

Return of Organization Exempt From Income Tax

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

2018

Department of the Treasury
Internal Revenue Service

▶ 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.

Open to Public Inspection

A For the **2018** calendar year, or tax year beginning and ending

B Check if applicable: <input type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial return <input type="checkbox"/> Final return/terminated <input type="checkbox"/> Amended return <input type="checkbox"/> Application pending	C Name of organization DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA		D Employer identification number 11-2519726
	Doing business as		E Telephone number 212.868.1573
	Number and street (or P.O. box if mail is not delivered to street address)	Room/suite	G Gross receipts \$ 2,082,612.
	75 BROAD ST	300	H(a) Is this a group return for subordinates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
City or town, state or province, country, and ZIP or foreign postal code NEW YORK, NY 10004		H(b) Are all subordinates included? <input type="checkbox"/> Yes <input type="checkbox"/> No	
F Name and address of principal officer: BRETT KOPELAN		If "No," attach a list. (see instructions)	
SAME AS C ABOVE		H(c) Group exemption number ▶	
I Tax-exempt status: <input checked="" type="checkbox"/> 501(c)(3) <input type="checkbox"/> 501(c) () (insert no.) <input type="checkbox"/> 4947(a)(1) or <input type="checkbox"/> 527			
J Website: ▶ WWW.DEBRA.ORG			
K Form of organization: <input checked="" type="checkbox"/> Corporation <input type="checkbox"/> Trust <input type="checkbox"/> Association <input type="checkbox"/> Other ▶			L Year of formation: 1979
M State of legal domicile: NY			

Part I Summary		Prior Year	Current Year
Activities & Governance	1 Briefly describe the organization's mission or most significant activities: <u>DEBRA IS DEDICATED TO FINDING A CURE FOR EB, WHICH AFFECTS 1 OUT OF EVERY 50,000 LIVE BIRTHS IN THE</u>		
	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)	3	14
	4 Number of independent voting members of the governing body (Part VI, line 1b)	4	14
	5 Total number of individuals employed in calendar year 2018 (Part V, line 2a)	5	0
	6 Total number of volunteers (estimate if necessary)	6	0
	7a Total unrelated business revenue from Part VIII, column (C), line 12	7a	0.
b Net unrelated business taxable income from Form 990-T, line 38	7b	0.	
Revenue	8 Contributions and grants (Part VIII, line 1h)	662,523.	947,956.
	9 Program service revenue (Part VIII, line 2g)	0.	0.
	10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)	554.	1,956.
	11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	706,975.	874,655.
	12 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	1,370,052.	1,824,567.
	Expenses	13 Grants and similar amounts paid (Part IX, column (A), lines 1-3)	0.
14 Benefits paid to or for members (Part IX, column (A), line 4)		0.	0.
15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)		929,474.	985,312.
16a Professional fundraising fees (Part IX, column (A), line 11e)		0.	0.
b Total fundraising expenses (Part IX, column (D), line 25) ▶ 194,884.			
17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)		487,099.	1,168,496.
18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	1,416,573.	2,153,808.	
19 Revenue less expenses. Subtract line 18 from line 12	<46,521.>	<329,241.>	
Net Assets or Fund Balances	20 Total assets (Part X, line 16)	Beginning of Current Year 2,874,508.	End of Year 2,398,499.
	21 Total liabilities (Part X, line 26)	165,523.	279,616.
	22 Net assets or fund balances. Subtract line 21 from line 20	2,708,985.	2,118,883.

Part II Signature Block

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

Sign Here	Signature of officer	Date 4/19/19			
	BRETT KOPELAN, EXEC.DIRECTOR Type or print name and title				
Paid Preparer Use Only	Print/Type preparer's name BRIAN C. WHITE	Preparer's signature 	Date 4-3-19	Check if self-employed <input type="checkbox"/>	PTIN P00058320
	Firm's name ▶ STUDLEY, WHITE & ASSOCIATES, P.C.	Firm's EIN ▶ 06-0990132	Firm's address ▶ P.O. BOX 399 DANBURY, CT 06813	Phone no. 203.748.6517	

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

DYSTROPHIC EPIDERMOLYSIS BULLOSA

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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 [X]

1 Briefly describe the organization's mission:

DEBRA IS DEDICATED TO FINDING A CURE FOR EB, WHICH AFFECTS 1 OUT OF EVERY 50,000 LIVE BIRTHS IN THE UNITED STATES TODAY. EB IS A GENETICALLY BASED DISEASE CHARACTERIZED BY CHRONIC, PAINFUL BLISTERING. THE SKIN AND MUCOUS MEMBRANES ARE SO FRAGILE THAT THE

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ? [] Yes [X] No 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 [X] 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 \$ 389,769. including grants of \$) (Revenue \$ 6,126.) PUBLIC AND PROFESSIONAL EDUCATION - EDUCATE THE PUBLIC & HEALTH PROFESSIONALS ABOUT DYSTROPHIC EPIDERMOLYSIS BULLOSA "EB"

4b (Code:) (Expenses \$ 1,218,364. including grants of \$) (Revenue \$) PATIENT & FAMILY SERVICES - PROVIDE SERVICES FOR PEOPLE WITH EB & THEIR FAMILIES THRU NEWSLETTERS, COUNSELING PEER SUPPORT SERVICES, CONFERENCES AND SEMINARS

4c (Code:) (Expenses \$ 58,465. including grants of \$) (Revenue \$) ADVOCACY - NETWORK WITH OTHER PROFESSIONAL ORGANIZATIONS & MEET KEY LEGISLATORS TO INFORM THEM OF EB AND SECURE RESEARCH FUNDS

4d Other program services (Describe in Schedule O.) (Expenses \$ 194,884. including grants of \$) (Revenue \$)

4e Total program service expenses 1,861,482.

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Part IV Checklist of Required Schedules

		Yes	No
1	Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? <i>If "Yes," complete Schedule A</i>	X	
2	Is the organization required to complete <i>Schedule B, Schedule of Contributors</i> ?	X	
3	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? <i>If "Yes," complete Schedule C, Part I</i>		X
4	Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? <i>If "Yes," complete Schedule C, Part II</i>		X
5	Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? <i>If "Yes," complete Schedule C, Part III</i>		X
6	Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? <i>If "Yes," complete Schedule D, Part I</i>		X
7	Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? <i>If "Yes," complete Schedule D, Part II</i>		X
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If "Yes," complete Schedule D, Part III</i>		X
9	Did the organization report an amount in Part X, line 21, for escrow or custodial account liability, serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? <i>If "Yes," complete Schedule D, Part IV</i>		X
10	Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi-endowments? <i>If "Yes," complete Schedule D, Part V</i>		X
11	If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable.		
a	Did the organization report an amount for land, buildings, and equipment in Part X, line 10? <i>If "Yes," complete Schedule D, Part VI</i>	X	
b	Did the organization report an amount for investments - other securities in Part X, line 12 that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VII</i>		X
c	Did the organization report an amount for investments - program related in Part X, line 13 that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VIII</i>		X
d	Did the organization report an amount for other assets in Part X, line 15 that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part IX</i>		X
e	Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X</i>	X	
f	Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? <i>If "Yes," complete Schedule D, Part X</i>	X	
12a	Did the organization obtain separate, independent audited financial statements for the tax year? <i>If "Yes," complete Schedule D, Parts XI and XII</i>	X	
b	Was the organization included in consolidated, independent audited financial statements for the tax year? <i>If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional</i>		X
13	Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E</i>		X
14a	Did the organization maintain an office, employees, or agents outside of the United States?		X
b	Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? <i>If "Yes," complete Schedule F, Parts I and IV</i>		X
15	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? <i>If "Yes," complete Schedule F, Parts II and IV</i>	X	
16	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? <i>If "Yes," complete Schedule F, Parts III and IV</i>		X
17	Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? <i>If "Yes," complete Schedule G, Part I</i>		X
18	Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? <i>If "Yes," complete Schedule G, Part II</i>	X	
19	Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? <i>If "Yes," complete Schedule G, Part III</i>		X
20a	Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H</i>		X
b	If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?		
21	Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>		X

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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? <i>If "Yes," complete Schedule I, Parts I and III</i>		X
23	Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J</i>	X	
24a	Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a</i>		X
b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?		
c	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?		
d	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? <i>If "Yes," complete Schedule L, Part I</i>		X
b	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I</i>		X
26	Did the organization report any amount on Part X, line 5, 6, or 22 for receivables from or payables to any current or former officers, directors, trustees, key employees, highest compensated employees, or disqualified persons? <i>If "Yes," complete Schedule L, Part II</i>		X
27	Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i>		X
28	Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions):		
a	A current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>		X
b	A family member of a current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>		X
c	An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer, director, trustee, or direct or indirect owner? <i>If "Yes," complete Schedule L, Part IV</i>		X
29	Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i>	X	
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i>		X
31	Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>		X
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II</i>		X
33	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If "Yes," complete Schedule R, Part I</i>		X
34	Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1</i>		X
35a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?		X
b	If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i>		
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i>		X
37	Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? <i>If "Yes," complete Schedule R, Part VI</i>		X
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19?	X	

Note. All Form 990 filers are required to complete Schedule O

Part V Statements Regarding Other IRS Filings and Tax Compliance

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

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

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

		Yes	No
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return	0	
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns? Note. If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)		
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?		X
b	If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation in Schedule O		
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?		X
b	If "Yes," enter the name of the foreign country: See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).		
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?		X
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?		X
c	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?		
6a	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions?		X
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?		
7	Organizations that may receive deductible contributions under section 170(c).		
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?		X
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?		
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?		X
d	If "Yes," indicate the number of Forms 8282 filed during the year		
e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?		
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?		
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?		
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?		
8	Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?		
9	Sponsoring organizations maintaining donor advised funds.		
a	Did the sponsoring organization make any taxable distributions under section 4966?		
b	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?		
10	Section 501(c)(7) organizations. Enter:		
a	Initiation fees and capital contributions included on Part VIII, line 12		
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities		
11	Section 501(c)(12) organizations. Enter:		
a	Gross income from members or shareholders		
b	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them.)		
12a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?		
b	If "Yes," enter the amount of tax-exempt interest received or accrued during the year		
13	Section 501(c)(29) qualified nonprofit health insurance issuers.		
a	Is the organization licensed to issue qualified health plans in more than one state? Note. See the instructions for additional information the organization must report on Schedule O.		
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		
c	Enter the amount of reserves on hand		
14a	Did the organization receive any payments for indoor tanning services during the tax year?		X
b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O		
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? If "Yes," see instructions and file Form 4720, Schedule N.		X
16	Is the organization an educational institution subject to the section 4968 excise tax on net investment income? If "Yes," complete Form 4720, Schedule O.		X

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

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

Section A. Governing Body and Management

Table with 3 columns: Question, Yes, No. Rows include: 1a Enter the number of voting members of the governing body at the end of the tax year (14); 1b Enter the number of voting members included in line 1a, above, who are independent (14); 2 Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee? (X); 3 Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors, or trustees, or key employees to a management company or other person? (X); 4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed? (X); 5 Did the organization become aware during the year of a significant diversion of the organization's assets? (X); 6 Did the organization have members or stockholders? (X); 7a Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body? (X); 7b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body? (X); 8a The governing body? (X); 8b Each committee with authority to act on behalf of the governing body? (X); 9 Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses in Schedule O (X).

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

Table with 3 columns: Question, Yes, No. Rows include: 10a Did the organization have local chapters, branches, or affiliates? (X); 10b 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?; 11a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? (X); 11b Describe in Schedule O the process, if any, used by the organization to review this Form 990.; 12a Did the organization have a written conflict of interest policy? If "No," go to line 13 (X); 12b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? (X); 12c Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done (X); 13 Did the organization have a written whistleblower policy? (X); 14 Did the organization have a written document retention and destruction policy? (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? 15a The organization's CEO, Executive Director, or top management official (X); 15b Other officers or key employees of the organization (X); 16a Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year? (X); 16b 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?

Section C. Disclosure

- 17 List the states with which a copy of this Form 990 is required to be filed NY, MI, MA, NJ, 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 [X] Upon request [] Other (explain in Schedule O)
19 Describe in Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.
20 State the name, address, and telephone number of the person who possesses the organization's books and records BRETT KOPELAN - 212.868.1573 75 BROAD ST SUITE 300, NEW YORK, NY 10004

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

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

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

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

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

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

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

(A) Name and Title	(B) Average hours per week (list any hours for related organizations below line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(1) FAITH DANIELS DIRECTOR	1.00	X					0.	0.	0.	
(2) J ALEC ALEXANDER TREASURER	1.00	X		X			0.	0.	0.	
(3) FRANK KACMARSKY DIRECTOR	1.00	X					0.	0.	0.	
(4) ANDREW TAVANI CHAIR	1.00	X		X			0.	0.	0.	
(5) RICHARD GALLAGHER DIRECTOR	1.00	X					0.	0.	0.	
(6) DR ROBERT MEIROWITZ DIRECTOR	1.00	X					0.	0.	0.	
(7) BRETT KOPELAN EXECUTIVE DIRECTOR	40.00	X		X			155,938.	0.	0.	
(8) JOHN LEE DIRECTOR	1.00	X					0.	0.	0.	
(9) WILLIAM CORNMAN DIRECTOR	1.00	X					0.	0.	0.	
(10) ROBERT RAYL DIRECTOR	1.00	X					0.	0.	0.	
(11) JAMES WETRICH DIRECTOR	1.00	X					0.	0.	0.	
(12) LESLIE RADER CHAIR EMERITUS	1.00	X					0.	0.	0.	
(13) JOUI UITTO MD, PH.D DIRECTOR	1.00	X					0.	0.	0.	
(14) ANGELA CHRISTIANO PH.D. DIRECTOR	1.00	X					0.	0.	0.	
(15) ROBERT RYAN PHD DIRECTOR	1.00						0.	0.	0.	

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
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Part VIII Statement of Revenue

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

			(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512 - 514
Contributions, Gifts, Grants and Other Similar Amounts	1 a Federated campaigns	1a				
	b Membership dues	1b				
	c Fundraising events	1c				
	d Related organizations	1d				
	e Government grants (contributions)	1e				
	f All other contributions, gifts, grants, and similar amounts not included above	1f	947,956.			
	g Noncash contributions included in lines 1a-1f: \$					
h Total. Add lines 1a-1f			947,956.			
Program Service Revenue	2 a _____ Business Code					
	b _____					
	c _____					
	d _____					
	e _____					
	f All other program service revenue					
	g Total. Add lines 2a-2f					
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)		1,956.			1,956.
	4 Income from investment of tax-exempt bond proceeds					
	5 Royalties					
	6 a Gross rents	(i) Real (ii) Personal				
	b Less: rental expenses					
	c Rental income or (loss)					
	d Net rental income or (loss)					
	7 a Gross amount from sales of assets other than inventory	(i) Securities (ii) Other				
	b Less: cost or other basis and sales expenses					
	c Gain or (loss)					
	d Net gain or (loss)					
	8 a Gross income from fundraising events (not including \$ _____ of contributions reported on line 1c). See Part IV, line 18	a	1,126,574.			
	b Less: direct expenses	b	258,045.			
	c Net income or (loss) from fundraising events		868,529.			868,529.
	9 a Gross income from gaming activities. See Part IV, line 19	a				
b Less: direct expenses	b					
c Net income or (loss) from gaming activities						
10 a Gross sales of inventory, less returns and allowances	a					
b Less: cost of goods sold	b					
c Net income or (loss) from sales of inventory						
Miscellaneous Revenue		Business Code				
11 a MISCELLANEOUS INCOME		900099	6,126.	6,126.		
b _____						
c _____						
d All other revenue						
e Total. Add lines 11a-11d			6,126.			
12 Total revenue. See instructions			1,824,567.	6,126.	0.	870,485.

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Part IX Statement of Functional Expenses

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

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

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21				
2 Grants and other assistance to domestic individuals. See Part IV, line 22				
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				
6 Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)				
7 Other salaries and wages	806,329.	685,380.	40,316.	80,633.
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
9 Other employee benefits	107,429.	91,315.	5,371.	10,743.
10 Payroll taxes	71,554.	60,821.	3,578.	7,155.
11 Fees for services (non-employees):				
a Management				
b Legal				
c Accounting				
d Lobbying				
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 Sch O.)	184,486.	156,813.	9,224.	18,449.
12 Advertising and promotion	9,401.	7,991.	470.	940.
13 Office expenses	84,646.	71,949.	4,232.	8,465.
14 Information technology				
15 Royalties				
16 Occupancy	94,200.	80,070.	4,710.	9,420.
17 Travel	141,094.	119,930.	7,055.	14,109.
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	363,053.	308,595.	18,153.	36,305.
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	2,371.	2,015.	119.	237.
23 Insurance	13,106.	11,140.	655.	1,311.
24 Other expenses. Itemize expenses not covered above. (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
a <u>PATIENT ASSISTANCE</u>	204,965.	204,965.		
b <u>DUES & SUBSCRIPTIONS</u>	30,166.	25,641.	1,508.	3,017.
c <u>TELEPHONE</u>	19,032.	16,177.	952.	1,903.
d <u>EQUIPMENT</u>	13,722.	11,664.	686.	1,372.
e All other expenses	8,254.	7,016.	413.	825.
25 Total functional expenses. Add lines 1 through 24e	2,153,808.	1,861,482.	97,442.	194,884.
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation.				

Check here if following SOP 98-2 (ASC 958-720)

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Part X Balance Sheet

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

		(A) Beginning of year		(B) End of year
Assets	1 Cash - non-interest-bearing	1,251,711.	1	1,135,515.
	2 Savings and temporary cash investments	742,540.	2	669,957.
	3 Pledges and grants receivable, net		3	
	4 Accounts receivable, net	72,681.	4	5,043.
	5 Loans and other receivables from current and former officers, directors, trustees, key employees, and highest compensated employees. Complete Part II of Schedule L		5	
	6 Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing employers and sponsoring organizations of section 501(c)(9) voluntary employees' beneficiary organizations (see instr). Complete Part II of Sch L		6	
	7 Notes and loans receivable, net		7	
	8 Inventories for sale or use	756,107.	8	579,177.
	9 Prepaid expenses and deferred charges	49,098.	9	8,807.
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	34,487.		
	b Less: accumulated depreciation	34,487.	2,371.	0.
	11 Investments - publicly traded securities		11	
	12 Investments - other securities. See Part IV, line 11		12	
	13 Investments - program-related. See Part IV, line 11		13	
	14 Intangible assets		14	
	15 Other assets. See Part IV, line 11		15	
16 Total assets. Add lines 1 through 15 (must equal line 34)	2,874,508.	16	2,398,499.	
Liabilities	17 Accounts payable and accrued expenses	73,617.	17	182,005.
	18 Grants payable		18	
	19 Deferred revenue		19	
	20 Tax-exempt bond liabilities		20	
	21 Escrow or custodial account liability. Complete Part IV of Schedule D		21	
	22 Loans and other payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons. Complete Part II of Schedule L		22	
	23 Secured mortgages and notes payable to unrelated third parties		23	
	24 Unsecured notes and loans payable to unrelated third parties		24	
	25 Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24). Complete Part X of Schedule D	91,906.	25	97,611.
	26 Total liabilities. Add lines 17 through 25	165,523.	26	279,616.
Net Assets or Fund Balances	Organizations that follow SFAS 117 (ASC 958), check here <input checked="" type="checkbox"/> and complete lines 27 through 29, and lines 33 and 34.			
	27 Unrestricted net assets	1,857,982.	27	1,304,758.
	28 Temporarily restricted net assets	851,003.	28	814,125.
	29 Permanently restricted net assets		29	
	Organizations that do not follow SFAS 117 (ASC 958), check here <input type="checkbox"/> and complete lines 30 through 34.			
	30 Capital stock or trust principal, or current funds		30	
	31 Paid-in or capital surplus, or land, building, or equipment fund		31	
	32 Retained earnings, endowment, accumulated income, or other funds		32	
33 Total net assets or fund balances	2,708,985.	33	2,118,883.	
34 Total liabilities and net assets/fund balances	2,874,508.	34	2,398,499.	

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Part XI Reconciliation of Net Assets

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	1,824,567.
2	Total expenses (must equal Part IX, column (A), line 25)	2	2,153,808.
3	Revenue less expenses. Subtract line 2 from line 1	3	<329,241.>
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	2,708,985.
5	Net unrealized gains (losses) on investments	5	<73,879.>
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain in Schedule O)	9	<186,982.>
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 33, column (B))	10	2,118,883.

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.		
2a Were the organization's financial statements compiled or reviewed by an independent accountant?		X
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		
b Were the organization's financial statements audited by an independent accountant?	X	
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		
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?	X	
If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O.		
3a As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133?		X
b If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits		

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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) 2014	(b) 2015	(c) 2016	(d) 2017	(e) 2018	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	1052072.	649,364.	749,944.	662,523.		3113903.
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
3 The value of services or facilities furnished by a governmental unit to the organization without charge						
4 Total. Add lines 1 through 3	1052072.	649,364.	749,944.	662,523.		3113903.
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)						
6 Public support. Subtract line 5 from line 4.						3113903.

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2014	(b) 2015	(c) 2016	(d) 2017	(e) 2018	(f) Total
7 Amounts from line 4	1052072.	649,364.	749,944.	662,523.		3113903.
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources	1,081.	3,168.	303.	554.		5,106.
9 Net income from unrelated business activities, whether or not the business is regularly carried on						
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
11 Total support. Add lines 7 through 10						3119009.
12 Gross receipts from related activities, etc. (see instructions)					12	
13 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here						<input type="checkbox"/>

Section C. Computation of Public Support Percentage

14 Public support percentage for 2018 (line 6, column (f) divided by line 11, column (f))	14	99.84 %
15 Public support percentage from 2017 Schedule A, Part II, line 14	15	99.77 %
16a 33 1/3% support test - 2018. 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 - 2017. 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 - 2018. 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 - 2017. 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"/>

DYSTROPHIC EPIDERMOLYSIS BULLOSA

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) 2014	(b) 2015	(c) 2016	(d) 2017	(e) 2018	(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) 2014	(b) 2015	(c) 2016	(d) 2017	(e) 2018	(f) Total
9 Amounts from line 6						
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b						
11 Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
13 Total support. (Add lines 9, 10c, 11, and 12.)						

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

Section C. Computation of Public Support Percentage

15 Public support percentage for 2018 (line 8, column (f), divided by line 13, column (f))	15	%
16 Public support percentage from 2017 Schedule A, Part III, line 15	16	%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2018 (line 10c, column (f), divided by line 13, column (f))	17	%
18 Investment income percentage from 2017 Schedule A, Part III, line 17	18	%

19a 33 1/3% support tests - 2018. 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 - 2017. 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

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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? <i>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.</i>		
2 Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? <i>If "Yes," explain in Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).</i>		
3a Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? <i>If "Yes," answer (b) and (c) below.</i>		
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)? <i>If "Yes," describe in Part VI when and how the organization made the determination.</i>		
c Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? <i>If "Yes," explain in Part VI what controls the organization put in place to ensure such use.</i>		
4a Was any supported organization not organized in the United States ("foreign supported organization")? <i>If "Yes," and if you checked 12a or 12b in Part I, answer (b) and (c) below.</i>		
b Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? <i>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.</i>		
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)? <i>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.</i>		
5a Did the organization add, substitute, or remove any supported organizations during the tax year? <i>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).</i>		
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? <i>If "Yes," provide detail in Part VI.</i>		
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? <i>If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).</i>		
8 Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? <i>If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).</i>		
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))? <i>If "Yes," provide detail in Part VI.</i>		
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? <i>If "Yes," provide detail in Part VI.</i>		
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? <i>If "Yes," provide detail in Part VI.</i>		
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)? <i>If "Yes," answer 10b below.</i>		
b Did the organization have any excess business holdings in the tax year? <i>(Use Schedule C, Form 4720, to determine whether the organization had excess business holdings.)</i>		

Part IV Supporting Organizations (continued)

Table with 3 columns: Question, Yes, No. Row 11: Has the organization accepted a gift or contribution from any of the following persons? Row 11a: 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? Row 11b: A family member of a person described in (a) above? Row 11c: 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

Table with 3 columns: Question, Yes, No. Row 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? Row 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

Table with 3 columns: Question, Yes, No. Row 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

Table with 3 columns: Question, Yes, No. Row 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? Row 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). Row 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

Table with 3 columns: Question, Yes, No. Row 1: Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions). Row 2: Activities Test. Answer (a) and (b) below. Row 2a: 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? Row 2b: 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? Row 3: Parent of Supported Organizations. Answer (a) and (b) below. Row 3a: 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? Row 3b: 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.

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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		(A) Prior Year	(B) Current Year
1	Adjusted net income for prior year (from Section A, line 8, Column A)	1	Current Year
2	Enter 85% of line 1	2	
3	Minimum asset amount for prior year (from Section B, line 8, Column A)	3	
4	Enter greater of line 2 or line 3	4	
5	Income tax imposed in prior year	5	
6	Distributable Amount. Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions)	6	

7 Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see instructions).

DYSTROPHIC EPIDERMOLYSIS BULLOSA

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 2018 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-2018	(iii) Distributable Amount for 2018
1 Distributable amount for 2018 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2018 (reasonable cause required- explain in Part VI). See instructions.			
3 Excess distributions carryover, if any, to 2018			
a From 2013			
b From 2014			
c From 2015			
d From 2016			
e From 2017			
f Total of lines 3a through e			
g Applied to underdistributions of prior years			
h Applied to 2018 distributable amount			
i Carryover from 2013 not applied (see instructions)			
j Remainder. Subtract lines 3g, 3h, and 3i from 3f.			
4 Distributions for 2018 from Section D, line 7: \$			
a Applied to underdistributions of prior years			
b Applied to 2018 distributable amount			
c Remainder. Subtract lines 4a and 4b from 4.			
5 Remaining underdistributions for years prior to 2018, 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 2018. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in Part VI. See instructions.			
7 Excess distributions carryover to 2019. Add lines 3j and 4c.			
8 Breakdown of line 7:			
a Excess from 2014			
b Excess from 2015			
c Excess from 2016			
d Excess from 2017			
e Excess from 2018			

Schedule B

(Form 990, 990-EZ, or 990-PF)

Department of the Treasury
Internal Revenue Service

Schedule of Contributors

▶ Attach to Form 990, Form 990-EZ, or Form 990-PF.
▶ Go to www.irs.gov/Form990 for the latest information.

OMB No. 1545-0047

2018

Name of the organization

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA**

Employer identification number

11-2519726

Organization type (check one):

Filers of:

Section:

Form 990 or 990-EZ

501(c)(3) (enter number) organization

4947(a)(1) nonexempt charitable trust **not** treated as a private foundation

527 political organization

Form 990-PF

501(c)(3) exempt private foundation

4947(a)(1) nonexempt charitable trust treated as a private foundation

501(c)(3) taxable private foundation

Check if your organization is covered by the **General Rule** or a **Special Rule**.

Note: Only a section 501(c)(7), (8), or (10) organization can check boxes for both the General Rule and a Special Rule. See instructions.

General Rule

For an organization filing Form 990, 990-EZ, or 990-PF that received, during the year, contributions totaling \$5,000 or more (in money or property) from any one contributor. Complete Parts I and II. See instructions for determining a contributor's total contributions.

Special Rules

For an organization described in section 501(c)(3) filing Form 990 or 990-EZ that met the 33 1/3% support test of the regulations under sections 509(a)(1) and 170(b)(1)(A)(vi), that checked Schedule A (Form 990 or 990-EZ), Part II, line 13, 16a, or 16b, and that received from any one contributor, during the year, total contributions of the greater of (1) \$5,000; or (2) 2% of the amount on (i) Form 990, Part VIII, line 1h; or (ii) Form 990-EZ, line 1. Complete Parts I and II.

For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, total contributions of more than \$1,000 *exclusively* for religious, charitable, scientific, literary, or educational purposes, or for the prevention of cruelty to children or animals. Complete Parts I (entering "N/A" in column (b) instead of the contributor name and address), II, and III.

For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions *exclusively* for religious, charitable, etc., purposes, but no such contributions totaled more than \$1,000. If this box is checked, enter here the total contributions that were received during the year for an *exclusively* religious, charitable, etc., purpose. Don't complete any of the parts unless the **General Rule** applies to this organization because it received *nonexclusively* religious, charitable, etc., contributions totaling \$5,000 or more during the year ▶ \$ _____

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

Name of organization DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA	Employer identification number 11-2519726
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Part I Contributors (see instructions). Use duplicate copies of Part I if additional space is needed.

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
1	J ALEC & CINDI ALEXANDER 3398 HARBOUR POINT PKWY GAINESVILLE, GA 30506	\$ 62,070.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
2	JOHN LEE 555 MONTGOMERY ST SAN FRANCISCO, CA 94111	\$ 100,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
3	RICHARD GALLAGHER 150 BOARDMAN CT LAKE BLUFF, IL 60044	\$ 53,390.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
4	MOLNLYCKE HEALTH CARE 5550 PEACHTREE PARKWAY NORCROSS, GA 30092	\$ 123,600.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
5	MCKESSON PATIENT CARE SOLUTIONS 540 LINDBERGH DR MOON TOWNSHIP, PA 15143	\$ 25,250.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
6	FIBROCELL 400 EAGLEVIEW BLVD EXTON, PA 19341	\$ 40,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)

Name of organization DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA	Employer identification number 11-2519726
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Part I Contributors (see instructions). Use duplicate copies of Part I if additional space is needed.

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
7	<u>ROBERT COULL & PAMELA MAYER</u> <u>229 W 60TH ST</u> <u>NEW YORK, NY 10023</u>	\$ <u>19,151.</u>	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
8	<u>WILLIAM & LINDA YOUNG</u> <u>3220 ARBOR LANE</u> <u>PRAIRIE GROVE, IL 60012</u>	\$ <u>22,825.</u>	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
9	<u>AMICUS THERAPEUTICS</u> <u>1 CEDAR BROOK DR</u> <u>CRANBURY, NJ 08512</u>	\$ <u>40,150.</u>	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
10	<u>CASTLE CREEK PHARMACEUTICALS</u> <u>6 CENTURY DR</u> <u>PARSIPPANY, NJ 07054</u>	\$ <u>39,400.</u>	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
11	<u>BERG</u> <u>500 OLD CONNECTICUT PATH</u> <u>FRAMINGHAM, MA 01701</u>	\$ <u>86,336.</u>	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
12	<u>FACEBOOK</u> <u>1601 WILLOW RD</u> <u>MENLO PARK, CA 94025</u>	\$ <u>55,642.</u>	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)

Name of organization DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA	Employer identification number 11-2519726
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Part I Contributors (see instructions). Use duplicate copies of Part I if additional space is needed.

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
13	3M 3M CENTER ST PAUL, MN 55144	\$ 33,217.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
14	ABEONA THERAPEUTICS 333 LEE PARKWAY DALLAS, TX 75219	\$ 34,878.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
_____	_____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
_____	_____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
_____	_____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
_____	_____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)

Name of organization

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA**

Employer identification number

11-2519726

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

(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
	<hr/> <hr/> <hr/> <hr/>	\$ _____	_____
	<hr/> <hr/> <hr/> <hr/>	\$ _____	_____
	<hr/> <hr/> <hr/> <hr/>	\$ _____	_____
	<hr/> <hr/> <hr/> <hr/>	\$ _____	_____
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	<hr/> <hr/> <hr/> <hr/>	\$ _____	_____
	<hr/> <hr/> <hr/> <hr/>	\$ _____	_____

Name of organization DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA	Employer identification number 11-2519726
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Part III Exclusively religious, charitable, etc., contributions to organizations described in section 501(c)(7), (8), or (10) that total more than \$1,000 for the year from any one contributor. Complete columns (a) through (e) and the following line entry. For organizations completing Part III, enter the total of exclusively religious, charitable, etc., contributions of \$1,000 or less for the year. (Enter this info. once.) ► \$ _____
Use duplicate copies of Part III if additional space is needed.

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
(e) Transfer of gift			
Transferee's name, address, and ZIP + 4		Relationship of transferor to transferee	
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
(e) Transfer of gift			
Transferee's name, address, and ZIP + 4		Relationship of transferor to transferee	
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
(e) Transfer of gift			
Transferee's name, address, and ZIP + 4		Relationship of transferor to transferee	
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
(e) Transfer of gift			
Transferee's name, address, and ZIP + 4		Relationship of transferor to transferee	

SCHEDULE D (Form 990)

Supplemental Financial Statements

OMB No. 1545-0047

2018

Open to Public Inspection

Department of the Treasury Internal Revenue Service

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.

Name of the organization DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA Employer identification number 11-2519726

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.

Table with 2 columns: (a) Donor advised funds, (b) Funds and other accounts. Rows include: 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?, 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?

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

Table with 2 columns: Held at the End of the Tax Year. Rows include: 1 Purpose(s) of conservation easements held by the organization (check all that apply), 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, 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?, 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)?, 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.

Table with 2 columns: \$. Rows include: 1a If the organization elected, as permitted under SFAS 116 (ASC 958), not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIII, the text of the footnote to its financial statements that describes these items. b If the organization elected, as permitted under SFAS 116 (ASC 958), to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items: (i) Revenue included 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 SFAS 116 (ASC 958) relating to these items: a Revenue included on Form 990, Part VIII, line 1, b Assets included in Form 990, Part X

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

Schedule D (Form 990) 2018

DYSTROPHIC EPIDERMOLYSIS BULLOSA

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

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

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

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

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

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

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

b If "Yes," explain the arrangement in Part XIII and complete the following table:

	Amount
c Beginning balance	1c
d Additions during the year	1d
e Distributions during the year	1e
f Ending balance	1f

2a Did the organization include an amount on Form 990, Part X, line 21, 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
1a Beginning of year balance					
b Contributions					
c Net investment earnings, gains, and losses					
d Grants or scholarships					
e Other expenditures for facilities and programs					
f Administrative expenses					
g End of year balance					

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

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

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

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

	Yes	No
(i) unrelated organizations	3a(i)	
(ii) related organizations	3a(ii)	

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

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

Part VI Land, Buildings, and Equipment.

Complete if the organization answered "Yes" 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
1a Land				
b Buildings				
c Leasehold improvements				
d Equipment				
e Other		34,487.	34,487.	0.
Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10c.)				0.

Part VII Investments - Other Securities.

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

Table with 3 columns: (a) Description of security or category, (b) Book value, (c) Method of valuation. Rows include Financial derivatives, Closely-held equity interests, and Other (A-H).

Part VIII Investments - Program Related.

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

Table with 3 columns: (a) Description of investment, (b) Book value, (c) Method of valuation. Rows numbered 1 through 9.

Part IX Other Assets.

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

Table with 2 columns: (a) Description, (b) Book value. Rows numbered 1 through 9.

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.

Table with 2 columns: (a) Description of liability, (b) Book value. Row 1 includes Federal income taxes and AGENCY FUNDS HELD FOR OTHER with a value of 97,611.

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

DYSTROPHIC EPIDERMOLYSIS BULLOSA

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	2,681,865.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
a	Net unrealized gains (losses) on investments	2a	<73,879.>	
b	Donated services and use of facilities	2b	931,177.	
c	Recoveries of prior year grants	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d	2e		857,298.
3	Subtract line 2e from line 1	3		1,824,567.
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a		
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b	4c		0.
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)	5		1,824,567.

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	3,271,967.
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.)	2d	1,118,159.	
e	Add lines 2a through 2d	2e		1,118,159.
3	Subtract line 2e from line 1	3		2,153,808.
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a		
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b	4c		0.
5	Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.)	5		2,153,808.

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, LINE 2:

THE ORGANIZATION RECOGNIZES THE EFFECT OF TAX POSITIONS ONLY WHEN THEY ARE MORE LIKELY THAN NOT OF BEING SUSTAINED. MANAGEMENT HAS DETERMINED THAT THE ORGANIZATION HAD NO UNCERTAIN TAX POSITIONS THAT WOULD REQUIRE FINANCIAL STATEMENT RECOGNITION. TAX YEARS DATING BACK TO 2016 REMAIN OPEN TO EXAMINATION BY FEDERAL AND STATE AUTHORITIES.

PART XII, LINE 2D - OTHER ADJUSTMENTS:

<u>DONATED MEDICAL SUPPLIES</u>	<u>1,106,503.</u>
<u>IN KIND LEGAL</u>	<u>11,656.</u>
<u>TOTAL TO SCHEDULE D, PART XII, LINE 2D</u>	<u>1,118,159.</u>

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA**

11-2519726

Schedule F (Form 990) 2018

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

1	(a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of noncash assistance	(h) Description of noncash assistance	(i) Method of valuation (book, FMV, appraisal, other)
			EUROPE	TO FUND INTERNATIONAL RESEARCH TO FIND A CURE FOR EPIDERMOLYSIS BULLOSA	35,000.	CASH TRANSFER	0.		FMV
			CENTRAL AMERICA	TO FUND INTERNATIONAL RESEARCH TO FIND A CURE FOR EPIDERMOLYSIS BULLOSA	20,500.	CASH TRANSFER	0.		FMV

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

3 Enter total number of other organizations or entities

Part IV Foreign Forms

- 1 Was the organization a U.S. transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926)* Yes No
- 2 Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to separately file Form 3520, Annual Return To Report Transactions With Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see Instructions for Forms 3520 and 3520-A; don't file with Form 990)* Yes No
- 3 Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons With Respect To Certain Foreign Corporations (see Instructions for Form 5471)* Yes No
- 4 Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see Instructions for Form 8621)* Yes No
- 5 Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign Partnerships (see Instructions for Form 8865)* Yes No
- 6 Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to separately file Form 5713, International Boycott Report (see Instructions for Form 5713; don't file with Form 990)* Yes No

Part V Supplemental Information

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

Lined area for supplemental information.

DYSTROPHIC EPIDERMOLYSIS BULLOSA

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 (add col. (a) through col. (c))
		ANNUAL FUNDRAISER (event type)	RAFFIS RUN/MARATHON (event type)	NONE (total number)	
Revenue	1	Gross receipts	322,256.	804,318.	1,126,574.
	2	Less: Contributions			
	3	Gross income (line 1 minus line 2)	322,256.	804,318.	1,126,574.
Direct Expenses	4	Cash prizes			
	5	Noncash prizes			
	6	Rent/facility costs			
	7	Food and beverages			
	8	Entertainment			
	9	Other direct expenses	138,630.	134,105.	272,735.
	10	Direct expense summary. Add lines 4 through 9 in column (d)			272,735.
	11	Net income summary. Subtract line 10 from line 3, column (d)			853,839.

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 col. (a) through col. (c))	
Revenue	1	Gross revenue				
	Direct Expenses	2	Cash prizes			
		3	Noncash prizes			
		4	Rent/facility costs			
		5	Other direct expenses			
6	Volunteer labor	<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: _____

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

**DYSTROPHIC EPIDERMOLYSIS BULLIOSA
RESEARCH ASSOCIATION OF AMERICA**

11-2519726 Page 2

Schedule I (Form 990) (2018)

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 non-cash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance

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:

THE BOARD OF DIRECTORS REVIEWS AND APPROVES ALL REQUEST FOR RESEARCH FUNDS.

THE ENTITY RECEIVING RESEARCH FUNDS PROVIDES WRITTEN UPDATES ON THE USE OF

THE FUNDS.

**SCHEDULE J
(Form 990)**

Compensation Information

OMB No. 1545-0047

2018

Open to Public Inspection

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.

Department of the Treasury
Internal Revenue Service

Name of the organization **DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA** Employer identification number **11-2519726**

Part I Questions Regarding Compensation

	Yes	No
1a 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. <input type="checkbox"/> First-class or charter travel <input type="checkbox"/> Travel for companions <input type="checkbox"/> Tax indemnification and gross-up payments <input type="checkbox"/> Discretionary spending account <input type="checkbox"/> Housing allowance or residence for personal use <input type="checkbox"/> Payments for business use of personal residence <input type="checkbox"/> Health or social club dues or initiation fees <input type="checkbox"/> 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	1b	
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?	2	
3 Indicate which, if any, of the following the filing 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. <input checked="" type="checkbox"/> Compensation committee <input type="checkbox"/> Independent compensation consultant <input type="checkbox"/> Form 990 of other organizations <input type="checkbox"/> Written employment contract <input type="checkbox"/> Compensation survey or study <input type="checkbox"/> 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?	4a	X
b Participate in, or receive payment from, a supplemental nonqualified retirement plan?	4b	X
c Participate in, or receive payment from, an equity-based compensation arrangement?	4c	X
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?	5a	X
b Any related organization?	5b	X
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?	6a	X
b Any related organization?	6b	X
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	7	X
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	8	X
9 If "Yes" on line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53.4958-6(c)?	9	

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

Schedule J (Form 990) 2018

**SCHEDULE M
(Form 990)**

Noncash Contributions

OMB No. 1545-0047

2018

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

- ▶ Complete if the organizations answered "Yes" on Form 990, Part IV, lines 29 or 30.
- ▶ Attach to Form 990.
- ▶ Go to www.irs.gov/Form990 for instructions and the latest information.

Name of the organization **DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA** Employer identification number **11-2519726**

Part I Types of Property

	(a) Check if applicable	(b) Number of contributions or items contributed	(c) Noncash contribution amounts reported on Form 990, Part VIII, line 1g	(d) Method of determining noncash contribution amounts
1 Art - Works of art				
2 Art - Historical treasures				
3 Art - Fractional interests				
4 Books and publications				
5 Clothing and household goods				
6 Cars and other vehicles				
7 Boats and planes				
8 Intellectual property				
9 Securities - Publicly traded				
10 Securities - Closely held stock				
11 Securities - Partnership, LLC, or trust interests				
12 Securities - Miscellaneous				
13 Qualified conservation contribution - Historic structures				
14 Qualified conservation contribution - Other				
15 Real estate - Residential				
16 Real estate - Commercial				
17 Real estate - Other				
18 Collectibles				
19 Food inventory				
20 Drugs and medical supplies	X	5	1,106,503.FMV	
21 Taxidermy				
22 Historical artifacts				
23 Scientific specimens				
24 Archeological artifacts				
25 Other ▶ (<u>LEGAL SERVICE</u>)	X	1	1.FAIR MARKET VALUE	
26 Other ▶ (_____)				
27 Other ▶ (_____)				
28 Other ▶ (_____)				

29 Number of Forms 8283 received by the organization during the tax year for contributions for which the organization completed Form 8283, Part IV, Donee Acknowledgement **29**

	Yes	No
30a During the year, did the organization receive by contribution any property reported in Part I, lines 1 through 28, that it must hold for at least three years from the date of the initial contribution, and which isn't required to be used for exempt purposes for the entire holding period?		X
b If "Yes," describe the arrangement in Part II.		
31 Does the organization have a gift acceptance policy that requires the review of any nonstandard contributions?		X
32a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash contributions?		X
b If "Yes," describe in Part II.		
33 If the organization didn't report an amount in column (c) for a type of property for which column (a) is checked, describe in Part II.		

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990. Schedule M (Form 990) 2018

SCHEDULE O
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

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

▶ Attach to Form 990 or 990-EZ.

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

OMB No. 1545-0047

2018

Open to Public
Inspection

Name of the organization	DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA	Employer identification number	11-2519726
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FORM 990, PART I, LINE 1, DESCRIPTION OF ORGANIZATION MISSION:

UNITED STATES TODAY. EB IS A GENETICALLY BASED DISEASE CHARACTERIZED BY CHRONIC, PAINFUL BLISTERING. THE SKIN AND MUCOUS MEMBRANES ARE SO FRAGILE THAT THE SLIGHTEST TOUCH CAN CAUSE SEVERE BLISTERING INSIDE AND OUTSIDE THE BODY. PRESENT AT BIRTH, EB AFFECTS MEN AND WOMEN OF ALL RACES AND ETHNIC GROUPS AND SOMETIMES, WHEN THERE IS NO FAMILY HISTORY, IT OCCURS AS THE RESULT OF A SPONTANEOUS GENETIC MUTATION. TODAY, THERE IS NO CURE OR TREATMENT FOR EB, EXCEPT DAILY WOUND CARE AND BANDAGING. GENETIC RESEARCH IS MAKING PROGRESS TOWARDS TREATMENTS AND A CURE.

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

SLIGHTEST TOUCH CAN CAUSE SEVERE BLISTERING INSIDE AND OUTSIDE THE BODY. PRESENT AT BIRTH, EB AFFECTS MEN AND WOMEN OF ALL RACES AND ETHNIC GROUPS AND SOMETIMES, WHEN THERE IS NO FAMILY HISTORY, IT OCCURS AS THE RESULT OF A SPONTANEOUS GENETIC MUTATION. TODAY, THERE IS NO CURE OR TREATMENT FOR EB, EXCEPT DAILY WOUND CARE AND BANDAGING. GENETIC RESEARCH IS MAKING PROGRESS TOWARDS TREATMENTS AND A CURE.

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

RESEARCH - PROVIDE GRANTS FOR RESEARCH INTO THE CAUSES, TREATMENT & PREVENTION OF EB AND ITS COMPLICATIONS

EXPENSES \$ 194,884. INCLUDING GRANTS OF \$ 0. REVENUE \$ 0.

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

THE BOARD OF DIRECTORS MEETS WITH THE CERTIFIED PUBLIC ACCOUNTANT TO REVIEW THE ANNUAL AUDITED FINANCIAL STATEMENTS, MANAGEMENT LETTER AND FORM 990.

Name of the organization	DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA	Employer identification number	11-2519726
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FORM 990, PART VI, SECTION B, LINE 12C:

THERE IS AN ANNUAL REVIEW PERFORMED OF ALL BOARD MEMBERS TO DETERMINE IF THERE ARE ANY CONFLICTS OF INTERESTS.

FORM 990, PART VI, SECTION B, LINE 15:

THE BOARD OF DIRECTORS REVIEWS THE EXECUTIVE DIRECTORS SALARY ON AN ANNUAL BASIS. A STUDY IS PERFORMED OF OTHER NOT FOR PROFIT AGENCY'S IN THE NEW YORK AREA AS WELL AS OTHER AGENCIES THAT PROVIDE A SIMILAR SERVICE TO DETERMINE IF THE SALARY PAID IS COMPETITIVE AND WITHIN ACCEPTABLE LIMITS.

FORM 990, PART VI, SECTION C, LINE 19:

THE ORGANIZATION'S ORGANIZING DOCUMENTS, ANNUAL AUDIT REPORT AND FORM 990 ARE AVAILABLE FOR PUBLIC INSPECTION UPON A WRITTEN REQUEST TO THE EXECUTIVE DIRECTOR.

FORM 990, PART XI, LINE 9, CHANGES IN NET ASSETS:

DONATED MEDICAL SUPPLIES	-186,982.
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