

Form **990**  
(Rev. January 2020)  
Department of the Treasury  
Internal Revenue Service

# Return of Organization Exempt From Income Tax

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

▶ Do not enter social security numbers on this form as it may be made public.  
▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

OMB No. 1545-0047

# 2019

Open to Public Inspection

**A** For the **2019** calendar year, or tax year beginning **2019**, and ending **20**

**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**  
 Doing business as  
 Number and street (or P.O. box if mail is not delivered to street address) Room/suite  
**75 BROAD ST 300**  
 City or town, state or province, country, and ZIP or foreign postal code  
**NEW YORK, NY 10004**

**D** Employer identification number  
**11-2519726**

**E** Telephone number  
**(212) 868-1573**

**F** Name and address of principal officer: **BRETT KOPELAN**  
**75 BROAD ST300, NEW YORK, NY 10004**

**G** Gross receipts \$ **1,918,351.**

**H(a)** Is this a group return for subordinates?  Yes  No  
**H(b)** Are all subordinates included?  Yes  No  
 If "No," attach a list. (see instructions)

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

**J** Website: ▶ **WWW.DEBRA.ORG**

**K** Form of organization:  Corporation  Trust  Association  Other ▶ **L** Year of formation: **1979** **M** State of legal domicile: **NY**

**H(c)** Group exemption number ▶

## Part I Summary

Activities & Governance	<b>1</b> Briefly describe the organization's mission or most significant activities: <b>DEBRA IS DEDICATED TO FINDING A CURE FOR EB THRU RESEARCH EB EFFECTS 1 OUT OF EVERY 50,000 LIVE BIRTHS IN THE U.S.</b>		
	<b>2</b> Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.		
	<b>3</b> Number of voting members of the governing body (Part VI, line 1a)	<b>3</b>	<b>13.</b>
	<b>4</b> Number of independent voting members of the governing body (Part VI, line 1b)	<b>4</b>	<b>13.</b>
	<b>5</b> Total number of individuals employed in calendar year 2019 (Part V, line 2a)	<b>5</b>	<b>11.</b>
	<b>6</b> Total number of volunteers (estimate if necessary)	<b>6</b>	
	<b>7a</b> Total unrelated business revenue from Part VIII, column (C), line 12	<b>7a</b>	<b>0.</b>
<b>7b</b> Net unrelated business taxable income from Form 990-T, line 39	<b>7b</b>		
Revenue	<b>8</b> Contributions and grants (Part VIII, line 1h)	<b>Prior Year</b> 947,956.	<b>Current Year</b> 705,872.
	<b>9</b> Program service revenue (Part VIII, line 2g)	0.	0.
	<b>10</b> Investment income (Part VIII, column (A), lines 3, 4, and 7d)	1,956.	1,696.
	<b>11</b> Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	874,655.	853,730.
	<b>12</b> Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	1,824,567.	1,561,298.
	Expenses	<b>13</b> Grants and similar amounts paid (Part IX, column (A), lines 1-3)	0.
<b>14</b> Benefits paid to or for members (Part IX, column (A), line 4)		0.	0.
<b>15</b> Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)		985,312.	945,728.
<b>16a</b> Professional fundraising fees (Part IX, column (A), line 11e)		0.	0.
<b>b</b> Total fundraising expenses (Part IX, column (D), line 25) ▶ <b>141,022.</b>			
<b>17</b> Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)		1,168,496.	469,217.
<b>18</b> Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)		2,153,808.	1,465,695.
<b>19</b> Revenue less expenses. Subtract line 18 from line 12	-329,241.	95,603.	
Net Assets or Fund Balances	<b>20</b> Total assets (Part X, line 16)	<b>Beginning of Current Year</b> 2,398,499.	<b>End of Year</b> 2,407,080.
	<b>21</b> Total liabilities (Part X, line 26)	279,616.	311,682.
	<b>22</b> Net assets or fund balances. Subtract line 21 from line 20	2,118,883.	2,095,398.

## 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: *Brett Kopelan* Date: **02/26/2020**  
 Signature ID: D83046E0A7DF445...  
**BRETT KOPELAN** EXECUTIVE DIRECTOR  
 Type or print name and title

**Paid Preparer Use Only**

Print/Type preparer's name: **BRIAN C WHITE** Preparer's signature: \_\_\_\_\_ Date: **02/26/2020** Check  if self-employed PTIN: **P00058320**

Firm's name: ▶ **NANAVATY DAVENPORT STUDLEY WHITE** Firm's EIN: ▶ **06-1402749**  
 Firm's address: ▶ **123 SOUTH MAIN ST., SUITE 140 NEWTOWN, CT 06470** Phone no.: **203/426-8500**

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

For Paperwork Reduction Act Notice, see the separate instructions.

Form **990** (2019)

**Part III** Statement of Program Service Accomplishments

Check if Schedule O contains a response or note to any line in this Part III  Yes  No

1 Briefly describe the organization's mission:

ATTACHMENT 1

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ?  Yes  No

If "Yes," describe these new services on Schedule O.

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services?  Yes  No

If "Yes," describe these changes on Schedule O.

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

4a (Code: ) (Expenses \$ 282,044. including grants of \$ ) (Revenue \$ 3,437. )

PUBLIC AND PROFESSIONAL EDUCATION - EDUCATE THE PUBLIC & HEALTH PROFESSIONALS ABOUT DYSTROPHIC EPIDERMOLYSIS BULLOSA "EB"

4b (Code: ) (Expenses \$ 788,790. including grants of \$ ) (Revenue \$ )

PATIENT & FAMILY SERVICES - PROVIDE SERVICES FOR THE PEOPLE WITH EB AND THEIR FAMILIES THROUGH NEWSLETTERS, COUNSELING, PEER SUPPORT SERVICES, CONFERENCES AND SEMINARS

4c (Code: ) (Expenses \$ 42,306. including grants of \$ ) (Revenue \$ )

ADVOCACY - NETWORK WITH OTHER PROFESSIONAL ORGANIZATIONS AND MEET KEY LEGISLATORS TO INFORM THEM OF EB AND SECURE RESEARCH FUNDS

4d Other program services (Describe on Schedule O.) ATTACHMENT 2 (Expenses \$ 141,022. including grants of \$ ) (Revenue \$ )

4e Total program service expenses 1,254,162.

Part IV Checklist of Required Schedules

Table with 3 columns: Question Number, Question Text, Yes, No. Rows include questions 1 through 21 regarding organizational requirements and reporting.

Part IV Checklist of Required Schedules (continued)

Table with 3 columns: Question, Yes, No. Rows 22-38 covering various organizational requirements and schedules.

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 [ ]

Table with 3 columns: Question, Yes, No. Rows 1a-1c regarding Form 1096, Forms W-2G, and backup withholding rules.

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

Table with columns for question number, question text, and Yes/No response boxes. Includes questions 2a through 16 regarding employee reporting, tax returns, business income, foreign accounts, prohibited transactions, and charitable contributions.

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

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

Section A. Governing Body and Management

Table with 3 columns: Question, Yes, No. Rows include 1a (13), 1b (13), 2, 3, 4, 5, 6, 7a, 7b, 8a, 8b, 9.

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, 10b, 11a, 11b, 12a, 12b, 12c, 13, 14, 15a, 15b, 16a, 16b.

Section C. Disclosure

- 17 List the states with which a copy of this Form 990 is required to be filed CA, MA, MI, NJ, NY,
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.
19 Describe on Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.
20 State the name, address, and telephone number of the person who possesses the organization's books and records

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

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(1) BRETT KOPELAN EXECUTIVE DIRECTOR	40.00 0.				X			233,349.	0.	0.
(2) FAITH DANIELS DIRECTOR	1.00 0.	X						0.	0.	0.
(3) J ALEC ALEXANDER TREASURER	1.00 0.	X		X				0.	0.	0.
(4) FRANK KACMARSKY DIRECTOR	1.00 0.	X						0.	0.	0.
(5) ANDREW TAVANI CHAIR	1.00 0.	X		X				0.	0.	0.
(6) RICHARD GALLAGHER CHAIR EMERITUS	1.00 0.	X						0.	0.	0.
(7) DR ROBERT MEIROWITZ DIRECTOR	1.00 0.	X						0.	0.	0.
(8) WILLIAM CORNMAN DIRECTOR	1.00 0.	X						0.	0.	0.
(9) ROBERT RAYL VICE CHAIR	1.00 0.	X		X				0.	0.	0.
(10) JAMES WETRICH DIRECTOR	1.00 0.	X						0.	0.	0.
(11) LESLIE RADER DIRECTOR	1.00 0.	X						0.	0.	0.
(12) JOUI UITTO MD, PH.D DIRECTOR	1.00 0.	X						0.	0.	0.
(13) ANGELA CHRISTIANO PH.D. DIRECTOR	1.00 0.	X						0.	0.	0.
(14) JOHN LEE SECRETARY	1.00 0.			X				0.	0.	0.

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

Table with 6 main columns: (A) Name and title, (B) Average hours per week, (C) Position, (D) Reportable compensation from the organization, (E) Reportable compensation from related organizations, (F) Estimated amount of other compensation.

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

Table with 3 columns: Question number, Yes, No. Contains questions 3, 4, and 5 regarding compensation reporting.

Section B. Independent Contractors

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

Table with 3 columns: (A) Name and business address, (B) Description of services, (C) Compensation.

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



**Part VIII Statement of Revenue**

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

				(A)	(B)	(C)	(D)	
				Total revenue	Related or exempt function revenue	Unrelated business revenue	Revenue excluded from tax under sections 512-514	
<b>Contributions, Gifts, Grants and Other Similar Amounts</b>	<b>1a</b>	Federated campaigns . . . . .	<b>1a</b>					
	<b>b</b>	Membership dues . . . . .	<b>1b</b>					
	<b>c</b>	Fundraising events . . . . .	<b>1c</b>					
	<b>d</b>	Related organizations . . . . .	<b>1d</b>					
	<b>e</b>	Government grants (contributions) . .	<b>1e</b>					
	<b>f</b>	All other contributions, gifts, grants, and similar amounts not included above .	<b>1f</b>	705,872.				
	<b>g</b>	Noncash contributions included in lines 1a-1f. . . . .	<b>1g</b>	\$				
	<b>h</b>	<b>Total.</b> Add lines 1a-1f . . . . . ▶			705,872.			
<b>Program Service Revenue</b>	<b>2a</b>	Business Code						
	<b>b</b>							
	<b>c</b>							
	<b>d</b>							
	<b>e</b>							
	<b>f</b>	All other program service revenue . . . . .						
	<b>g</b>	<b>Total.</b> Add lines 2a-2f . . . . . ▶			0.			
<b>Other Revenue</b>	<b>3</b>	Investment income (including dividends, interest, and other similar amounts). . . . . ▶			1,696.		1,696.	
	<b>4</b>	Income from investment of tax-exempt bond proceeds . ▶			0.			
	<b>5</b>	Royalties . . . . . ▶			0.			
	<b>6a</b>	Gross rents . . . . .	<b>6a</b>	(i) Real	(ii) Personal			
	<b>b</b>	Less: rental expenses	<b>6b</b>					
	<b>c</b>	Rental income or (loss)	<b>6c</b>					
	<b>d</b>	Net rental income or (loss) . . . . . ▶				0.		
	<b>7a</b>	Gross amount from sales of assets other than inventory	<b>7a</b>	(i) Securities	(ii) Other			
	<b>b</b>	Less: cost or other basis and sales expenses . .	<b>7b</b>					
	<b>c</b>	Gain or (loss) . . . . .	<b>7c</b>					
	<b>d</b>	Net gain or (loss) . . . . . ▶				0.		
<b>8a</b>	Gross income from fundraising events (not including \$ 357,053. of contributions reported on line 1c). See Part IV, line 18 . . . . .	<b>8a</b>		1,207,436.				
<b>b</b>	Less: direct expenses . . . . .	<b>8b</b>		357,053.				
<b>c</b>	Net income or (loss) from fundraising events. . . . . ▶				850,383.		850,383.	
<b>9a</b>	Gross income from gaming activities. See Part IV, line 19 . . . . .	<b>9a</b>		0.				
<b>b</b>	Less: direct expenses . . . . .	<b>9b</b>		0.				
<b>c</b>	Net income or (loss) from gaming activities. . . . . ▶				0.			
<b>10a</b>	Gross sales of inventory, less returns and allowances . . . . .	<b>10a</b>		0.				
<b>b</b>	Less: cost of goods sold . . . . .	<b>10b</b>		0.				
<b>c</b>	Net income or (loss) from sales of inventory. . . . . ▶				0.			
<b>Miscellaneous Revenue</b>	<b>11a</b>	MISCELLANEOUS INCOME						
	<b>b</b>							
	<b>c</b>							
	<b>d</b>	All other revenue . . . . .						
	<b>e</b>	<b>Total.</b> Add lines 11a-11d . . . . . ▶				3,347.		
<b>12</b>	<b>Total revenue.</b> See instructions . . . . . ▶				1,561,298.	3,347.	852,079.	

**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 . . . . .	0.			
2 Grants and other assistance to domestic individuals. See Part IV, line 22 . . . . .	0.			
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16 . . . . .	50,750.	50,750.		
4 Benefits paid to or for members . . . . .	0.			
5 Compensation of current officers, directors, trustees, and key employees . . . . .	233,349.	198,347.	11,667.	23,335.
6 Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B) . . . . .	0.			
7 Other salaries and wages . . . . .	539,430.	458,515.	26,972.	53,943.
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions) . . . . .	0.			
9 Other employee benefits . . . . .	106,803.	90,783.	5,340.	10,680.
10 Payroll taxes . . . . .	66,146.	56,224.	3,307.	6,615.
11 Fees for services (nonemployees):				
a Management . . . . .	0.			
b Legal . . . . .	0.			
c Accounting . . . . .	0.			
d Lobbying . . . . .	0.			
e Professional fundraising services. See Part IV, line 17 . . . . .	0.			
f Investment management fees . . . . .	0.			
g Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O.) . . . . .	121,657.	103,408.	6,083.	12,166.
12 Advertising and promotion . . . . .	7,980.	6,783.	399.	798.
13 Office expenses . . . . .	78,522.	66,744.	3,926.	7,852.
14 Information technology . . . . .	0.			
15 Royalties . . . . .	0.			
16 Occupancy . . . . .	101,471.	86,250.	5,074.	10,147.
17 Travel . . . . .	78,974.	67,128.	3,949.	7,897.
18 Payments of travel or entertainment expenses for any federal, state, or local public officials . . . . .	0.			
19 Conferences, conventions, and meetings . . . . .	0.			
20 Interest . . . . .	0.			
21 Payments to affiliates . . . . .	0.			
22 Depreciation, depletion, and amortization . . . . .	381.	322.	20.	39.
23 Insurance . . . . .	17,408.	14,797.	870.	1,741.
24 Other expenses. Itemize expenses not covered above (List miscellaneous expenses on line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
a PATIENT ASSISTANCE	4,726.	4,726.		
b DUES & SUBSCRIPTIONS	22,743.	19,332.	1,137.	2,274.
c TELEPHONE	17,089.	14,526.	854.	1,709.
d EQUIPMENT	11,401.	9,691.	570.	1,140.
e All other expenses	6,865.	5,836.	343.	686.
<b>25 Total functional expenses.</b> Add lines 1 through 24e	1,465,695.	1,254,162.	70,511.	141,022.
<b>26 Joint costs.</b> Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here <input type="checkbox"/> if following SOP 98-2 (ASC 958-720) . . . . .	0.			

**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
<b>Assets</b>	<b>1</b> Cash - non-interest-bearing . . . . .	1,135,515.	<b>1</b>	972,811.
	<b>2</b> Savings and temporary cash investments . . . . .	0.	<b>2</b>	0.
	<b>3</b> Pledges and grants receivable, net . . . . .	0.	<b>3</b>	0.
	<b>4</b> Accounts receivable, net. . . . .	5,043.	<b>4</b>	5,360.
	<b>5</b> Loans and other receivables from any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons . . . . .	0.	<b>5</b>	0.
	<b>6</b> Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B) . . . . .	0.	<b>6</b>	0.
	<b>7</b> Notes and loans receivable, net . . . . .	0.	<b>7</b>	0.
	<b>8</b> Inventories for sale or use . . . . .	579,177.	<b>8</b>	467,518.
	<b>9</b> Prepaid expenses and deferred charges . . . . . <b>ATCH 3</b>	8,807.	<b>9</b>	38,570.
	<b>10a</b> Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D . . . . .	<b>10a</b> 42,896.		
	<b>b</b> Less: accumulated depreciation . . . . .	<b>10b</b> 34,867.	<b>10c</b>	8,029.
	<b>11</b> Investments - publicly traded securities. . . . . <b>ATCH 4</b>	669,957.	<b>11</b>	664,792.
	<b>12</b> Investments - other securities. See Part IV, line 11 . . . . .	0.	<b>12</b>	250,000.
	<b>13</b> Investments - program-related. See Part IV, line 11. . . . .	0.	<b>13</b>	0.
	<b>14</b> Intangible assets . . . . .	0.	<b>14</b>	0.
	<b>15</b> Other assets. See Part IV, line 11 . . . . .	0.	<b>15</b>	0.
<b>16 Total assets.</b> Add lines 1 through 15 (must equal line 33) . . . . .	2,398,499.	<b>16</b>	2,407,080.	
<b>Liabilities</b>	<b>17</b> Accounts payable and accrued expenses . . . . .	182,005.	<b>17</b>	214,071.
	<b>18</b> Grants payable . . . . .	0.	<b>18</b>	0.
	<b>19</b> Deferred revenue. . . . .	0.	<b>19</b>	0.
	<b>20</b> Tax-exempt bond liabilities. . . . .	0.	<b>20</b>	0.
	<b>21</b> Escrow or custodial account liability. Complete Part IV of Schedule D. . . . .	0.	<b>21</b>	0.
	<b>22</b> Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons . . . . .	0.	<b>22</b>	0.
	<b>23</b> Secured mortgages and notes payable to unrelated third parties . . . . .	0.	<b>23</b>	0.
	<b>24</b> Unsecured notes and loans payable to unrelated third parties. . . . .	0.	<b>24</b>	0.
	<b>25</b> 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 . . . . .	97,611.	<b>25</b>	97,611.
	<b>26 Total liabilities.</b> Add lines 17 through 25. . . . .	279,616.	<b>26</b>	311,682.
<b>Net Assets or Fund Balances</b>	<b>Organizations that follow FASB ASC 958, check here</b> <input checked="" type="checkbox"/> <b>and complete lines 27, 28, 32, and 33.</b>			
	<b>27</b> Net assets without donor restrictions . . . . .	1,304,758.	<b>27</b>	1,283,751.
	<b>28</b> Net assets with donor restrictions. . . . .	814,125.	<b>28</b>	811,647.
	<b>Organizations that do not follow FASB ASC 958, check here</b> <input type="checkbox"/> <b>and complete lines 29 through 33.</b>			
	<b>29</b> Capital stock or trust principal, or current funds . . . . .		<b>29</b>	
	<b>30</b> Paid-in or capital surplus, or land, building, or equipment fund. . . . .		<b>30</b>	
	<b>31</b> Retained earnings, endowment, accumulated income, or other funds. . . . .		<b>31</b>	
	<b>32</b> Total net assets or fund balances . . . . .	2,118,883.	<b>32</b>	2,095,398.
<b>33</b> Total liabilities and net assets/fund balances. . . . .	2,398,499.	<b>33</b>	2,407,080.	

**Part XI Reconciliation of Net Assets**

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

<b>1</b>	Total revenue (must equal Part VIII, column (A), line 12)	<b>1</b>	1,561,298.
<b>2</b>	Total expenses (must equal Part IX, column (A), line 25)	<b>2</b>	1,465,695.
<b>3</b>	Revenue less expenses. Subtract line 2 from line 1	<b>3</b>	95,603.
<b>4</b>	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	<b>4</b>	2,118,883.
<b>5</b>	Net unrealized gains (losses) on investments	<b>5</b>	-6,280.
<b>6</b>	Donated services and use of facilities	<b>6</b>	-1,193,594.
<b>7</b>	Investment expenses	<b>7</b>	0.
<b>8</b>	Prior period adjustments	<b>8</b>	0.
<b>9</b>	Other changes in net assets or fund balances (explain on Schedule O)	<b>9</b>	1,080,786.
<b>10</b>	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B))	<b>10</b>	2,095,398.

**Part XII Financial Statements and Reporting**

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

- 1** Accounting method used to prepare the Form 990:  Cash  Accrual  Other \_\_\_\_\_  
If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule O.
- 2a** Were the organization's financial statements compiled or reviewed by an independent accountant? . . . . .  
If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both:  
 Separate basis  Consolidated basis  Both consolidated and separate basis
- b** Were the organization's financial statements audited by an independent accountant? . . . . .  
If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both:  
 Separate basis  Consolidated basis  Both consolidated and separate basis
- c** If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? . . . . .  
If the organization changed either its oversight process or selection process during the tax year, explain on Schedule O.
- 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? . . . . .
- b** If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why on Schedule O and describe any steps taken to undergo such audits . . . . .

	Yes	No
<b>2a</b>		X
<b>2b</b>	X	
<b>2c</b>	X	
<b>3a</b>		X
<b>3b</b>		

**SCHEDULE A**  
**(Form 990 or 990-EZ)**

**Public Charity Status and Public Support**

OMB No. 1545-0047

**2019**

**Open to Public Inspection**

Department of the Treasury  
Internal Revenue Service

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

▶ Attach to Form 990 or Form 990-EZ.

▶ Go to [www.irs.gov/Form990](http://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 Reason for Public Charity Status** (All organizations must complete this part.) See instructions.

The organization is not a private foundation because it is: (For lines 1 through 12, check only one box.)

- 1  A church, convention of churches, or association of churches described in **section 170(b)(1)(A)(i)**.
- 2  A school described in **section 170(b)(1)(A)(ii)**. (Attach Schedule E (Form 990 or 990-EZ).)
- 3  A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii)**.
- 4  A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii)**. Enter the hospital's name, city, and state: \_\_\_\_\_
- 5  An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv)**. (Complete Part II.)
- 6  A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v)**.
- 7  An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi)**. (Complete Part II.)
- 8  A community trust described in **section 170(b)(1)(A)(vi)**. (Complete Part II.)
- 9  An agricultural research organization described in **section 170(b)(1)(A)(ix)** operated in conjunction with a land-grant college or university or a non-land-grant college of agriculture (see instructions). Enter the name, city, and state of the college or university: \_\_\_\_\_
- 10  An organization that normally receives: (1) more than 33 1/3 % of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions - subject to certain exceptions, and (2) no more than 33 1/3 % of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See **section 509(a)(2)**. (Complete Part III.)
- 11  An organization organized and operated exclusively to test for public safety. See **section 509(a)(4)**.
- 12  An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in **section 509(a)(1)** or **section 509(a)(2)**. See **section 509(a)(3)**.  
Check the box in lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g.
  - a  **Type I.** A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization. **You must complete Part IV, Sections A and B.**
  - b  **Type II.** A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s). **You must complete Part IV, Sections A and C.**
  - c  **Type III functionally integrated.** A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions). **You must complete Part IV, Sections A, D, and E.**
  - d  **Type III non-functionally integrated.** A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions). **You must complete Part IV, Sections A and D, and Part V.**
  - e  Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization.

f Enter the number of supported organizations . . . . .

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

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1-10 above (see instructions))	(iv) Is the organization listed in your governing document?		(v) Amount of monetary support (see instructions)	(vi) Amount of other support (see instructions)
			Yes	No		
(A)						
(B)						
(C)						
(D)						
(E)						
<b>Total</b>						

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

Table with 7 columns: (a) 2015, (b) 2016, (c) 2017, (d) 2018, (e) 2019, (f) Total. Rows include: 1 Gifts, grants, contributions, and membership fees received; 2 Tax revenues levied for the organization's benefit; 3 The value of services or facilities furnished by a governmental unit; 4 Total; 5 The portion of total contributions by each person; 6 Public support.

Section B. Total Support

Table with 7 columns: (a) 2015, (b) 2016, (c) 2017, (d) 2018, (e) 2019, (f) Total. Rows include: 7 Amounts from line 4; 8 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources; 9 Net income from unrelated business activities; 10 Other income; 11 Total support; 12 Gross receipts from related activities; 13 First five years.

Section C. Computation of Public Support Percentage

Table with 2 columns: Line number, Percentage. Rows include: 14 Public support percentage for 2019 (99.77%); 15 Public support percentage from 2018 Schedule A, Part II, line 14 (99.81%); 16a 33 1/3% support test - 2019 (checked); 16b 33 1/3% support test - 2018; 17a 10%-facts-and-circumstances test - 2019; 17b 10%-facts-and-circumstances test - 2018; 18 Private foundation.

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

Table with 7 columns: (a) 2015, (b) 2016, (c) 2017, (d) 2018, (e) 2019, (f) Total. Rows include: 1 Gifts, grants, contributions, and membership fees received; 2 Gross receipts from admissions, merchandise sold or services performed; 3 Gross receipts from activities that are not an unrelated trade or business; 4 Tax revenues levied for the organization's benefit; 5 The value of services or facilities furnished by a governmental unit; 6 Total. Add lines 1 through 5; 7a Amounts included on lines 1, 2, and 3 received from disqualified persons; 7b Amounts included on lines 2 and 3 received from other than disqualified persons; 7c Add lines 7a and 7b; 8 Public support. (Subtract line 7c from line 6.)

Section B. Total Support

Table with 7 columns: (a) 2015, (b) 2016, (c) 2017, (d) 2018, (e) 2019, (f) Total. Rows include: 9 Amounts from line 6; 10a Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources; 10b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975; 10c Add lines 10a and 10b; 11 Net income from unrelated business activities not included in line 10b; 12 Other income. Do not include gain or loss from the sale of capital assets; 13 Total support. (Add lines 9, 10c, 11, and 12.)

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

Section C. Computation of Public Support Percentage

Table with 3 columns: Description, 2019, 2018. Row 15: Public support percentage for 2019 (line 8, column (f), divided by line 13, column (f)). Row 16: Public support percentage from 2018 Schedule A, Part III, line 15.

Section D. Computation of Investment Income Percentage

Table with 3 columns: Description, 2019, 2018. Row 17: Investment income percentage for 2019 (line 10c, column (f), divided by line 13, column (f)). Row 18: Investment income percentage from 2018 Schedule A, Part III, line 17.

19a 33 1/3% support tests - 2019. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization.

19b 33 1/3% support tests - 2018. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3%, and line 18 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization.

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

**Part IV Supporting Organizations**

(Complete only if you checked a box in line 12 on Part I. If you checked 12a of Part I, complete Sections A and B. If you checked 12b of Part I, complete Sections A and C. If you checked 12c of Part I, complete Sections A, D, and E. If you checked 12d of Part I, complete Sections A and D, and complete Part V.)

**Section A. All Supporting Organizations**

	Yes	No
<b>1</b> 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>		
<b>2</b> 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>		
<b>3a</b> 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>b</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>		
<b>c</b> 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>		
<b>4a</b> 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>b</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>		
<b>c</b> 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>		
<b>5a</b> 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>b Type I or Type II only.</b> Was any added or substituted supported organization part of a class already designated in the organization's organizing document?		
<b>c Substitutions only.</b> Was the substitution the result of an event beyond the organization's control?		
<b>6</b> 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>		
<b>7</b> 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>		
<b>8</b> 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>		
<b>9a</b> 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>b</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>		
<b>c</b> 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>		
<b>10a</b> 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>b</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)

		Yes	No
<b>11</b>	Has the organization accepted a gift or contribution from any of the following persons?		
<b>a</b>	A person who directly or indirectly controls, either alone or together with persons described in (b) and (c) below, the governing body of a supported organization?	<b>11 a</b>	
<b>b</b>	A family member of a person described in (a) above?	<b>11 b</b>	
<b>c</b>	A 35% controlled entity of a person described in (a) or (b) above? <i>If "Yes" to a, b, or c, provide detail in Part VI.</i>	<b>11 c</b>	

**Section B. Type I Supporting Organizations**

		Yes	No
<b>1</b>	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? <i>If "No," describe in Part VI how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove directors or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.</i>	<b>1</b>	
<b>2</b>	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? <i>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.</i>	<b>2</b>	

**Section C. Type II Supporting Organizations**

		Yes	No
<b>1</b>	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)? <i>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).</i>	<b>1</b>	

**Section D. All Type III Supporting Organizations**

		Yes	No
<b>1</b>	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?	<b>1</b>	
<b>2</b>	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? <i>If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).</i>	<b>2</b>	
<b>3</b>	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? <i>If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.</i>	<b>3</b>	

**Section E. Type III Functionally Integrated Supporting Organizations**

<b>1</b>	Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).			
<b>a</b>	<input type="checkbox"/> The organization satisfied the Activities Test. Complete <b>line 2</b> below.			
<b>b</b>	<input type="checkbox"/> The organization is the parent of each of its supported organizations. Complete <b>line 3</b> below.			
<b>c</b>	<input type="checkbox"/> The organization supported a governmental entity. Describe in <b>Part VI</b> how you supported a government entity (see instructions).			
<b>2</b>	Activities Test. <b>Answer (a) and (b) below.</b>		Yes	No
<b>a</b>	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? <i>If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.</i>	<b>2a</b>		
<b>b</b>	Did the activities described in (a) constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? <i>If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.</i>	<b>2b</b>		
<b>3</b>	Parent of Supported Organizations. <b>Answer (a) and (b) below.</b>			
<b>a</b>	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? <i>Provide details in Part VI.</i>	<b>3a</b>		
<b>b</b>	Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? <i>If "Yes," describe in Part VI the role played by the organization in this regard.</i>	<b>3b</b>		

**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.

<b>Section A - Adjusted Net Income</b>		(A) Prior Year	(B) Current Year (optional)
<b>1</b> Net short-term capital gain	<b>1</b>		
<b>2</b> Recoveries of prior-year distributions	<b>2</b>		
<b>3</b> Other gross income (see instructions)	<b>3</b>		
<b>4</b> Add lines 1 through 3.	<b>4</b>		
<b>5</b> Depreciation and depletion	<b>5</b>		
<b>6</b> 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)	<b>6</b>		
<b>7</b> Other expenses (see instructions)	<b>7</b>		
<b>8 Adjusted Net Income</b> (subtract lines 5, 6, and 7 from line 4)	<b>8</b>		
<b>Section B - Minimum Asset Amount</b>		(A) Prior Year	(B) Current Year (optional)
<b>1</b> Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year):			
<b>a</b> Average monthly value of securities	<b>1a</b>		
<b>b</b> Average monthly cash balances	<b>1b</b>		
<b>c</b> Fair market value of other non-exempt-use assets	<b>1c</b>		
<b>d Total</b> (add lines 1a, 1b, and 1c)	<b>1d</b>		
<b>e Discount</b> claimed for blockage or other factors (explain in detail in <b>Part VI</b> ):			
<b>2</b> Acquisition indebtedness applicable to non-exempt-use assets	<b>2</b>		
<b>3</b> Subtract line 2 from line 1d.	<b>3</b>		
<b>4</b> Cash deemed held for exempt use. Enter 1-1/2% of line 3 (for greater amount, see instructions).	<b>4</b>		
<b>5</b> Net value of non-exempt-use assets (subtract line 4 from line 3)	<b>5</b>		
<b>6</b> Multiply line 5 by .035.	<b>6</b>		
<b>7</b> Recoveries of prior-year distributions	<b>7</b>		
<b>8 Minimum Asset Amount</b> (add line 7 to line 6)	<b>8</b>		
<b>Section C - Distributable Amount</b>			Current Year
<b>1</b> Adjusted net income for prior year (from Section A, line 8, Column A)	<b>1</b>		
<b>2</b> Enter 85% of line 1.	<b>2</b>		
<b>3</b> Minimum asset amount for prior year (from Section B, line 8, Column A)	<b>3</b>		
<b>4</b> Enter greater of line 2 or line 3.	<b>4</b>		
<b>5</b> Income tax imposed in prior year	<b>5</b>		
<b>6 Distributable Amount.</b> Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions).	<b>6</b>		
<b>7</b> <input type="checkbox"/> Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see instructions).			

**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 <b>Total annual distributions.</b> Add lines 1 through 6.	
8 Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI). See instructions.	
9 Distributable amount for 2019 from Section C, line 6	
10 Line 8 amount divided by line 9 amount	

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

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

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

# Schedule of Contributors

OMB No. 1545-0047

# 2019

▶ **Attach to Form 990, Form 990-EZ, or Form 990-PF.**  
▶ **Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest information.**

Name of the organization DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA	Employer identification number 11-2519726
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**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, 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 <b>DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA</b>	Employer identification number <b>11-2519726</b>
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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	JOHN LEE  555 MONTGOMERY ST SUITE 603  SAN FRANCISCO, CA 94111	\$ 200,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
2	MR JOHNNY MCCRANIE  HOLIDAY PROPERTIES  VALDOSTA, GA 31604	\$ 25,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
3	BENEVITY COMMUNITY IMPACT FUND  1521 GEORGETOWN ROD  HUDSON, OH 44236	\$ 21,628.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
4	KATHLEEN MARQUARDT  23 TARIFF ST  SAYVILLE, NY 11782	\$ 20,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
5	SARAH SCHMIDT  223 CEDAR CREST LANE  KENNETT SQUARE, PA 19348	\$ 17,216.	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.)

Name of organization <b>DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA</b>	<b>Employer identification number</b> 11-2519726
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**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
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____

Name of organization <b>DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA</b>	Employer identification number <b>11-2519726</b>
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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 information once. See instructions.) ► \$ \_\_\_\_\_  
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

2019

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

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

Schedule D (Form 990) 2019

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

- 3 Using the organization's acquisition, accession, and other records, check any of the following that make significant use of its collection items (check all that apply):
a Public exhibition
b Scholarly research
c Preservation for future generations
d Loan or exchange program
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?

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?
b If "Yes," explain the arrangement in Part XIII and complete the following table:
Table with columns: Description, Amount
1c Beginning balance
1d Additions during the year
1e Distributions during the year
1f Ending balance
2a Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability?
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.

Table with 6 columns: (a) Current year, (b) Prior year, (c) Two years back, (d) Three years back, (e) Four years back. Rows include: 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 Term 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:

- (i) Unrelated organizations
(ii) Related organizations

Table with 2 columns: Yes, No. Rows: 3a(i), 3a(ii), 3b

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

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

Part VI Land, Buildings, and Equipment.

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

Table with 5 columns: (a) Cost or other basis (investment), (b) Cost or other basis (other), (c) Accumulated depreciation, (d) Book value. Rows include: 1a Land, b Buildings, c Leasehold improvements, d Equipment, e Other, Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10c.)

**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.

(a) Description of security or category (including name of security)	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1) Financial derivatives . . . . .		
(2) Closely held equity interests . . . . .		
(3) Other		
(A) PREFERRED STOCK	250,000.	COST
(B)		
(C)		
(D)		
(E)		
(F)		
(G)		
(H)		
<b>Total.</b> (Column (b) must equal Form 990, Part X, col. (B) line 12.) . ▶	250,000.	

**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.

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

**Part IX Other Assets.**

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

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

**Part X Other Liabilities.**

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

1. (a) Description of liability	(b) Book value
(1) Federal income taxes	
(2) AGENCY FUNDS HELD FOR OTHERS	97,611.
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
<b>Total.</b> (Column (b) must equal Form 990, Part X, col. (B) line 25.) . . . . . ▶	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 FASB ASC 740. Check here if the text of the footnote has been provided in Part XIII

Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per Return. Complete if the organization answered "Yes" on Form 990, Part IV, line 12a.

Table with 5 main rows and sub-rows (a-e) for adjustments. Total revenue reported as 1,561,298.

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.

Table with 5 main rows and sub-rows (a-e) for adjustments. Total expenses reported as 1,465,695.

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.

SCHEDULE D PART X LINE 2

THE ORGANIZATION RECOGNIZES THE EFFECT OF TAX POSITIONS ONLYWHN 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. THE THREE PREVIOUS TAX YEARS REMAIN OPEN

TO EXAMINATION BY FEDERAL AND STATE AUTHORITIES

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**Part XIII** Supplemental Information *(continued)*

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**SCHEDULE F  
(Form 990)**

**Statement of Activities Outside the United States**

OMB No. 1545-0047

**2019**

**Open to Public Inspection**

Department of the Treasury  
Internal Revenue Service

▶ **Complete if the organization answered "Yes" on Form 990, Part IV, line 14b, 15, or 16.**  
▶ **Attach to Form 990.**  
▶ **Go to [www.irs.gov/Form990](http://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** **General Information on Activities Outside the United States.** Complete if the organization answered "Yes" on Form 990, Part IV, line 14b.

- 1 For grantmakers.** Does the organization maintain records to substantiate the amount of its grants and other assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? . . . . .  **Yes**  **No**
- 2 For grantmakers.** Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.

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

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in the region	(d) Activities conducted in the region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in the region	(f) Total expenditures for and investments in the region
(1)					
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					
(8)					
(9)					
(10)					
(11)					
(12)					
(13)					
(14)					
(15)					
(16)					
(17)					
<b>3a</b> Subtotal . . . . .					
<b>b</b> Total from continuation sheets to Part I . . . . .					
<b>c Totals</b> (add lines 3a and 3b)					

**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)
(1)			EUROPE/ICELAND/GREENLAND	TO FUND INTE	32,750.	CASH TRANSFE		NONE	FMV
(2)			CENT. AMERICA/CARIBBEAN	TO FUND INTE	18,000.	CASH TRANSFE		NONE	FMV
(3)									
(4)									
(5)									
(6)									
(7)									
(8)									
(9)									
(10)									
(11)									
(12)									
(13)									
(14)									
(15)									
(16)									

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

(a) Type of grant or assistance	(b) Region	(c) Number of recipients	(d) Amount of cash grant	(e) Manner of cash disbursement	(f) Amount of noncash assistance	(g) Description of noncash assistance	(h) Method of valuation (book, FMV, appraisal, other)
(1)							
(2)							
(3)							
(4)							
(5)							
(6)							
(7)							
(8)							
(9)							
(10)							
(11)							
(12)							
(13)							
(14)							
(15)							
(16)							
(17)							
(18)							



**Part IV Foreign Forms**

- 1 Was the organization a U.S. transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926)* . . . . .  Yes  No
- 2 Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to 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).

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**SCHEDULE G**  
**(Form 990 or 990-EZ)**

**Supplemental Information Regarding Fundraising or Gaming Activities**

OMB No. 1545-0047

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

**2019**

**Open to Public Inspection**

Department of the Treasury  
Internal Revenue Service

▶ Attach to Form 990 or Form 990-EZ.

▶ Go to [www.irs.gov/Form990](http://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 Fundraising Activities.** Complete if the organization answered "Yes" on Form 990, Part IV, line 17. Form 990-EZ filers are not required to complete this part.

- 1** Indicate whether the organization raised funds through any of the following activities. Check all that apply.
- |  |   |
|--|---|
| <b>a</b> <input type="checkbox"/> Mail solicitations               | <b>e</b> <input type="checkbox"/> Solicitation of non-government grants |
| <b>b</b> <input type="checkbox"/> Internet and email solicitations | <b>f</b> <input type="checkbox"/> Solicitation of government grants     |
| <b>c</b> <input type="checkbox"/> Phone solicitations              | <b>g</b> <input type="checkbox"/> Special fundraising events            |
| <b>d</b> <input type="checkbox"/> In-person solicitations          |   |
- 2a** Did the organization have a written or oral agreement with any individual (including officers, directors, trustees, or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services?  **Yes**  **No**
- b** If "Yes," list the 10 highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization.

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

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

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**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
		ANNUAL FUND	OTHER EVENTS	(total number)	(add col. (a) through col. (c))
	(event type)	(event type)			
Revenue	1 Gross receipts . . . . .	529,572.	677,864.		1,207,436.
	2 Less: Contributions . . . . .				
	3 Gross income (line 1 minus line 2) . . . . .	529,572.	677,864.		1,207,436.
Direct Expenses	4 Cash prizes . . . . .				
	5 Noncash prizes . . . . .				
	6 Rent/facility costs . . . . .				
	7 Food and beverages . . . . .				
	8 Entertainment . . . . .				
	9 Other direct expenses . . . . .	173,376.	183,677.		357,053.
	10 Direct expense summary. Add lines 4 through 9 in column (d) . . . . . ▶				357,053.
	11 Net income summary. Subtract line 10 from line 3, column (d) . . . . . ▶				850,383.

**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: \_\_\_\_\_

- 11 Does the organization conduct gaming activities with nonmembers?  Yes  No
- 12 Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity formed to administer charitable gaming?  Yes  No
- 13 Indicate the percentage of gaming activity conducted in:
 

a The organization's facility	<b>13a</b>	%
b An outside facility	<b>13b</b>	%

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

Name ▶ \_\_\_\_\_

Address ▶ \_\_\_\_\_

- 15 a Does the organization have a contract with a third party from whom the organization receives gaming revenue?  Yes  No
- b If "Yes," enter the amount of gaming revenue received by the organization ▶ \$ \_\_\_\_\_ and the amount of gaming revenue retained by the third party ▶ \$ \_\_\_\_\_.
- c If "Yes," enter name and address of the third party:
 

Name ▶ \_\_\_\_\_

Address ▶ \_\_\_\_\_

16 Gaming manager information:

Name ▶ \_\_\_\_\_

Gaming manager compensation ▶ \$ \_\_\_\_\_

Description of services provided ▶ \_\_\_\_\_

Director/officer       Employee       Independent contractor

- 17 Mandatory distributions:
  - a Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license?  Yes  No
  - b Enter the amount of distributions required under state law to be distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year ▶ \$ \_\_\_\_\_

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

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SCHEDULE J (Form 990)

Compensation Information

OMB No. 1545-0047

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.

2019

Open to Public Inspection

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

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.

- First-class or charter travel, Travel for companions, Tax indemnification and gross-up payments, Discretionary spending account, Housing allowance or residence for personal use, Payments for business use of personal residence, Health or social club dues or initiation fees, Personal services (such as maid, chauffeur, chef)

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

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

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

- Compensation committee, Independent compensation consultant, Form 990 of other organizations, Written employment contract, Compensation survey or study, Approval by the board or compensation committee

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

- a Receive a severance payment or change-of-control payment?
b Participate in, or receive payment from, a supplemental nonqualified retirement plan?
c Participate in, or receive payment from, an equity-based compensation arrangement?

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

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

- a The organization?
b Any related organization?
If "Yes" on line 5a or 5b, describe in Part III.

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

- a The organization?
b Any related organization?
If "Yes" on line 6a or 6b, describe in Part III.

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

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

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

Table with 3 columns: Question ID, Yes, No. Rows 1a-9 with 'X' marks in Yes/No columns.

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

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

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

(A) Name and Title		(B) Breakdown of W-2 and/or 1099-MISC compensation			(C) Retirement and other deferred compensation	(D) Nontaxable benefits	(E) Total of columns (B)(i)-(D)	(F) Compensation in column (B) reported as deferred on prior Form 990
		(i) Base compensation	(ii) Bonus & incentive compensation	(iii) Other reportable compensation				
1 BRETT KOPELAN EXECUTIVE DIRECTOR	(i)	233,349.	0.	0.		233,349.		
	(ii)	0.	0.	0.				
2	(i)							
	(ii)							
3	(i)							
	(ii)							
4	(i)							
	(ii)							
5	(i)							
	(ii)							
6	(i)							
	(ii)							
7	(i)							
	(ii)							
8	(i)							
	(ii)							
9	(i)							
	(ii)							
10	(i)							
	(ii)							
11	(i)							
	(ii)							
12	(i)							
	(ii)							
13	(i)							
	(ii)							
14	(i)							
	(ii)							
15	(i)							
	(ii)							
16	(i)							
	(ii)							

DYSTROPHIC EPIDERMOLYSIS BULLOSA

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**Part III Supplemental Information**

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

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**SCHEDULE M  
(Form 990)**

**Noncash Contributions**

OMB No. 1545-0047

**2019**

**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](http://www.irs.gov/Form990) for instructions and the latest information.

Name of the organization <b>DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA</b>	Employer identification number <b>11-2519726</b>
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**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	2,500.	1,165,503.	FMV
21 Taxidermy . . . . .				
22 Historical artifacts . . . . .				
23 Scientific specimens . . . . .				
24 Archeological artifacts . . . . .				
25 Other ▶ ( LEGAL SERVICES ) . . . . .	X	1.	28,291.	FMV
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? . . . . .	<b>30a</b>		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? . . . . .	<b>31</b>		X
32a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash contributions? . . . . .	<b>32a</b>		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.			

---

**Part II** **Supplemental Information.** Provide the information required by Part I, lines 30b, 32b, and 33, and whether the organization is reporting in Part I, column (b), the number of contributions, the number of items received, or a combination of both. Also complete this part for any additional information.

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**SCHEDULE O**  
**(Form 990 or 990-EZ)**Department of the Treasury  
Internal Revenue Service**Supplemental Information to Form 990 or 990-EZ**Complete to provide information for responses to specific questions on  
Form 990 or 990-EZ or to provide any additional information.

▶ Attach to Form 990 or 990-EZ.

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

OMB No. 1545-0047

**2019****Open to Public  
Inspection**Name of the organization  
DYSTROPHIC EPIDERMOLYSIS BULLOSA  
RESEARCH ASSOCIATION OF AMERICAEmployer identification number  
11-2519726

FORM 990 PART VI SECTION B LINE 11B ORGANIZATION PROVIDED A COPY  
THE BOARD OF DIRECTORS MEETS WITH THE CERTIFIED PUBLIC ACCOUNTANT TO  
REVIEW THE ANNUAL AUDITED FINANCIAL STATEMENTS, MANAGEMENT LETTER AND FORM  
990

PART VI SECTION B LINE 12C

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

PART VI SECTION B LINE 15

THE BOARD OF DIRECTORS REVIEWS THE EXECUTIVE DIRECTOR'S SALARY ON AN  
ANNUAL BASIS. A STUDY IS PERFORMED OF OTHER NOT-FOR-PROFIT AGENCIES 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.

PART VI SECTION C LINE 19

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

PART XI LINE 9

VALUE OF DONATED MEDICAL SUPPLIES, LEGAL SERVICES AND DONATED INVENTORY

Name of the organization DYSTROPHIC EPIDERMOLYSIS BULLOSA  
RESEARCH ASSOCIATION OF AMERICA

Employer identification number  
11-2519726

ATTACHMENT 1

FORM 990, PART III, LINE 1 - ORGANIZATION'S MISSION

DEBRA IS DEDICATED TO FINDING A CURE FOR EBIDERMOLYSIS BULLOSA " EB" WHICH EFFECTS 1 OUT OF EVERY 50,000 LIVE BIRTHS IN THE UNITED STATES TODAY. EB IS A GENETICALLY BASED DISEASE CHARACTERIZED BY CHRONIC, PAINFULL 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 EFFECTS 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 GENTIC 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.

ATTACHMENT 2

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

<u>DESCRIPTION</u>	<u>GRANTS</u>	<u>EXPENSES</u>	<u>REVENUE</u>
RESEARCH		141,022.	
	TOTALS	<u>141,022.</u>	

ATTACHMENT 3

FORM 990, PART X - PREPAID EXPENSES AND DEFERRED CHARGES

<u>DESCRIPTION</u>	<u>ENDING BOOK VALUE</u>
PREPAID EXPENSES	38,570.
TOTALS	<u>38,570.</u>

Schedule O (Form 990 or 990-EZ) 2019

Page **2**

Name of the organization **DYSTROPHIC EPIDERMOLYSIS BULLOSA  
RESEARCH ASSOCIATION OF AMERICA**

**Employer identification number**  
11-2519726

ATTACHMENT 4

FORM 990, PART X - INVESTMENTS - PUBLICLY TRADED SECURITIES

<u>DESCRIPTION</u>	<u>ENDING BOOK VALUE</u>	<u>COST OR FMV</u>
MUTUAL FUNDS	664,792.	FMV
TOTALS	<u>664,792.</u>	

Form **4562**

**Depreciation and Amortization**  
(Including Information on Listed Property)

OMB No. 1545-0172

**2019**

Department of the Treasury  
Internal Revenue Service (99)

▶ Attach to your tax return.

▶ Go to [www.irs.gov/Form4562](http://www.irs.gov/Form4562) for instructions and the latest information.

Attachment  
Sequence No. **179**

Name(s) shown on return

DYSTROPHIC EPIDERMOLYSIS BULLOSA

Identifying number

11-2519726

Business or activity to which this form relates

**GENERAL DEPRECIATION**

**Part I Election To Expense Certain Property Under Section 179**

**Note:** If you have any listed property, complete Part V before you complete Part I.

1	Maximum amount (see instructions)	1	
2	Total cost of section 179 property placed in service (see instructions)	2	
3	Threshold cost of section 179 property before reduction in limitation (see instructions)	3	
4	Reduction in limitation. Subtract line 3 from line 2. If zero or less, enter -0-	4	
5	Dollar limitation for tax year. Subtract line 4 from line 1. If zero or less, enter -0-. If married filing separately, see instructions	5	
6	(a) Description of property	(b) Cost (business use only)	(c) Elected cost
7	Listed property. Enter the amount from line 29	7	
8	Total elected cost of section 179 property. Add amounts in column (c), lines 6 and 7	8	
9	Tentative deduction. Enter the smaller of line 5 or line 8	9	
10	Carryover of disallowed deduction from line 13 of your 2018 Form 4562	10	
11	Business income limitation. Enter the smaller of business income (not less than zero) or line 5. See instructions	11	
12	Section 179 expense deduction. Add lines 9 and 10, but don't enter more than line 11	12	
13	Carryover of disallowed deduction to 2020. Add lines 9 and 10, less line 12	13	

**Note:** Don't use Part II or Part III below for listed property. Instead, use Part V.

**Part II Special Depreciation Allowance and Other Depreciation (Don't include listed property. See instructions.)**

14	Special depreciation allowance for qualified property (other than listed property) placed in service during the tax year. See instructions	14	
15	Property subject to section 168(f)(1) election	15	
16	Other depreciation (including ACRS)	16	380.

**Part III MACRS Depreciation (Don't include listed property. See instructions.)**

**Section A**

17	MACRS deductions for assets placed in service in tax years beginning before 2019	17	
18	If you are electing to group any assets placed in service during the tax year into one or more general asset accounts, check here		<input type="checkbox"/>

**Section B - Assets Placed in Service During 2019 Tax Year Using the General Depreciation System**

(a) Classification of property	(b) Month and year placed in service	(c) Basis for depreciation (business/investment use only - see instructions)	(d) Recovery period	(e) Convention	(f) Method	(g) Depreciation deduction
19a	3-year property					
b	5-year property					
c	7-year property					
d	10-year property					
e	15-year property					
f	20-year property					
g	25-year property		25 yrs.		S/L	
h	Residential rental property		27.5 yrs.	MM	S/L	
i	Nonresidential real property		27.5 yrs.	MM	S/L	
			39 yrs.	MM	S/L	
				MM	S/L	

**Section C - Assets Placed in Service During 2019 Tax Year Using the Alternative Depreciation System**

20a	Class life				S/L	
b	12-year		12 yrs.		S/L	
c	30-year		30 yrs.	MM	S/L	
d	40-year		40 yrs.	MM	S/L	

**Part IV Summary (See instructions.)**

21	Listed property. Enter amount from line 28	21	
22	<b>Total.</b> Add amounts from line 12, lines 14 through 17, lines 19 and 20 in column (g), and line 21. Enter here and on the appropriate lines of your return. Partnerships and S corporations - see instructions.	22	380.
23	For assets shown above and placed in service during the current year, enter the portion of the basis attributable to section 263A costs	23	

For Paperwork Reduction Act Notice, see separate instructions.

Form **4562** (2019)

Form 4562 (2019)

Part V Listed Property (Include automobiles, certain other vehicles, certain aircraft, and property used for entertainment, recreation, or amusement.)

Note: For any vehicle for which you are using the standard mileage rate or deducting lease expense, complete only 24a, 24b, columns (a) through (c) of Section A, all of Section B, and Section C if applicable.

Section A - Depreciation and Other Information (Caution: See the instructions for limits for passenger automobiles.)

24a Do you have evidence to support the business/investment use claimed? Yes No 24b If "Yes," is the evidence written? Yes No

Table with 9 columns: (a) Type of property, (b) Date placed in service, (c) Business/investment use percentage, (d) Cost or other basis, (e) Basis for depreciation, (f) Recovery period, (g) Method/Convention, (h) Depreciation deduction, (i) Elected section 179 cost. Includes rows 25-29.

Section B - Information on Use of Vehicles

Complete this section for vehicles used by a sole proprietor, partner, or other "more than 5% owner," or related person. If you provided vehicles to your employees, first answer the questions in Section C to see if you meet an exception to completing this section for those vehicles.

Table with 6 columns: (a) Vehicle 1, (b) Vehicle 2, (c) Vehicle 3, (d) Vehicle 4, (e) Vehicle 5, (f) Vehicle 6. Includes rows 30-36.

Section C - Questions for Employers Who Provide Vehicles for Use by Their Employees

Answer these questions to determine if you meet an exception to completing Section B for vehicles used by employees who aren't more than 5% owners or related persons. See instructions.

Table with 2 columns: Yes, No. Includes rows 37-41.

Part VI Amortization

Table with 6 columns: (a) Description of costs, (b) Date amortization begins, (c) Amortizable amount, (d) Code section, (e) Amortization period or percentage, (f) Amortization for this year. Includes rows 42-44.







DYSTROPHIC EPIDERMOLYSIS BULLOSA  
RESEARCH ASSOCIATION OF AMERICA  
Instructions for Filing  
Form CHAR500  
New York State Annual Filing for Charitable Organizations  
For the year ended December 31, 2019

The original return should be signed (use full name) and dated on page 1 by two authorized officers of the organization, including the chief fiscal officer.

File the signed return by May 15, 2020 with:

NYS Office of the AG, Charities Bureau Registration Section  
28 Liberty Street  
New York, NY 10005

A check or money order payable to "Department of Law" in the amount of \$25 should be attached to the return. Be sure to include the federal EIN and "2019 Form CHAR500" on the check.

To document the timely filing of your tax return(s), we suggest that you obtain and retain proof of mailing. Proof of mailing can be accomplished by sending the tax return(s) by registered or certified mail (metered by the U.S. Postal Service) or through the use of an IRS approved delivery method provided by an IRS designated private delivery service.

**CHAR500**

NYS Annual Filing for Charitable Organizations  
www.CharitiesNYS.com

Send with fee and attachments to:  
NYS Office of the Attorney General  
Charities Bureau Registration Section  
28 Liberty Street  
New York, NY 10005

**2019**  
**Open to Public**  
**Inspection**

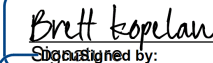
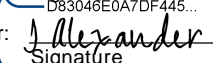
**1. General Information**

For Fiscal Year Beginning (mm/dd/yyyy) <u>01</u> / <u>01</u> / <b>2019</b> and Ending (mm/dd/yyyy) <u>12</u> / <u>31</u> / <u>2019</u>		
Check if Applicable: <input type="checkbox"/> Address Change <input type="checkbox"/> Name Change <input type="checkbox"/> Initial Filing <input type="checkbox"/> Final Filing <input type="checkbox"/> Amended Filing <input type="checkbox"/> Reg ID Pending	Name of Organization: <b>DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA</b>	Employer Identification Number (EIN): <b>11-2519726</b>
	Mailing Address: <b>75 BROAD ST</b>	NY Registration Number:
	City / State / Zip: <b>NEW YORK, NY 10004</b>	Telephone: <b>(212) 868-1573</b>
	Website: <b>WWW.DEBRA.ORG</b>	Email: <b>STAFF@DEBRA.ORG</b>
	Check your organization's registration category: <input checked="" type="checkbox"/> 7A only <input type="checkbox"/> EPTL only <input type="checkbox"/> DUAL (7A & EPTL) <input type="checkbox"/> EXEMPT*	

**2. Certification**

See instructions for certification requirements. Improper certification is a violation of law that may be subject to penalties. The certification requires two signatories.

*We certify under penalties of perjury that we reviewed this report, including all attachments, and to the best of our knowledge and belief, they are true, correct and complete in accordance with the laws of the State of New York applicable to this report.*

President or Authorized Officer:	 DocuSigned by: Brett Kopelan	<b>Brett Kopelan</b>	<b>4/15/2020</b>
Chief Financial Officer or Treasurer:	 DocuSigned by: J Alexander	<b>J Alexander</b>	<b>4/15/2020</b>

**3. Annual Reporting Exemption**

Check the exemption(s) that apply to your filing. If your organization is claiming an exemption under one category (7A or EPTL only filers) or both categories (DUAL filers) that apply to your registration, complete only parts 1, 2, and 3, and submit the certified Char500. No fee, schedules, or additional attachments are required. If you cannot claim an exemption or are a DUAL filer that claims only one exemption, you must file applicable schedules and attachments and pay applicable fees.

- 3a. 7A filing exemption:** Total contributions from NY State including residents, foundations, government agencies, etc. did not exceed \$25,000 and the organization did not engage a professional fund raiser (PFR) or fund raising counsel (FRC) to solicit contributions during the fiscal year.
- 3b. EPTL filing exemption:** Gross receipts did not exceed \$25,000 and the market value of assets did not exceed \$25,000 at any time during the fiscal year.

**4. Schedules and Attachments**

See the following page for a checklist of schedules and attachments to complete your filing.	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	4a. Did your organization use a professional fund raiser, fund raising counsel or commercial co-venturer for fund raising activity in NY State? If yes, complete Schedule 4a.
	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	4b. Did the organization receive government grants? If yes, complete Schedule 4b.

**5. Fee**

See the checklist on the next page to calculate your fee(s). Indicate fee(s) you are submitting here:	7A filing fee: \$ <u>25.</u>	EPTL filing fee: \$ _____	Total fee: \$ <u>25.</u>	Make a single check or money order payable to: <b>"Department of Law"</b>
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CHAR500 Annual Filing for Charitable Organizations (Updated January 2020)

\*The "Exempt" category refers to an organization's NYS registration status. It does not refer to its IRS tax designation.

Page 1

# CHAR500

## Annual Filing Checklist

Simply submit the certified CHAR500 with no fee, schedule, or additional attachments IF:

- Your organization is registered as 7A only and you marked the 7A filing exemption in Part 3.
- Your organization is registered as EPTL only and you marked the EPTL filing exemption in Part 3.
- Your organization is registered as DUAL and you marked both the 7A and EPTL filing exemption in Part 3.

### Checklist of Schedules and Attachments

Check the schedules you must submit with your CHAR500 as described in Part 4:

- If you answered "yes" in Part 4a, submit Schedule 4a: Professional Fund Raisers (PFR), Fund Raising Counsel (FRC), Commercial Co-Venturers (CCV)
- If you answered "yes" in Part 4b, submit Schedule 4b: Government Grants

Check the financial attachments you must submit with your CHAR500:

- IRS Form 990, 990-EZ, or 990-PF, and 990-T if applicable
- All additional IRS Form 990 Schedules, including Schedule B (Schedule of Contributors). Schedule B of public charities is exempt from disclosure and will not be available for public review.
- Our organization was eligible for and filed an IRS 990-N e-postcard. Our revenue exceeded \$25,000 and/or our assets exceeded \$25,000 in the filing year. We have included an IRS Form 990-EZ for state purposes only.

If you are a 7A only or DUAL filer, submit the applicable independent Certified Public Accountant's Review or Audit Report:

- Review Report if you received total revenue and support greater than \$250,000 and up to \$750,000.
- Audit Report if you received total revenue and support greater than \$750,000
- No Review Report or Audit Report is required because total revenue and support is less than \$250,000
- We are a DUAL filer and checked box 3a, no Review Report or Audit Report is required

### Calculate Your Fee

For 7A and DUAL filers, calculate the 7A fee:

- \$0, if you checked the 7A exemption in Part 3a
- \$25, if you did not check the 7A exemption in Part 3a

For EPTL and DUAL filers, calculate the EPTL fee:

- \$0, if you checked the EPTL exemption in Part 3b
- \$25, if the NET WORTH is less than \$50,000
- \$50, if the NET WORTH is \$50,000 or more but less than \$250,000
- \$100, if the NET WORTH is \$250,000 or more but less than \$1,000,000
- \$250, if the NET WORTH is \$1,000,000 or more but less than \$10,000,000
- \$750, if the NET WORTH is \$10,000,000 or more but less than \$50,000,000
- \$1500, if the NET WORTH is \$50,000,000 or more

### Send Your Filing

Send your CHAR500, all schedules and attachments, and total fee to:

NYS Office of the Attorney General  
Charities Bureau Registration Section  
28 Liberty Street  
New York, NY 10005

#### Need Assistance?

Visit: [www.CharitiesNYS.com](http://www.CharitiesNYS.com)  
Call: (212) 416-8401  
Email: [Charities.Bureau@ag.ny.gov](mailto:Charities.Bureau@ag.ny.gov)

### Is my Registration Category 7A, EPTL, DUAL or EXEMPT?

Organizations are assigned a Registration Category upon registration with the NY Charities Bureau:

**7A** filers are registered to solicit contributions in New York under Article 7-A of the Executive Law ("7A")

**EPTL** filers are registered under the Estates, Powers & Trusts Law ("EPTL") because they hold assets and/or conduct activities for charitable purposes in NY.

**DUAL** filers are registered under both 7A and EPTL.

**EXEMPT** filers have registered with the NY Charities Bureau and meet conditions in **Schedule E - Registration Exemption for Charitable Organizations**. These organizations are not required to file annual financial reports but may do so voluntarily.

Confirm your Registration Category and learn more about NY law at [www.CharitiesNYS.com](http://www.CharitiesNYS.com).

### Where do I find my organization's NET WORTH?

NET WORTH for fee purposes is calculated on:

- IRS Form 990 Part I, line 22
- IRS Form 990 EZ Part I line 21
- IRS Form 990 PF, calculate the difference between Total Assets at Fair Market Value (Part II, line 16(c)) and Total Liabilities (Part II, line 23(b)).

**CHAR500**Schedule 4a: Professional Fund Raisers, Fund Raising Counsels, Commercial Co-Venturers  
www.CharitiesNYS.com**2019**  
Open to Public  
Inspection

If you checked the box in question 4a in Part 4 on the CHAR500 Annual Filing for Charitable Organizations, complete this schedule for EACH Professional Fund Raiser (PFR), Fund Raising Counsel (FRC) or Commercial Co-Venturer (CCV) that the organization engaged for fund raising activity in NY State. The PFR or FRC should provide its NY Registration Number to you. Include this schedule with your certified CHAR500 NYS Annual Filing for Charitable Organizations and use additional pages if necessary.

**Definitions**

A **Professional Fund Raiser (PFR)**, in addition to other activities, conducts solicitation of contributions and/or handles the donations (Article 7A, 171-a.4).

A **Fund Raising Counsel (FRC)** does not solicit or handle contributions but limits activities to advising or assisting a charitable organization to perform such functions for itself (Article 7A, 171-a.9).

A **Commercial Co-Venturer (CCV)** is an individual or for-profit company that is regularly and primarily engaged in trade or commerce other than raising funds for a charitable organization and who advertises that the purchase or use of goods, services, entertainment or any other thing of value will benefit a charitable organization (Article 7A, 171-a.6).

**Professional fund raising** does not include activities by an organization's development staff, volunteers, or a grantwriter who has been hired solely to draft applications for funding from a government agency or tax exempt organization.

**1. Organization Information**

Name of Organization: DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA	NY Registration Number:
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**2. Professional Fund Raiser, Fund Raising Counsel, Commercial Co-Venturer Information**

Fund Raising Professional type:  <input type="checkbox"/> Professional Fund Raiser  <input type="checkbox"/> Fund Raising Counsel  <input type="checkbox"/> Commercial Co-Venturer	Name of FRP:	NY Registration Number:
	Mailing Address:	Telephone:
	City / State / Zip:	

**3. Contract Information**

Contract Start Date:	Contract End Date:
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**4. Description of Services**

Services provided by FRP:
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**5. Description of Compensation**

Compensation arrangement with FRP:	Amount Paid to FRP:
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**6. Commercial Co-Venturer (CCV) Report**

<input type="checkbox"/> Yes <input type="checkbox"/> No	If services were provided by a CCV, did the CCV provide the charitable organization with the interim or closing report(s) required by Section 173(a) part 3 of the Executive Law Article 7A?
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**CHAR500**Schedule 4b: Government Grants  
www.CharitiesNYS.com**2019**Open to Public  
Inspection

If you checked the box in question 4b in Part 4, complete this schedule and list EACH government grant award by a domestic (federal, state or local) agency; interstate or intergovernmental agency (for example Port Authority of New York and New Jersey); and state or local authorities.

**Use additional pages if necessary.** Include this schedule with your certified CHAR500 NYS Annual Filing for Charitable Organizations.**1. Organization Information**

Name of Organization:

NY Registration Number:

**2. Government Grants**

Name of Government Agency	Amount of Grant
1.	1.
2.	2.
3.	3.
4.	4.
5.	5.
6.	6.
7.	7.
8.	8.
9.	9.
10.	10.
11.	11.
12.	12.
13.	13.
14.	14.
15.	15.
Total Government Grants:	Total: