Yes

☒ No
- 3

Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons with Respect to Certain Foreign Corporations. (see Instructions for Form 5471)*

☐ Yes

☒ No
- 4

Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund. (see Instructions for Form 8621)*

☐ Yes

☒ No
- 5

Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons with Respect to Certain Foreign Partnerships. (see Instructions for Form 8865)*

☐ Yes

☒ No
- 6

Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to file Form 5713, International Boycott Report (see Instructions for Form 5713; do not file with Form 990)*

☐ Yes

☒ No

Part V

Supplemental Information

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

990 Schedule F, Supplemental Information

Return Reference	Explanation
Part I, Line 2 - Grantmakers Explanation For Monitoring Use of Funds Outside US	A budget is prepared in advance of all grants earmarked for nternational recipients. Individuals working in the designated foreign countries provide ongoing reports regarding progress of work. Expenditures are made against budget amounts and analyzed continuously by US-based management. Discussions, e-mails, and other techniques of communication are employed to ensure that funds are utilized according to the original intent. Accomplishments are documented in writing and submitted by field volunteers to the head office.

990 Schedule F, Supplemental Information

Return Reference	Explanation
Part I, Line 3f - Method of Accounting	Cash basis method of accounting is used for grants to foreign entities

Schedule I
(Form 990)

Department of the Treasury
Internal Revenue Service

Name of the organization
Everylife Foundation for Rare Diseases

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

2014

Open to Public
Inspection

Employer identification number
26-4614274

Part I

General Information on Grants and Assistance

- 1

Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance?

☐ Yes ☒ No
- 2

Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States

Part II

Grants and Other Assistance to Domestic Organizations and Domestic Governments. Complete if the organization answered "Yes" 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.

(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

2

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

0

3

Enter total number of other organizations listed in the line 1 table

0

Part III

Grants and Other Assistance to Domestic Individuals. 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
(1) Awards and Scholarships	109	55,889			

Part IV

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

Return Reference	Explanation
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SCHEDULE O
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

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

▶ Attach to Form 990 or 990-EZ.

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

OMB No 1545-0047

2014

**Open to Public
Inspection**

Name of the organization Everylife Foundation for Rare Diseases	Employer identification number 26-4614274
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Return Reference	Explanation
Form 990, Part III, Line 4d Other Program Services Description	OTHER PROGRAM SERVICES 4 Everylife Foundation (continued from Form 990 Page 2)Administration (FDA), and National Institutes of Health (NIH) to improve the clinical development process through our CureTheProcess Campaign, Rare Disease Workshop Series, and legislation The Foundation was the driving force behind the grassroots movement that ensured the ULTRA/FAST language, to improve access to the FDAs Accelerated Approval pathway for rare diseases, was included into the FDASIA final bill, which was signed by the President in July of 2012 The Foundation is working with rare disease stakeholders, Congress and the FDA to ensure the timely implementation of the legislation While the Foundation remains mainly focused on regulatory issues, it also works to grow the rare disease community by spearheading programs that fulfill unmet need for patients and by supporting other organizations working to help empower the rare disease community

Return Reference	Explanation
Form 990, Part VI, Line 2 Description of Business or Family Relationship of Officers, Directors, Et	Jenny Soriano, MD , a member of the Board of Directors, is the wife of Emil D Kakkis, MD , President and Founder of the organization

Return Reference	Explanation
Form 990, Part VI, Line 11b Form 990 Review Process	FORM 990 IS PREPARED BY AN OUTSIDE TAX PROFESSIONAL THE FORM IS THEN REVIEWED BY THE ORGANIZATION'S MANAGEMENT, A MEMBER OF THE BOARD OF DIRECTORS, AND THE EXECUTIVEDIRECTOR THIS GROUP OF INDIVIDUALS THEN DISCUSSES THE CONTENTS OF THE RETURN WITHTHE OUTSIDE TAX PROFESSIONAL AFTER A FULL REVIEW (WITH MODIFICATIONS WHERE NECESSARY), THE FINAL VERSION OF THE TAX RETURN IS PROVIDED TO ALL MEMBERS OF THE ORGANIZATION'S VOTING BODY A REPRESENTATIVE OF MANAGEMENT AUTHORIZES THE FINAL FORM 990 WHICH IS THEN E-FILED WITH THE INTERNAL REVENUE SERVICE

Return Reference	Explanation
Form 990, Part VI, Line 12c Explanation of Monitoring and Enforcement of Conflicts	MEMBERS OF THE BOARD OF DIRECTORS REVIEW ALL POTENTIAL CONFLICTS OF INTEREST ATLEAST ANNUALLY ALL PERSONNEL AND BOARD MEMBERS ARE REQUIRED TO DISCLOSE (INWRITING) POTENTIAL CONFLICTS AND ANY RELATED PARTY AFFILIATIONS LOANS BETWEEN THEORGANIZATION AND MEMBERS OF MANAGEMENT AND THE BOARD ARE STRICTLY PROHIBITED THEORGANIZATION SEEKS FULL TRANSPARENCY ON ALL RELATIONSHIPS ANY POTENTIAL CONFLICTS (IN FACT OR APPEARANCE) ARE DISCUSSED OPENLY AND RESOLVED IN ACCORDANCE WITH THE ORGANIZATION'S POLICIES AND PROCEDURES

Return Reference	Explanation
Form 990, Part VI, Line 15a Compensation Review & Approval Process - CEO, Top Management	MEMBERS OF THE BOARD OF DIRECTORS REVIEW THE COMPENSATION OF ALL HIGH-LEVEL PERSONNEL PERIODICALLY IN ACCORDANCE WITH IRS RULES AND REGULATIONS. EFFORTS ARE MADE TO SECURE COMPENSATION DATA FROM INDUSTRY SOURCES IN ORDER TO DETERMINE COMPETITIVENESS AND APPROPRIATENESS OF SALARIES. EVERY EFFORT IS MADE TO ENSURE THAT THE PROCESS IS THOROUGH AND TRANSPARENT IN ACCORDANCE WITH IRS GUIDELINES AND THE ORGANIZATION'S POLICIES AND PROCEDURES.

Return Reference	Explanation
Form 990, Part VI, Line 15b Compensation Review and Approval Process for Officers and Key Employees	COMPENSATION OF OTHER HIGH-LEVEL PERSONNEL AND KEY EMPLOYEES IS REVIEWED PERIODICALLY BY MEMBERS OF MANAGEMENT. EFFORTS ARE MADE TO SECURE COMPENSATION DATA FROM INDUSTRY SOURCES IN ORDER TO DETERMINE COMPETITIVENESS AND APPROPRIATENESS OF SALARIES AND ALL RELATED BENEFITS. ALL DECISIONS ARE THEN DOCUMENTED IN PERSONNEL FILES.

Return Reference	Explanation
Form 990, Part VI, Line 19 Other Organization Documents Publicly Available	ALL OF THE ORGANIZATION'S GOVERNING DOCUMENTS, FINANCIAL STATEMENTS AND OTHER LEGAL FILINGS ARE MAINTAINED IN A SECURE ENVIRONMENT AND HELD AVAILABLE FOR INSPECTION BY TAX AUTHORITIES AND THE GENERAL PUBLIC. TAX RETURNS ARE POSTED ANNUALLY TO WWW.GUIDESTAR.ORG (WHERE THEY ARE AVAILABLE FOR VIEWING AS ELECTRONIC COPIES) AND ARE ALSO AVAILABLE AT THE ORGANIZATION'S OFFICE IN NOVATO, CALIFORNIA (FOR A PHYSICAL INSPECTION).

Return Reference	Explanation
Other Changes In Net Assets Or Fund Balances - Other Decreases	Prior year adjustments = -\$42644