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Form **990**

(Rev. January 2020)

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

OMB No 1545-0047

2019Open to Public
Inspection**A** For the 2019 calendar year, or tax year beginning , 2019, and ending**B** Check if applicable

- ☐ Address change
☐ Name change
☐ Initial return
☐ Final return/terminated
☐ Amended return
☐ Application pending

C EVERYLIFE FOUNDATION FOR RARE DISEASES
 1012 14TH STREET NW #500
 WASHINGTON, DC 20005

D Employer identification number

26-4614274

E Telephone number

(202) 697-7273

G Gross receipts \$ 4,838,888.

F Name and address of principal officer JULIA JENKINS
 SAME AS C ABOVE

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)

I Tax-exempt status ☒ 501(c)(3) ☐ 501(c) () (insert no.) ☐ 4947(a)(1) or ☐ 527 **3****J** Website: WWW.EVERYLIFEFOUNDATION.ORG**H(c)** Group exemption number**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: THE EVERYLIFE FOUNDATION FOR RARE DISEASES IS DEDICATED TO ADVANCING THE DEVELOPMENT OF TREATMENT AND DIAGNOSTIC OPPORTUNITIES FOR RARE DISEASE PATIENTS THROUGH SCIENCE-DRIVEN PUBLIC POLICY.	
	2	Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.	
	3	Number of voting members of the governing body (Part VI, line 1a)	8
	4	Number of independent voting members of the governing body (Part VI, line 1b)	7
	5	Total number of individuals employed in calendar year 2019 (Part V, line 2a)	18
	6	Total number of volunteers (estimate if necessary)	12
	7a	Total unrelated business revenue from Part VIII, column (C), line 2	0.
	b	Net unrelated business taxable income from Form 990-T, line 39	0.
Revenue	8	Contributions and grants (Part VIII, line 1h)	Prior Year 2,842,619. Current Year 4,718,319.
	9	Program service revenue (Part VIII, line 2g)	72,398. 42,955.
	10	Investment income (Part VIII, column (A), lines 3, 4, and 7d)	177. 429.
	11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	1,972. 49,505.
	12	Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	2,917,166. 4,811,208.
Expenses	13	Grants and similar amounts paid (Part IX, column (A), lines 1-3)	162,600. 219,503.
	14	Benefits paid to or for members (Part IX, column (A), line 4)	
	15	Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	1,231,677. 1,449,425.
	16a	Professional fundraising fees (Part IX, column (A), line 11e)	
	b	Total fundraising expenses (Part IX, column (D), line 25) 240,854.	
	17	Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	1,120,748. 1,627,027.
	18	Total expenses Add lines 13-17 (must equal Part IX, column (A), line 25)	2,515,025. 3,295,955.
	19	Revenue less expenses. Subtract line 18 from line 12	402,141. 1,515,253.
Net Assets or Fund Balances	20	Total assets (Part X, line 16)	Beginning of Current Year 1,672,693. End of Year 3,488,491.
	21	Total liabilities (Part X, line 26)	601,405. 888,065.
	22	Net assets or fund balances Subtract line 21 from line 20	1,071,288. 2,600,426.

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 <i>[Signature]</i> Date 9/14/2020				
	JULIA JENKINS EXECUTIVE DIRECTOR Type or print name and title				
Paid Preparer Use Only	Print/Type preparer's name	Preparer's signature	Date	Check <input type="checkbox"/> if self-employed	PTIN
	CHRIS SCHOLTES, CPA	<i>Chris Scholtes</i>	8/31/2020		P01607734
	Firm's name	C.E.A. SCHOLTES AND ASSOCIATES			
	Firm's address	106 TUNBRIDGE RD BALTIMORE, MD 21212			
				Firm's EIN	03-0483170
				Phone no	410-323-0010

May the IRS discuss this return with the preparer shown above? (see instructions)

☒ Yes ☐ No

BAA For Paperwork Reduction Act Notice, see the separate instructions.

TEEA0101L 01/21/20

Form 990 (2019)

SCANNED JUL 01 2021

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Part III Statement of Program Service Accomplishments

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

☒

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 \$ 1,042,274. including grants of \$ 35,120.) (Revenue \$)
 SEE SCHEDULE O

4b (Code) (Expenses \$ 815,693. including grants of \$ 100,971.) (Revenue \$)
 RARE DISEASE LEGISLATIVE ADVOCATES - RARE DISEASE LEGISLATIVE ADVOCATES (RDLA) IS A COLLABORATIVE PROGRAM 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.

4c (Code) (Expenses \$ 407,846. including grants of \$ 83,411.) (Revenue \$ 42,955.)
 ITALIAN STREET PAINTING MARIN - ITALIAN STREET PAINTING MARIN (ISPM), A LOCAL 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 on Schedule O) SEE SCHEDULE O
 (Expenses \$ including grants of \$) (Revenue \$ 4,652.)

4e Total program service expenses ▶ 2,265,813.

OJABCDGI

Part IV Checklist of Required Schedules

	Yes	No
1 Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? If 'Yes,' complete Schedule A	X	
2 Is the organization required to complete Schedule B, Schedule of Contributors (see instructions)?	X	
3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If 'Yes,' complete Schedule C, Part I		X
4 Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? If 'Yes,' complete Schedule C, Part II	X	
5 Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? If 'Yes,' complete Schedule C, Part III		X
6 Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? If 'Yes,' complete Schedule D, Part I		X
7 Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? If 'Yes,' complete Schedule D, Part II		X
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? If 'Yes,' complete Schedule D, Part III		X
9 Did the organization report an amount in Part X, line 21, 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		X
10 Did the organization, directly or through a related organization, hold assets in donor-restricted endowments or in quasi endowments? If 'Yes,' complete Schedule D, Part V		X
11 If the organization's answer to any of the following questions is 'Yes,' then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable		
a Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If 'Yes,' complete Schedule D, Part VI	X	
b Did the organization report an amount for investments – other securities in Part X, line 12, that is 5% or more of its total assets reported in Part X, line 16? If 'Yes,' complete Schedule D, Part VII		X
c Did the organization report an amount for investments – program related in Part X, line 13, that is 5% or more of its total assets reported in Part X, line 16? If 'Yes,' complete Schedule D, Part VIII		X
d Did the organization report an amount for other assets in Part X, line 15, that is 5% or more of its total assets reported in Part X, line 16? If 'Yes,' complete Schedule D, Part IX		X
e Did the organization report an amount for other liabilities in Part X, line 25? If 'Yes,' complete Schedule D, Part X	X	
f Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? If 'Yes,' complete Schedule D, Part X	X	
12a Did the organization obtain separate, independent audited financial statements for the tax year? If 'Yes,' complete Schedule D, Parts XI and XII	X	
b Was the organization included in consolidated, independent audited financial statements for the tax year? If 'Yes,' and if the organization answered 'No' to line 12a, then completing Schedule D, Parts XI and XII is optional		X
13 Is the organization a school described in section 170(b)(1)(A)(ii)? If 'Yes,' complete Schedule E		X
14a Did the organization maintain an office, employees, or agents outside of the United States?		X
b Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? If 'Yes,' complete Schedule F, Parts I and IV		X
15 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? If 'Yes,' complete Schedule F, Parts II and IV		X
16 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? If 'Yes,' complete Schedule F, Parts III and IV		X
17 Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? If 'Yes,' complete Schedule G, Part I (see instructions)		X
18 Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? If 'Yes,' complete Schedule G, Part II	X	
19 Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? If 'Yes,' complete Schedule G, Part III		X
20a Did the organization operate one or more hospital facilities? If 'Yes,' complete Schedule H		X
b If 'Yes' to line 20a, did the organization attach a copy of its audited financial statements to this return?		
21 Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? If 'Yes,' complete Schedule I, Parts I and II		X

Part IV Checklist of Required Schedules (continued)

	Yes	No
22 Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? If 'Yes,' complete Schedule I, Parts I and III	X	
23 Did the organization answer 'Yes' to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? If 'Yes,' complete Schedule J	X	
24a Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? If 'Yes,' answer lines 24b through 24d and complete Schedule K. If 'No,' go to line 25a		X
24b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?		
24c Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?		
24d Did the organization act as an 'on behalf of' issuer for bonds outstanding at any time during the year?		
25a Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? If 'Yes,' complete Schedule L, Part I		X
25b Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? If 'Yes,' complete Schedule L, Part I		X
26 Did the organization report any amount on Part X, line 5 or 22, for receivables from or payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons? If 'Yes,' complete Schedule L, Part II		X
27 Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity (including an employee thereof) or family member of any of these persons? If 'Yes,' complete Schedule L, Part III		X
28 Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions, for applicable filing thresholds, conditions, and exceptions)		
28a A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? If 'Yes,' complete Schedule L, Part IV		X
28b A family member of any individual described in line 28a? If 'Yes,' complete Schedule L, Part IV		X
28c A 35% controlled entity of one or more individuals and/or organizations described in lines 28a or 28b? If 'Yes,' complete Schedule L, Part IV		X
29 Did the organization receive more than \$25,000 in non-cash contributions? If 'Yes,' complete Schedule M		X
30 Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? If 'Yes,' complete Schedule M		X
31 Did the organization liquidate, terminate, or dissolve and cease operations? If 'Yes,' complete Schedule N, Part I		X
32 Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If 'Yes,' complete Schedule N, Part II		X
33 Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? If 'Yes,' complete Schedule R, Part I		X
34 Was the organization related to any tax-exempt or taxable entity? If 'Yes,' complete Schedule R, Part II, III, or IV, and Part V, line 1		X
35a Did the organization have a controlled entity within the meaning of section 512(b)(13)?		X
35b If 'Yes' to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? If 'Yes,' complete Schedule R, Part V, line 2		
36 Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? If 'Yes,' complete Schedule R, Part V, line 2		X
37 Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? If 'Yes,' complete Schedule R, Part VI		X
38 Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? Note: All Form 990 filers are required to complete Schedule O	X	

Part V Statements Regarding Other IRS Filings and Tax ComplianceCheck if Schedule O contains a response or note to any line in this Part V ☐

	Yes	No
1 a Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable		
1 b Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable		
1 c Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	X	

Part V Statements Regarding Other IRS Filings and Tax Compliance (continued)

	Yes	No
2 a Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return	2 a	18
b If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	2 b	X
Note: If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)		
3 a Did the organization have unrelated business gross income of \$1,000 or more during the year?	3 a	X
b If 'Yes,' has it filed a Form 990-T for this year? If 'No' to line 3b, provide an explanation on Schedule O	3 b	
4 a At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?	4 a	X
b If 'Yes,' enter the name of the foreign country		
See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR)		
5 a Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5 a	X
b Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5 b	X
c If 'Yes,' to line 5a or 5b, did the organization file Form 8886-T?	5 c	
6 a 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?	6 a	X
b If 'Yes,' did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	6 b	
7 Organizations that may receive deductible contributions under section 170(c).		
a Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?	7 a	X
b If 'Yes,' did the organization notify the donor of the value of the goods or services provided?	7 b	X
c Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?	7 c	X
d If 'Yes,' indicate the number of Forms 8282 filed during the year	7 d	
e Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	7 e	X
f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7 f	X
g If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	7 g	
h If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?	7 h	
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?	8	
9 Sponsoring organizations maintaining donor advised funds.		
a Did the sponsoring organization make any taxable distributions under section 4966?	9 a	
b Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?	9 b	
10 Section 501(c)(7) organizations. Enter		
a Initiation fees and capital contributions included on Part VIII, line 12	10 a	
b Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities	10 b	
11 Section 501(c)(12) organizations. Enter		
a Gross income from members or shareholders	11 a	
b Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them)	11 b	
12 a Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?	12 a	
b If 'Yes,' enter the amount of tax-exempt interest received or accrued during the year	12 b	
13 Section 501(c)(29) qualified nonprofit health insurance issuers.		
a Is the organization licensed to issue qualified health plans in more than one state?	13 a	
Note: See the instructions for additional information the organization must report on Schedule O		
b Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans	13 b	
c Enter the amount of reserves on hand	13 c	
14 a Did the organization receive any payments for indoor tanning services during the tax year?	14 a	X
b If 'Yes,' has it filed a Form 720 to report these payments? If 'No,' provide an explanation on Schedule O	14 b	
15 Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or excess parachute payment(s) during the year?	15	X
If 'Yes,' see instructions and file Form 4720, Schedule N		
16 Is the organization an educational institution subject to the section 4968 excise tax on net investment income?	16	X
If 'Yes,' complete Form 4720, Schedule O		

Part VI Governance, Management, and Disclosure For each 'Yes' response to lines 2 through 7b below, and for a 'No' response to line 8a, 8b, or 10b below, describe the circumstances, processes, or changes on Schedule O. See instructions.

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

☒**Section A. Governing Body and Management**

	Yes	No
1 a Enter the number of voting members of the governing body at the end of the tax year. If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain on Schedule O.	8	
1 b Enter the number of voting members included on 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	X
3 Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors, trustees, or key employees to a management company or other person?	3	X
4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?	4	X
5 Did the organization become aware during the year of a significant diversion of the organization's assets?	5	X
6 Did the organization have members or stockholders?	6	X
7 a 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?	7 a	X
7 b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?	7 b	X
8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:		
a The governing body?	8 a	X
b Each committee with authority to act on behalf of the governing body?	8 b	X
9 Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If 'Yes,' provide the names and addresses on Schedule O.	9	X

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

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

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 Forms 1023 (1024 or 1024-A, if applicable), 990, and 990-T (Section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.

☐ Own website ☒ Another's website ☒ Upon request ☐ Other (explain on Schedule O)

19 Describe on Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year. SEE SCHEDULE O

20 State the name, address, and telephone number of the person who possesses the organization's books and records: ▶

CEA SCHOLTES AND ASSOCIATES 106 TUNBRIDGE ROAD BALTIMORE MD 21212 (410) 323-0010

Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent ContractorsCheck 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****1 a** Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year.

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

See instructions for the order in which to list the persons above.

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below 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) JULIA JENKINS EXECUTIVE DIR.	50 0	X		X				203,777.	0.	11,682.
(2) CAROL KENNEDY PROGRAMS	40 0					X		127,791.	0.	0.
(3) BRITTA DORNAN COMMUNICATIONS	40 0					X		107,000.	0.	0.
(4) STEVEN SILVESTRI PUBLIC POLICY	40 0					X		103,700.	0.	0.
(5) MARK DANT PRESIDENT	10 0	X		X				0.	0.	0.
(6) FRANK SASINOWSKI VICE PRESIDENT	1 0	X		X				0.	0.	0.
(7) VICKY SEYFERT-MARGOLIS TREASURER	1 0	X		X				0.	0.	0.
(8) RITU BARAL DIRECTOR	1 0	X						0.	0.	0.
(9) RAY AMRIT DIRECTOR	1 0	X						0.	0.	0.
(10) JENNIFER BERNSTEIN DIRECTOR	1 0	X						0.	0.	0.
(11) EMIL KAKKIS DIRECTOR	1 0	X						0.	0.	0.
(12)										
(13)										
(14)										

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			
(15) -----	-----								
(16) -----	-----								
(17) -----	-----								
(18) -----	-----								
(19) -----	-----								
(20) -----	-----								
(21) -----	-----								
(22) -----	-----								
(23) -----	-----								
(24) -----	-----								
(25) -----	-----								
1 b Subtotal							542,268.	0.	11,682.
c Total from continuation sheets to Part VII, Section A							0.	0.	0.
d Total (add lines 1b and 1c)							542,268.	0.	11,682.

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 **4**

3 Did the organization list any **former** officer, director, trustee, key employee, or highest compensated employee on line 1a? If 'Yes,' complete Schedule J for such individual

4 For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? If 'Yes,' complete Schedule J for such individual

5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? If 'Yes,' complete Schedule J for such person

	Yes	No
3		X
4	X	
5		X

Section B. Independent Contractors

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

(A) Name and business address	(B) Description of services	(C) Compensation

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 RevenueCheck 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	1 a Federated campaigns	1 a				
	b Membership dues	1 b 481,000.				
	c Fundraising events	1 c 75,000.				
	d Related organizations	1 d				
	e Government grants (contributions)	1 e				
	f All other contributions, gifts, grants, and similar amounts not included above	1 f 4,162,319.				
	g Noncash contributions included in lines 1a-1f	1 g				
	h Total. Add lines 1a-1f		4,718,319.			
Program Service Revenue	2 a <u>CONTRACTS</u>		Business Code 900099	42,955.	42,955.	
	b					
	c					
	d					
	e					
	f All other program service revenue					
	g Total. Add lines 2a-2f		42,955.			
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)		429.			429.
	4 Income from investment of tax-exempt bond proceeds					
	5 Royalties					
	6 a Gross rents	(i) Real 39,250.				
	b Less rental expenses	6 b				
	c Rental income or (loss)	6 c 39,250.				
	d Net rental income or (loss)		39,250.			39,250.
	7 a Gross amount from sales of assets other than inventory	(i) Securities (ii) Other				
	b Less cost or other basis and sales expenses	7 b				
	c Gain or (loss)	7 c				
	d Net gain or (loss)					
	8 a Gross income from fundraising events (not including \$ 75,000. of contributions reported on line 1c) See Part IV, line 18	8 a 33,283.				
	b Less direct expenses	8 b 27,680.				
	c Net income or (loss) from fundraising events		5,603.			5,603.
	9 a Gross income from gaming activities See Part IV, line 19	9 a				
	b Less direct expenses	9 b				
	c Net income or (loss) from gaming activities					
10 a Gross sales of inventory, less returns and allowances	10 a					
b Less cost of goods sold	10 b					
c Net income or (loss) from sales of inventory						
Miscellaneous Revenue	11 a <u>OTHER INCOME</u>		Business Code 900099	4,652.	4,652.	
	b					
	c					
	d All other revenue					
	e Total. Add lines 11a-11d		4,652.			
12 Total revenue. See instructions		4,811,208.	47,607.	0.	45,282.	

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

☒ X

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	704.	704.		
2 Grants and other assistance to domestic individuals See Part IV, line 22	218,799.	218,799.		
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals See Part IV, lines 15 and 16				
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	203,777.	107,565.	65,107.	31,105.
6 Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)	0.	0.	0.	0.
7 Other salaries and wages	975,539.	514,944.	311,685.	148,910.
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	51,895.	27,393.	16,581.	7,921.
9 Other employee benefits	130,666.	68,973.	41,748.	19,945.
10 Payroll taxes	87,548.	46,212.	27,972.	13,364.
11 Fees for services (nonemployees)				
a Management				
b Legal				
c Accounting	30,045.		30,045.	
d Lobbying	22,500.	22,500.		
e Professional fundraising services See Part IV, line 17				
f Investment management fees				
g Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O, SCH O)	664,528.	634,949.	26,080.	3,499.
12 Advertising and promotion	27,631.	26,883.	748.	
13 Office expenses	76,219.	58,663.	17,156.	400.
14 Information technology	102,596.	72,146.	29,800.	650.
15 Royalties				
16 Occupancy	162,338.	33,276.	129,062.	
17 Travel	142,986.	83,418.	50,242.	9,326.
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	311,761.	309,306.		2,455.
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	3,916.		3,916.	
23 Insurance	5,764.		5,764.	
24 Other expenses. Itemize expenses not covered above (List miscellaneous expenses on line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
a MISCELLANEOUS	38,516.	33,843.	3,100.	1,573.
b STAFF DEVELOPMENT	35,946.	6,014.	28,226.	1,706.
c BANK CHARGES AND FEES	2,281.	225.	2,056.	
d				
e All other expenses				
25 Total functional expenses. Add lines 1 through 24e	3,295,955.	2,265,813.	789,288.	240,854.
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 <input type="checkbox"/> if following SOP 98-2 (ASC 958-720)				

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

		(A) Beginning of year		(B) End of year
Assets	1 Cash — non-interest-bearing	704,394.	1	1,238,113.
	2 Savings and temporary cash investments	14.	2	
	3 Pledges and grants receivable, net	694,422.	3	1,021,300.
	4 Accounts receivable, net		4	916,408.
	5 Loans and other receivables from any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		5	
	6 Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B)		6	
	7 Notes and loans receivable, net		7	
	8 Inventories for sale or use		8	
	9 Prepaid expenses and deferred charges	114,832.	9	97,189.
	10a Land, buildings, and equipment cost or other basis. Complete Part VI of Schedule D	10a 36,866.		
	b Less accumulated depreciation	10b 4,320.	10c 19,356.	32,546.
	11 Investments — publicly traded securities		11	24,762.
	12 Investments — other securities. See Part IV, line 11		12	
	13 Investments — program-related. See Part IV, line 11		13	
	14 Intangible assets		14	
	15 Other assets. See Part IV, line 11	139,675.	15	158,173.
16 Total assets. Add lines 1 through 15 (must equal line 33)	1,672,693.	16	3,488,491.	
Liabilities	17 Accounts payable and accrued expenses	259,109.	17	520,891.
	18 Grants payable		18	
	19 Deferred revenue	259,463.	19	329,925.
	20 Tax-exempt bond liabilities		20	
	21 Escrow or custodial account liability. Complete Part IV of Schedule D		21	
	22 Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		22	
	23 Secured mortgages and notes payable to unrelated third parties		23	5,100.
	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	82,833.	25	32,149.
	26 Total liabilities. Add lines 17 through 25	601,405.	26	888,065.
Net Assets or Fund Balances	Organizations that follow FASB ASC 958, check here ▶ <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33.			
	27 Net assets without donor restrictions	770,738.	27	538,626.
	28 Net assets with donor restrictions	300,550.	28	2,061,800.
	Organizations that do not follow FASB ASC 958, check here ▶ <input type="checkbox"/> and complete lines 29 through 33.			
	29 Capital stock or trust principal, or current funds		29	
	30 Paid-in or capital surplus, or land, building, or equipment fund		30	
	31 Retained earnings, endowment, accumulated income, or other funds		31	
	32 Total net assets or fund balances	1,071,288.	32	2,600,426.
	33 Total liabilities and net assets/fund balances	1,672,693.	33	3,488,491.

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	4,811,208.
2	Total expenses (must equal Part IX, column (A), line 25)	2	3,295,955.
3	Revenue less expenses Subtract line 2 from line 1	3	1,515,253.
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	1,071,288.
5	Net unrealized gains (losses) on investments	5	57.
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 on Schedule O) SEE SCHEDULE O	9	13,828.
10	Net assets or fund balances at end of year Combine lines 3 through 9 (must equal Part X, line 32, column (B))	10	2,600,426.

Part XII Financial Statements and Reporting

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

☐

	Yes	No
1 Accounting method used to prepare the Form 990 <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other _____ If the organization changed its method of accounting from a prior year or checked 'Other,' explain in Schedule O		
2 a Were the organization's financial statements compiled or reviewed by an independent accountant? If 'Yes,' check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		X
b Were the organization's financial statements audited by an independent accountant? If 'Yes,' check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both <input checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis	X	
c If 'Yes' to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? If the organization changed either its oversight process or selection process during the tax year, explain on Schedule O	X	
3 a As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133?		X
b If 'Yes,' did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why on Schedule O and describe any steps taken to undergo such audits		

SCHEDULE A
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support

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

► Attach to Form 990 or Form 990-EZ.

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

OMB No 1545-0047

2019

Open to Public Inspection

Name of the organization

EVERYLIFE FOUNDATION FOR RARE DISEASES

Employer identification number

26-4614274

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 12, 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 (Form 990 or 990-EZ))
- 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 agricultural research organization described in **section 170(b)(1)(A)(ix)** operated in conjunction with a land-grant college or university or a non-land-grant college of agriculture (see instructions) Enter the name, city, and state of the college or university _____
- 10 ☐ 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)
- 11 ☐ An organization organized and operated exclusively to test for public safety See **section 509(a)(4).**
- 12 ☐ 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 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g
- 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 1-10 above (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		
(A)						
(B)						
(C)						
(D)						
(E)						
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) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any 'unusual grants'.)	1,655,552.	2,141,041.	2,339,862.	2,842,619.	4,718,319.	13,697,393.
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	1,655,552.	2,141,041.	2,339,862.	2,842,619.	4,718,319.	13,697,393.
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).						4,888,473.
6 Public support. Subtract line 5 from line 4						8,808,920.

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
7 Amounts from line 4	1,655,552.	2,141,041.	2,339,862.	2,842,619.	4,718,319.	13,697,393.
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources				177.	39,679.	39,856.
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.) SEE PART VI		259.			4,652.	4,911.
11 Total support. Add lines 7 through 10						13,742,160.
12 Gross receipts from related activities, etc. (see instructions)					12	434,464.
13 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here ▶ <input type="checkbox"/>						

Section C. Computation of Public Support Percentage

14 Public support percentage for 2019 (line 6, column (f) divided by line 11, column (f))	14	64.10 %
15 Public support percentage from 2018 Schedule A, Part II, line 14	15	64.29 %
16a 33-1/3% support test—2019. If the organization did not check the box on line 13, and line 14 is 33-1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization ▶ <input checked="" type="checkbox"/>		
b 33-1/3% support test—2018. If the organization did not check a box on line 13 or 16a, and line 15 is 33-1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization ▶ <input type="checkbox"/>		
17a 10%-facts-and-circumstances test—2019. 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 ▶ <input type="checkbox"/>		
b 10%-facts-and-circumstances test—2018. 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 ▶ <input type="checkbox"/>		
18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions ▶ <input type="checkbox"/>		

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

(Complete only if you checked the box on line 10 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) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(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) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(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 ▶ <input type="checkbox"/>						

Section C. Computation of Public Support Percentage

15 Public support percentage for 2019 (line 8, column (f), divided by line 13, column (f)).	15	%
16 Public support percentage from 2018 Schedule A, Part III, line 15.	16	%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2019 (line 10c, column (f), divided by line 13, column (f)).	17	%
18 Investment income percentage from 2018 Schedule A, Part III, line 17.	18	%

- 19a 33-1/3% support tests—2019.** 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—2018.** 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 in line 12 on Part I. If you checked 12a of Part I, complete Sections A and B. If you checked 12b of Part I, complete Sections A and C. If you checked 12c of Part I, complete Sections A, D, and E. If you checked 12d 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.		
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).		
3a Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? If 'Yes,' answer (b) and (c) below.		
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.		
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.		
4a Was any supported organization not organized in the United States ('foreign supported organization')? If 'Yes' and if you checked 12a or 12b in Part I, answer (b) and (c) below.		
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.		
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.		
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).		
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?		
c Substitutions only. Was the substitution the result of an event beyond the organization's control?		
6 Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) 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 .		
7 Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (as defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? If 'Yes,' complete Part I of Schedule L (Form 990 or 990-EZ).		
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 I of Schedule L (Form 990 or 990-EZ).		
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 .		
b Did one or more disqualified persons (as defined in line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? If 'Yes,' provide detail in Part VI .		
c Did a disqualified person (as defined in line 9a) 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 .		
10a Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? If 'Yes,' answer 10b below.		
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.)		

Part IV. Supporting Organizations (continued)

	Yes	No
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?		
b A family member of a person described in (a) above?		
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 .		

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, (i) a written notice describing the type and amount of support provided during the prior tax year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) 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 Activities Test. Answer (a) and (b) below.

	Yes	No
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 Parent of Supported Organizations. 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 (explain in Part VI). **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)		
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	<input type="checkbox"/> Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see instructions)		

BAA

Schedule A (Form 990 or 990-EZ) 2019

Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations (continued)**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 2019 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-2019(iii)
Distributable
Amount for 2019

1	Distributable amount for 2019 from Section C, line 6			
2	Underdistributions, if any, for years prior to 2019 (reasonable cause required – explain in Part VI) See instructions			
3	Excess distributions carryover, if any, to 2019			
a	From 2014			
b	From 2015			
c	From 2016			
d	From 2017			
e	From 2018			
f	Total of lines 3a through e			
g	Applied to underdistributions of prior years			
h	Applied to 2019 distributable amount			
i	Carryover from 2014 not applied (see instructions)			
j	Remainder Subtract lines 3g, 3h, and 3i from 3f			
4	Distributions for 2019 from Section D, line 7 \$			
a	Applied to underdistributions of prior years			
b	Applied to 2019 distributable amount			
c	Remainder Subtract lines 4a and 4b from 4			
5	Remaining underdistributions for years prior to 2019, if any Subtract lines 3g and 4a from line 2 For result greater than zero, explain in Part VI See instructions			
6	Remaining underdistributions for 2019 Subtract lines 3h and 4b from line 1 For result greater than zero, explain in Part VI See instructions			
7	Excess distributions carryover to 2020. Add lines 3j and 4c			
8	Breakdown of line 7			
a	Excess from 2015			
b	Excess from 2016			
c	Excess from 2017			
d	Excess from 2018			
e	Excess from 2019			

BAA

Schedule A (Form 990 or 990-EZ) 2019

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.)

PART II, LINE 10 - OTHER INCOME

NATURE AND SOURCE		2019	2018	2017	2016	2015
OTHER INCOME		\$ 4,652.			\$ 259.	
	TOTAL	<u>\$ 4,652.</u>	<u>\$ 0.</u>	<u>\$ 0.</u>	<u>\$ 259.</u>	<u>\$ 0.</u>

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

OMB No 1545-0047

2019

**Open to Public
Inspection**

If the organization answered 'Yes,' on 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,' on 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,' on 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 organization

Employer identification number

EVERYLIFE FOUNDATION FOR RARE DISEASES

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 (see instructions for definition of 'political campaign activities')

2 Political campaign activity expenditures (see instructions)

► \$

3 Volunteer hours for political campaign activities (see instructions)

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

► \$ 0.

2 Enter the amount of any excise tax incurred by organization managers under section 4955

► \$ 0.

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-
(1)				
(2)				
(3)				
(4)				
(5)				
(6)				

BAA For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ.

Schedule C (Form 990 or 990-EZ) 2019

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												
1 a Total lobbying expenditures to influence public opinion (grassroots lobbying)															
b Total lobbying expenditures to influence a legislative body (direct lobbying)		22,500.													
c Total lobbying expenditures (add lines 1a and 1b)		22,500.	0.												
d Other exempt purpose expenditures		3,273,455.													
e Total exempt purpose expenditures (add lines 1c and 1d)		3,295,955.	0.												
f Lobbying nontaxable amount Enter the amount from the following table in both columns		314,798.													
<table border="1"> <thead> <tr> <th>If the amount on line 1e, column (a) or (b) is</th> <th>The lobbying nontaxable amount is</th> </tr> </thead> <tbody> <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> </tbody> </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)		78,700.	0.												
h Subtract line 1g from line 1a. If zero or less, enter -0-		0.	0.												
i Subtract line 1f from line 1c. If zero or less, enter -0-		0.	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?			<input type="checkbox"/> Yes <input type="checkbox"/> 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) 2016	(b) 2017	(c) 2018	(d) 2019	(e) Total
2 a Lobbying nontaxable amount	260,358.	274,017.	275,751.	314,798.	1,124,924.
b Lobbying ceiling amount (150% of line 2a, column (e))					1,687,386.
c Total lobbying expenditures	225,000.	260,201.	60,000.	22,500.	567,701.
d Grassroots nontaxable amount	65,090.	68,504.	68,938.	78,700.	281,232.
e Grassroots ceiling amount (150% of line 2d, column (e))					421,848.
f Grassroots lobbying expenditures	100,000.	60,000.			160,000.

BAA

Schedule C (Form 990 or 990-EZ) 2019

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 on 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			
2 a 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).

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

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	2 a	
b Carryover from last year	2 b	
c Total	2 c	
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.

**SCHEDULE D
(Form 990)**Department of the Treasury
Internal Revenue Service

Name of the organization

Supplemental Financial Statements

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

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

OMB No 1545 0047

2019**Open to Public
Inspection**

Employer identification number

EVERYLIFE FOUNDATION FOR RARE DISEASES

26-4614274

Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 6

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

5 Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control? ☐ 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' on Form 990, Part IV, line 7.

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

<input type="checkbox"/> Preservation of land for public use (for example, recreation or education)	<input type="checkbox"/> Preservation of a historically important land area
<input type="checkbox"/> Protection of natural habitat	<input type="checkbox"/> Preservation of a certified historic structure
<input type="checkbox"/> Preservation of open space	

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

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

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, handling of violations, and enforcing conservation easements during the year ► _____

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

8 Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)? ☐ 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' on Form 990, Part IV, line 8.

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

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

(i) Revenue included on Form 990, Part VIII, line 1 ► \$ _____

(ii) Assets included in Form 990, Part X ► \$ _____

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

a Revenue included on Form 990, Part VIII, line 1 ► \$ _____

b Assets included in Form 990, Part X ► \$ _____

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

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

a ☐ Public exhibition

d ☐ Loan or exchange program

b ☐ Scholarly research

e ☐ Other _____

c ☐ Preservation for future generations

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

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

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

1 a 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

c Beginning balance

d Additions during the year

e Distributions during the year

f Ending balance

	Amount
1 c	
1 d	
1 e	
1 f	

2 a Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability? ☐ Yes ☐ No

b If 'Yes,' explain the arrangement in Part XIII. Check here if the explanation has been provided on Part XIII ☐

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

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

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

a Board designated or quasi-endowment ▶ _____ %

b Permanent endowment ▶ _____ %

c Term endowment ▶ _____ %

The percentages on lines 2a, 2b, and 2c should equal 100%

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

(i) Unrelated organizations

(ii) Related organizations

b If 'Yes' on line 3a(ii), are the related organizations listed as required on Schedule R?

	Yes	No
3a(i)		
3a(ii)		
3b		

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

Part VI Land, Buildings, and Equipment.

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

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1 a Land				
b Buildings				
c Leasehold improvements		18,046.	2,493.	15,553.
d Equipment				
e Other		18,820.	1,827.	16,993.
Total. Add lines 1a through 1e (Column (d) must equal Form 990, Part X, column (B), line 10c.)				32,546.

BAA

Schedule D (Form 990) 2019

Part VII Investments – Other Securities.

N/A

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

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

Part VIII Investments – Program Related.

N/A

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

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

Part IX Other Assets.

N/A

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

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

Part X Other Liabilities.

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

1. (a) Description of liability	(b) Book value
(1) Federal income taxes	
(2) DEFERRED RENT ABATEMENT	32,149.
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
(10)	
(11)	
Total (Column (b) must equal Form 990, Part X, column (B) line 25) ▶	32,149.

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

SEE PART XIII ☒

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

Complete if the organization answered 'Yes' on Form 990, Part IV, line 12a.

1	Total revenue, gains, and other support per audited financial statements		1	4,838,945.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12			
	a Net unrealized gains (losses) on investments	2a 57.		
	b Donated services and use of facilities	2b		
	c Recoveries of prior year grants	2c		
	d Other (Describe in Part XIII) SEE PART XIII	2d 27,680.		
	e Add lines 2a through 2d		2e	27,737.
3	Subtract line 2e from line 1		3	4,811,208.
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1			
	a Investment expenses not included on Form 990, Part VIII, line 7b	4a		
	b Other (Describe in Part XIII)	4b		
	c Add lines 4a and 4b		4c	
5	Total revenue Add lines 3 and 4c. (This must equal Form 990, Part I, line 12)		5	4,811,208.

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

Complete if the organization answered 'Yes' on Form 990, Part IV, line 12a.

1	Total expenses and losses per audited financial statements		1	3,323,635.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25			
	a Donated services and use of facilities	2a		
	b Prior year adjustments	2b		
	c Other losses	2c		
	d Other (Describe in Part XIII) SEE PART XIII	2d 27,680.		
	e Add lines 2a through 2d		2e	27,680.
3	Subtract line 2e from line 1		3	3,295,955.
4	Amounts included on Form 990, Part IX, line 25, but not on line 1			
	a Investment expenses not included on Form 990, Part VIII, line 7b	4a		
	b Other (Describe in Part XIII)	4b		
	c Add lines 4a and 4b		4c	
5	Total expenses Add lines 3 and 4c. (This must equal Form 990, Part I, line 18)		5	3,295,955.

Part XIII Supplemental Information.

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

PART X - FASB ASC 740 FOOTNOTE

FOR THE YEAR ENDED DECEMBER 31, 2019, THE FOUNDATION HAS DOCUMENTED ITS CONSIDERATION OF FASB ASC 740-10, INCOME TAXES, THAT PROVIDES GUIDANCE FOR REPORTING UNCERTAINTY IN INCOME TAXES AND HAS DETERMINED THAT NO MATERIAL UNCERTAIN TAX POSITIONS QUALIFY FOR EITHER RECOGNITION OR DISCLOSURE IN THE FINANCIAL STATEMENTS.

Part XIII Supplemental Information *(continued)***SCHEDULE D, PART XI, LINE 2D****OTHER REVENUE INCLUDED IN F/S BUT NOT INCLUDED ON FORM 990**

RARE AFFAIR DIRECT EXPENSES

TOTAL \$ 27,680.
\$ 27,680.**SCHEDULE D, PART XII, LINE 2D****OTHER EXPENSES AND LOSSES PER AUDITED F/S**

RARE AFFAIR DIRECT EXPENSES

TOTAL \$ 27,680.
\$ 27,680.

SCHEDULE G
(Form 990 or 990-EZ)Department of the Treasury
Internal Revenue Service**Supplemental Information Regarding Fundraising or Gaming Activities**

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

▶ Attach to Form 990 or Form 990-EZ

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

OMB No 1545-0047

2019**Open to Public Inspection**

Name of the organization

EVERYLIFE FOUNDATION FOR RARE DISEASES

Employer identification number

26-4614274

Part I**Fundraising Activities.** Complete if the organization answered 'Yes' on Form 990, Part IV, line 17
Form 990-EZ filers are not required to complete this part**1** Indicate whether the organization raised funds through any of the following activities. Check all that apply.**a** ☐ Mail solicitations**b** ☐ Internet and email solicitations**c** ☐ Phone solicitations**d** ☐ In-person solicitations**e** ☐ Solicitation of non-government grants**f** ☐ Solicitation of government grants**g** ☐ Special fundraising events**2a** Did the organization have a written or oral agreement with any individual (including officers, directors, trustees, or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services? ☐ Yes ☒ No**b** If 'Yes,' list the 10 highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization.

(i) Name and address of individual or entity (fundraiser)	(ii) Activity	(iii) Did fundraiser have custody or control of contributions?		(iv) Gross receipts from activity	(v) Amount paid to (or retained by) fundraiser listed in column (i)	(vi) Amount paid to (or retained by) organization
		Yes	No			
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						
Total ▶						0.

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

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

		(a) Event #1	(b) Event #2	(c) Other events	(d) Total events
		<u>RARE AFFAIR</u> (event type)	(event type)	<u>NONE</u> (total number)	(add column (a) through column (c))
REVENUE	1 Gross receipts	108,283.			108,283.
	2 Less Contributions	75,000.			75,000.
	3 Gross income (line 1 minus line 2)	33,283.			33,283.
DIRECT EXPENSES	4 Cash prizes				
	5 Noncash prizes				
	6 Rent/facility costs	25,731.			25,731.
	7 Food and beverages	1,949.			1,949.
	8 Entertainment				
	9 Other direct expenses				
	10 Direct expense summary Add lines 4 through 9 in column (d)				27,680.
	11 Net income summary Subtract line 10 from line 3, column (d)				5,603.

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

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

9 Enter the state(s) in which the organization conducts gaming activities _____

a Is the organization licensed to conduct gaming activities in each of these states?

☐ Yes ☐ No

b If 'No,' explain _____

10 a Were any of the organization's gaming licenses revoked, suspended, or terminated during the tax year?

☐ Yes ☐ No

b If 'Yes,' explain _____

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

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

13 Indicate the percentage of gaming activity conducted in

a The organization's facility

13a %

b An outside facility

13b %

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

Name ▶ _____

Address ▶ _____

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

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

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

Name ▶ _____

Address ▶ _____

16 Gaming manager information

Name ▶ _____

Gaming manager compensation ▶ \$ _____

Description of services provided ▶ _____

☐ Director/officer

☐ Employee

☐ Independent contractor

17 Mandatory distributions

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

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

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

SCHEDULE I
(Form 990)

Department of the Treasury
Internal Revenue Service

**Grants and Other Assistance to Organizations,
Governments, and Individuals in the United States**

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

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

OMB No. 1545-0047

2019

Open to Public
Inspection

Name of the organization

EVERYLIFE FOUNDATION FOR RARE DISEASES

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?

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

SEE PART IV

Part II Grants and Other Assistance to Domestic Organizations and Domestic Governments. Complete if the organization answered 'Yes' on Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Part II can be duplicated if additional space is needed.

1 (a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
(1) -----							
(2) -----							
(3) -----							
(4) -----							
(5) -----							
(6) -----							
(7) -----							
(8) -----							

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

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

0
0

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

TEEA3901L 07/10/19

Schedule I (Form 990) (2019)

Part III Grants and Other Assistance to Domestic Individuals. Complete if the organization answered 'Yes' on Form 990, Part IV, line 22. Part III can be duplicated if additional space is needed.

	(a) Type of grant or assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of noncash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance
1	TRAVEL REIMBURSEMENTS AND GRANTS	215	134,659.			
2	SPONSORSHIPS	44	84,140.			
3						
4						
5						
6						
7						
Part IV	Supplemental Information. Provide the information required in Part I, line 2, Part III, column (b); and any other additional information					

PART I, LINE 2 - PROCEDURES FOR MONITORING USE OF GRANTS FUNDS IN U.S.

EVERYLIFE FOUNDATION FOR RARE DISEASES REQUIRES ONGOING FEEDBACK IN THE FORM OF ORAL

AND WRITTEN REPORTS IN ORDER TO MONITOR THE PROGRESS OF EACH GRANT DISTRIBUTION.

SCHEDULE J
(Form 990)

Department of the Treasury
Internal Revenue Service

Compensation Information

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

► Complete if the organization answered 'Yes' on Form 990, Part IV, line 23.

► Attach to Form 990.

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

OMB No 1545-0047

2019

**Open to Public
Inspection**

Name of the organization

EVERYLIFE FOUNDATION FOR RARE DISEASES

Employer identification number

26-4614274

Part I Questions Regarding Compensation

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

☐ First-class or charter travel

☐ Housing allowance or residence for personal use

☐ Travel for companions

☐ Payments for business use of personal residence

☐ Tax indemnification and gross-up payments

☐ Health or social club dues or initiation fees

☐ Discretionary spending account

☐ Personal services (such as maid, chauffeur, chef)

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

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

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

☐ Compensation committee

☐ Written employment contract

☐ Independent compensation consultant

☐ Compensation survey or study

☐ Form 990 of other organizations

☐ Approval by the board or compensation committee

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

a Receive a severance payment or change-of-control payment?

b Participate in, or receive payment from, a supplemental nonqualified retirement plan?

c Participate in, or receive payment from, an equity-based compensation arrangement?

If 'Yes' to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III

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

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

a The organization?

b Any related organization?

If 'Yes' on line 5a or 5b, describe in Part III

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

a The organization?

b Any related organization?

If 'Yes' on line 6a or 6b, describe in Part III

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

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

If 'Yes,' describe in Part III

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

Yes No

1 b

2

4 a

4 b

4 c

5 a

5 b

6 a

6 b

7

8

9

X

X

X

X

X

X

X

X

X

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

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

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

(A) Name and Title	(B) Breakdown of W-2 and/or 1099-MISC compensation			(C) Retirement and other deferred compensation	(D) Nontaxable benefits	(E) Total of columns (B)(i)-(D)	(F) Compensation in column (B) reported as deferred on prior Form 990
	(i) Base compensation	(ii) Bonus & incentive compensation	(iii) Other reportable compensation				
JULIA JENKINS 1 EXECUTIVE DIR.	(i) 203,777.	0.	0.	0.	11,682.	215,459.	0.
	(ii) 0.	0.	0.	0.	0.	0.	0.
2	(i)						
	(ii)						
3	(i)						
	(ii)						
4	(i)						
	(ii)						
5	(i)						
	(ii)						
6	(i)						
	(ii)						
7	(i)						
	(ii)						
8	(i)						
	(ii)						
9	(i)						
	(ii)						
10	(i)						
	(ii)						
11	(i)						
	(ii)						
12	(i)						
	(ii)						
13	(i)						
	(ii)						
14	(i)						
	(ii)						
15	(i)						
	(ii)						
16	(i)						
	(ii)						

Part III Supplemental Information

Provide the information, explanation, or descriptions required for Part I, lines 1a, 1b, 3, 4a, 4b, 4c, 5a, 5b, 6a, 6b, 7, and 8, and for Part II. Also complete this part for any additional information.

SCHEDULE O
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Name of the organization

Supplemental Information to Form 990 or 990-EZ

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

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

OMB No 1545-0047

2019

**Open to Public
Inspection**

Employer identification number

EVERYLIFE FOUNDATION FOR RARE DISEASES

26-4614274

FORM 990, PART III, LINE 4A - PROGRAM SERVICE ACCOMPLISHMENTS

EVERYLIFE FOUNDATION - THE 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 ADMINISTRATION (FDA), AND NATIONAL INSTITUTES OF HEALTH (NIH) TO IMPROVE THE CLINICAL DEVELOPMENT PROCESS THROUGH OUR RARE DISEASE WORKSHOP SERIES, AND LEGISLATION.

FORM 990, PART III, LINE 4D - OTHER PROGRAM SERVICES DESCRIPTION

THE EVERYLIFE FOUNDATION FOR RARE DISEASES IS A 501(C)(3) NONPROFIT DEDICATED TO ADVANCING THE DEVELOPMENT OF TREATMENT AND DIAGNOSTIC OPPORTUNITIES FOR RARE DISEASE PATIENTS THROUGH SCIENCE-DRIVEN PUBLIC POLICY. WE DO NOT SPEAK FOR PATIENTS. WE PROVIDE THE TRAINING, EDUCATION, RESOURCES AND OPPORTUNITIES TO MAKE THEIR VOICES HEARD. BY ACTIVATING THE PATIENT ADVOCATE, WE CAN CHANGE PUBLIC POLICY AND SAVE LIVES.

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, AUDIT COMMITTEE, AND THE EXECUTIVE DIRECTOR. THIS GROUP OF INDIVIDUALS THEN DISCUSSES THE CONTENTS OF THE RETURN WITH THE OUTSIDE TAX PROFESSIONAL. AFTER A FULL REVIEW, THE FINAL VERSION OF THE TAX RETURN IS PROVIDED

Name of the organization

EVERYLIFE FOUNDATION FOR RARE DISEASES

Employer identification number

26-4614274

FORM 990, PART VI, LINE 11B - FORM 990 REVIEW PROCESS (CONTINUED)

TO ALL MEMBERS OF THE ORGANIZATION'S VOTING BODY. A REPRESENTATIVE OF MANAGEMENT AUTHORIZES THE FINAL FORM 990 WHICH IS THEN FILED WITH THE INTERNAL REVENUE SERVICE.

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 AT LEAST ANNUALLY. ALL PERSONNEL AND BOARD MEMBERS ARE REQUIRED TO DISCLOSE (IN WRITING) POTENTIAL CONFLICTS AND ANY RELATED PARTY AFFILIATIONS. LOANS BETWEEN THE ORGANIZATION AND MEMBERS OF MANAGEMENT AND THE BOARD ARE STRICTLY PROHIBITED. THE ORGANIZATION SEEKS FULL TRANSPARENCY ON ALL INTEREST AT LEAST ANNUALLY. ANY POTENTIAL CONFLICTS (IN FACT OR APPEARANCE) ARE DISCUSSED OPENLY AND RESOLVED IN ACCORDANCE WITH THE ORGANIZATION'S POLICIES AND PROCEDURES.

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. 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.

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

Name of the organization

Employer identification number

EVERYLIFE FOUNDATION FOR RARE DISEASES

26-4614274

FORM 990, PART VI, LINE 19 - OTHER ORGANIZATION DOCUMENTS PUBLICLY AVAILABLE (CONTINUED)

ARE ALSO AVAILABLE FOR A PHYSICAL INSPECTION AT THE ORGANIZATION'S OFFICE IN NOVATO, CALIFORNIA.

**FORM 990, PART IX, LINE 11G
OTHER FEES FOR SERVICES**

	(A) TOTAL	(B) PROGRAM SERVICES	(C) MANAGEMENT & GENERAL	(D) FUND- RAISING
CONSULTING	627,527.	624,028.		3,499.
PROFESSIONAL FEES - OTHER	37,001.	10,921.	26,080.	
TOTAL	\$ 664,528.	\$ 634,949.	\$ 26,080.	\$ 3,499.

**FORM 990, PART XI, LINE 9
OTHER CHANGES IN NET ASSETS OR FUND BALANCES**

GAIN ON NET TRANSFER OF ASSETS	\$ 13,828.
TOTAL	\$ 13,828.