

Form **990**

Return of Organization Exempt From Income Tax

OMB No. 1545-0047

2020

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

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

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

A For the 2020 calendar year, or tax year beginning , 2020, and ending , 20

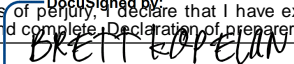
B Check if applicable: <input type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial return <input type="checkbox"/> Final return/terminated <input type="checkbox"/> Amended return <input type="checkbox"/> Application pending	C Name of organization DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA Doing business as			D Employer identification number 11-2519726		
	Number and street (or P.O. box if mail is not delivered to street address) Room/suite 75 BROAD ST SUITE 300		E Telephone number (212) 868-1573			
	City or town, state or province, country, and ZIP or foreign postal code NEW YORK, NY 10004			G Gross receipts \$ 1,975,484.		
	F Name and address of principal officer: BRETT KOPELAN 75 BROAD ST 300, NEW YORK, NY 10004			H(a) Is this a group return for subordinates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No H(b) Are all subordinates included? <input type="checkbox"/> Yes <input type="checkbox"/> No If "No," attach a list. See instructions		
I Tax-exempt status: <input checked="" type="checkbox"/> 501(c)(3) <input type="checkbox"/> 501(c) () ◀ (insert no.) <input type="checkbox"/> 4947(a)(1) or <input type="checkbox"/> 527						
J Website: ▶ WWW.DEBRA.ORG						
K Form of organization: <input checked="" type="checkbox"/> Corporation <input type="checkbox"/> Trust <input type="checkbox"/> Association <input type="checkbox"/> Other ▶						
L Year of formation: 1979				M State of legal domicile: NY		
H(c) Group exemption number ▶						


Part I Summary

Activities & Governance	1 Briefly describe the organization's mission or most significant activities: DEBRA IS DEDICATED TO FINDING A CURE FOR EB THRU RESEARCH EB AFFECTS 1 OUT OF EVERY 50,000 LIVE BIRTHS IN THE U.S.		
	2 Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.		
	3 Number of voting members of the governing body (Part VI, line 1a)	3	11.
	4 Number of independent voting members of the governing body (Part VI, line 1b)	4	11.
	5 Total number of individuals employed in calendar year 2020 (Part V, line 2a)	5	11.
	6 Total number of volunteers (estimate if necessary)	6	0.
	7a Total unrelated business revenue from Part VIII, column (C), line 12	7a	0.
b Net unrelated business taxable income from Form 990-T, Part I, line 11	7b		
Revenue	8 Contributions and grants (Part VIII, line 1h)	Prior Year	Current Year
	9 Program service revenue (Part VIII, line 2g)	705,872.	936,305.
	10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)	0.	0.
	11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	1,696.	1,046.
	12 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	853,730.	938,498.
		1,561,298.	1,875,849.
Expenses	13 Grants and similar amounts paid (Part IX, column (A), lines 1-3)	50,750.	80,454.
	14 Benefits paid to or for members (Part IX, column (A), line 4)	0.	0.
	15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	945,728.	1,020,960.
	16a Professional fundraising fees (Part IX, column (A), line 11e)	0.	0.
	b Total fundraising expenses (Part IX, column (D), line 25) ▶ 131,160.		
	17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	469,217.	527,547.
18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	1,465,695.	1,628,961.	
19 Revenue less expenses. Subtract line 18 from line 12	95,603.	246,888.	
Net Assets or Fund Balances	20 Total assets (Part X, line 16)	Beginning of Current Year	End of Year
	21 Total liabilities (Part X, line 26)	2,407,080.	2,976,485.
	22 Net assets or fund balances. Subtract line 21 from line 20	311,682.	321,584.
	2,095,398.	2,654,901.	

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	DocuSigned by:  D83046E0A7DF445... Signature of officer	03/27/2021 Date
	BRETT KOPELAN EXECUTIVE DIRECTOR Type or print name and title	

Paid Preparer Use Only	Print/Type preparer's name bcwhite	Preparer's signature 	Date 5/3/2021	Check <input type="checkbox"/> if self-employed PTIN P00058320
	Firm's name ▶ NANA VATY 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** (2020)

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 \$ 262,323. including grants of \$) (Revenue \$ 5,641.)

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

4b (Code:) (Expenses \$ 999,391. 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 \$ 39,349. 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 \$ 131,160. including grants of \$) (Revenue \$)

4e Total program service expenses 1,432,223.

Part IV Checklist of Required Schedules

Table with 3 columns: Question ID, 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, W-2G forms, 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, unrelated 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 (11), 1b (11), 2 (X), 3 (X), 4 (X), 5 (X), 6 (X), 7a (X), 7b (X), 8a (X), 8b (X), 9 (X).

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

Table with 3 columns: Question, Yes, No. Rows include 10a (X), 10b, 11a (X), 11b, 12a (X), 12b (X), 12c (X), 13 (X), 14 (X), 15a (X), 15b, 16a (X), 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			0.	261,529.	0.
(2) J ALEC ALEXANDER TREASURER	1.00 0.	X		X				0.	0.	0.
(3) ANDREW TAVANI CHAIR	1.00 0.	X		X				0.	0.	0.
(4) RICHARD GALLAGHER CHAIR EMERITUS	1.00 0.	X						0.	0.	0.
(5) ROBERT RYAN PH. D. DIRECTOR	1.00 0.	X						0.	0.	0.
(6) JOHN LEE SECRETARY	1.00 0.	X		X				0.	0.	0.
(7) WILLIAM CORNMAN DIRECTOR	1.00 0.	X						0.	0.	0.
(8) JAMES WETRICH DIRECTOR	1.00 0.	X						0.	0.	0.
(9) LESLIE RADER DIRECTOR	1.00 0.	X						0.	0.	0.
(10) JOUI UITTO MD, PH.D DIRECTOR	1.00 0.	X						0.	0.	0.
(11) ANGELA CHRISTIANO PH.D. DIRECTOR	1.00 0.	X						0.	0.	0.
(12) THOMAS TRIMARCHI DIRECTOR	1.00 0.	X						0.	0.	0.
(13)										
(14)										

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 (Individual trustee or director, Institutional trustee, Officer, Key employee, Highest compensated employee, Former), (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. Includes sub-totals and totals for lines 1b, 1c, and 1d.

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

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

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. Includes a total line for the number of independent contractors.

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) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512-514	
Contributions, Gifts, Grants and Other Similar Amounts	1a Federated campaigns	1a						
	b Membership dues	1b						
	c Fundraising events	1c						
	d Related organizations	1d						
	e Government grants (contributions) . .	1e						
	f All other contributions, gifts, grants, and similar amounts not included above .	1f		936,305.				
	g Noncash contributions included in lines 1a-1f.	1g	\$	495,605.				
	h Total. Add lines 1a-1f			936,305.				
	Program Service Revenue				Business Code			
2a _____								
b _____								
c _____								
d _____								
e _____								
f All other program service revenue								
g Total. Add lines 2a-2f					0.			
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts).			1,046.			1,046.	
	4 Income from investment of tax-exempt bond proceeds .			0.				
	5 Royalties			0.				
	6a Gross rents	6a	(i) Real	(ii) Personal				
	b Less: rental expenses	6b						
	c Rental income or (loss)	6c						
	d Net rental income or (loss)				0.			
	7a Gross amount from sales of assets other than inventory	7a	(i) Securities	(ii) Other				
	b Less: cost or other basis and sales expenses . .	7b						
	c Gain or (loss)	7c						
	d Net gain or (loss)				0.			
8a Gross income from fundraising events (not including \$ _____ of contributions reported on line 1c). See Part IV, line 18	8a			1,032,492.				
				99,635.				
				932,857.			932,857.	
b Less: direct expenses	8b							
c Net income or (loss) from fundraising events.								
9a Gross income from gaming activities. See Part IV, line 19	9a			0.				
				0.				
				0.				
b Less: direct expenses	9b							
c Net income or (loss) from gaming activities.				0.				
10a Gross sales of inventory, less returns and allowances	10a			0.				
				0.				
				0.				
b Less: cost of goods sold	10b							
c Net income or (loss) from sales of inventory.				0.				
Miscellaneous Revenue				Business Code				
	11a MISCELLANEOUS INCOME			900099	5,641.	5,641.		
	b _____							
	c _____							
	d All other revenue							
	e Total. Add lines 11a-11d				5,641.			
12 Total revenue. See instructions				1,875,849.	5,641.		933,903.	

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	80,454.	80,454.		
4 Benefits paid to or for members	0.			
5 Compensation of current officers, directors, trustees, and key employees	261,529.	222,300.	13,076.	26,153.
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	590,535.	501,955.	29,527.	59,053.
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	0.			
9 Other employee benefits	100,127.	85,108.	5,006.	10,013.
10 Payroll taxes	68,769.	58,454.	3,438.	6,877.
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.)	8,300.	7,055.	415.	830.
12 Advertising and promotion	10,173.	8,647.	509.	1,017.
13 Office expenses	58,905.	50,070.	2,945.	5,890.
14 Information technology	0.			
15 Royalties	0.			
16 Occupancy	103,927.	88,338.	5,196.	10,393.
17 Travel	19,161.	16,287.	958.	1,916.
18 Payments of travel or entertainment expenses for any federal, state, or local public officials	0.			
19 Conferences, conventions, and meetings	14,351.	12,198.	718.	1,435.
20 Interest	0.			
21 Payments to affiliates	0.			
22 Depreciation, depletion, and amortization	2,968.	2,523.	148.	297.
23 Insurance	23,282.	19,790.	1,164.	2,328.
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	236,900.	236,900.		
b DUES & SUBSCRIPTIONS	3,306.	2,810.	165.	331.
c TELEPHONE	17,463.	14,844.	873.	1,746.
d EQUIPMENT	10,808.	9,187.	540.	1,081.
e All other expenses	18,003.	15,303.	900.	1,800.
25 Total functional expenses. Add lines 1 through 24e	1,628,961.	1,432,223.	65,578.	131,160.
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here <input type="checkbox"/> if following SOP 98-2 (ASC 958-720)	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
Assets	1 Cash - non-interest-bearing	972,811.	1	651,965.
	2 Savings and temporary cash investments	0.	2	0.
	3 Pledges and grants receivable, net	0.	3	0.
	4 Accounts receivable, net.	5,360.	4	527,541.
	5 Loans and other receivables from any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons	0.	5	0.
	6 Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B).	0.	6	0.
	7 Notes and loans receivable, net	0.	7	0.
	8 Inventories for sale or use	467,518.	8	648,724.
	9 Prepaid expenses and deferred charges ATCH 3	38,570.	9	58,958.
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D 10a 44,082.			
	b Less: accumulated depreciation 10b 37,834.	8,029.	10c	6,248.
	11 Investments - publicly traded securities. ATCH 4	664,792.	11	833,049.
	12 Investments - other securities. See Part IV, line 11	250,000.	12	250,000.
	13 Investments - program-related. See Part IV, line 11.	0.	13	0.
	14 Intangible assets	0.	14	0.
	15 Other assets. See Part IV, line 11	0.	15	0.
16 Total assets. Add lines 1 through 15 (must equal line 33)	2,407,080.	16	2,976,485.	
Liabilities	17 Accounts payable and accrued expenses	214,071.	17	321,584.
	18 Grants payable	0.	18	0.
	19 Deferred revenue.	0.	19	0.
	20 Tax-exempt bond liabilities.	0.	20	0.
	21 Escrow or custodial account liability. Complete Part IV of Schedule D.	0.	21	0.
	22 Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons	0.	22	0.
	23 Secured mortgages and notes payable to unrelated third parties	0.	23	0.
	24 Unsecured notes and loans payable to unrelated third parties.	0.	24	0.
	25 Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24). Complete Part X of Schedule D	97,611.	25	0.
	26 Total liabilities. Add lines 17 through 25.	311,682.	26	321,584.
Net Assets or Fund Balances	Organizations that follow FASB ASC 958, check here <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33.			
	27 Net assets without donor restrictions	1,283,751.	27	2,107,054.
	28 Net assets with donor restrictions.	811,647.	28	547,847.
	Organizations that do not follow FASB ASC 958, check here <input type="checkbox"/> and complete lines 29 through 33.			
	29 Capital stock or trust principal, or current funds		29	
	30 Paid-in or capital surplus, or land, building, or equipment fund.		30	
	31 Retained earnings, endowment, accumulated income, or other funds.		31	
	32 Total net assets or fund balances	2,095,398.	32	2,654,901.
33 Total liabilities and net assets/fund balances.	2,407,080.	33	2,976,485.	

Part XI Reconciliation of Net Assets

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	1,875,849.
2	Total expenses (must equal Part IX, column (A), line 25)	2	1,628,961.
3	Revenue less expenses. Subtract line 2 from line 1	3	246,888.
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	2,095,398.
5	Net unrealized gains (losses) on investments	5	138,689.
6	Donated services and use of facilities	6	173,926.
7	Investment expenses	7	0.
8	Prior period adjustments	8	0.
9	Other changes in net assets or fund balances (explain on Schedule O)	9	0.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B))	10	2,654,901.

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
2a		X
2b	X	
2c	X	
3a		X
3b		

SCHEDULE A
(Form 990 or 990-EZ)

Public Charity Status and Public Support

OMB No. 1545-0047

2020

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 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)						
Total						

Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)
(Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

Table with 7 columns: (a) 2016, (b) 2017, (c) 2018, (d) 2019, (e) 2020, (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. Add lines 1 through 3; 5 The portion of total contributions by each person; 6 Public support. Subtract line 5 from line 4.

Section B. Total Support

Table with 7 columns: (a) 2016, (b) 2017, (c) 2018, (d) 2019, (e) 2020, (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. Add lines 7 through 10; 12 Gross receipts from related activities; 13 First 5 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 2 columns: Line number, Percentage. Rows include: 14 Public support percentage for 2020 (99.84%); 15 Public support percentage from 2019 Schedule A, Part II, line 14 (99.77%); 16a 33 1/3% support test - 2020 (checked); 16b 33 1/3% support test - 2019; 17a 10%-facts-and-circumstances test - 2020; 17b 10%-facts-and-circumstances test - 2019; 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) 2016, (b) 2017, (c) 2018, (d) 2019, (e) 2020, (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; 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.

Section B. Total Support

Table with 7 columns: (a) 2016, (b) 2017, (c) 2018, (d) 2019, (e) 2020, (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; 13 Total support.

14 First 5 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 2 columns: Line number, Percentage. Row 15: Public support percentage for 2020 (line 8, column (f), divided by line 13, column (f)) 15%. Row 16: Public support percentage from 2019 Schedule A, Part III, line 15 16%.

Section D. Computation of Investment Income Percentage

Table with 2 columns: Line number, Percentage. Row 17: Investment income percentage for 2020 (line 10c, column (f), divided by line 13, column (f)) 17%. Row 18: Investment income percentage from 2019 Schedule A, Part III, line 17 18%.

19a 33 1/3% support tests - 2020. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization.

b 33 1/3% support tests - 2019. 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 box 12a, Part I, complete Sections A and B. If you checked box 12b, Part I, complete Sections A and C. If you checked box 12c, Part I, complete Sections A, D, and E. If you checked box 12d, Part I, complete Sections A and D, and complete Part V.)

Section A. All Supporting Organizations

	Yes	No
1 Are all of the organization's supported organizations listed by name in the organization's governing documents? <i>If "No," describe in Part VI how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.</i>		
2 Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? <i>If "Yes," explain in Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).</i>		
3a Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? <i>If "Yes," answer lines 3b and 3c below.</i>		
b Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? <i>If "Yes," describe in Part VI when and how the organization made the determination.</i>		
c Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? <i>If "Yes," explain in Part VI what controls the organization put in place to ensure such use.</i>		
4a Was any supported organization not organized in the United States ("foreign supported organization")? <i>If "Yes," and if you checked box 12a or 12b in Part I, answer lines 4b and 4c below.</i>		
b Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? <i>If "Yes," describe in Part VI how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.</i>		
c Did the organization support any foreign supported organization that does not have an IRS determination under sections 501(c)(3) and 509(a)(1) or (2)? <i>If "Yes," explain in Part VI what controls the organization used to ensure that all support to the foreign supported organization was used exclusively for section 170(c)(2)(B) purposes.</i>		
5a Did the organization add, substitute, or remove any supported organizations during the tax year? <i>If "Yes," answer lines 5b and 5c below (if applicable). Also, provide detail in Part VI, including (i) the names and EIN numbers of the supported organizations added, substituted, or removed; (ii) the reasons for each such action; (iii) the authority under the organization's organizing document authorizing such action; and (iv) how the action was accomplished (such as by amendment to the organizing document).</i>		
b Type I or Type II only. Was any added or substituted supported organization part of a class already designated in the organization's organizing document?		
c Substitutions only. Was the substitution the result of an event beyond the organization's control?		
6 Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? <i>If "Yes," provide detail in Part VI.</i>		
7 Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (as defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? <i>If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).</i>		
8 Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? <i>If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).</i>		
9a Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons, as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? <i>If "Yes," provide detail in Part VI.</i>		
b Did one or more disqualified persons (as defined in line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? <i>If "Yes," provide detail in Part VI.</i>		
c Did a disqualified person (as defined in line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? <i>If "Yes," provide detail in Part VI.</i>		
10a Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? <i>If "Yes," answer line 10b below.</i>		
b Did the organization have any excess business holdings in the tax year? <i>(Use Schedule C, Form 4720, to determine whether the organization had excess business holdings.)</i>		

Part IV Supporting Organizations (continued)

Table with 3 columns: Question, Yes, No. Row 11: Has the organization accepted a gift or contribution from any of the following persons? Row 11a: A person who directly or indirectly controls... Row 11b: A family member... Row 11c: A 35% controlled entity...

Section B. Type I Supporting Organizations

Table with 3 columns: Question, Yes, No. Row 1: Did the governing body, members of the governing body, officers acting in their official capacity... Row 2: Did the organization operate for the benefit of any supported organization other than the supported organization(s)...

Section C. Type II Supporting Organizations

Table with 3 columns: Question, Yes, No. Row 1: Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)...

Section D. All Type III Supporting Organizations

Table with 3 columns: Question, Yes, No. Row 1: Did the organization provide to each of its supported organizations, by the last day of the fifth month of the organization's tax year... Row 2: Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported organization(s) or (ii) serving on the governing body... Row 3: By reason of the relationship described in line 2, above, did the organization's supported organizations have a significant voice...

Section E. Type III Functionally Integrated Supporting Organizations

Table with 3 columns: Question, Yes, No. Row 1: Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions). Row 2: Activities Test. Answer lines 2a and 2b below. Row 2a: Did substantially all of the organization's activities during the tax year directly further the exempt purposes... Row 2b: Did the activities described in line 2a, above, constitute activities that, but for the organization's involvement... Row 3: Parent of Supported Organizations. Answer lines 3a and 3b below. Row 3a: Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees... Row 3b: Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations...

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

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

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

Section B - Minimum Asset Amount		(A) Prior Year	(B) Current Year (optional)
1	Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year):		
a	Average monthly value of securities	1a	
b	Average monthly cash balances	1b	
c	Fair market value of other non-exempt-use assets	1c	
d	Total (add lines 1a, 1b, and 1c)	1d	
e	Discount claimed for blockage or other factors (<i>explain in detail in Part VI</i>):	1e	
2	Acquisition indebtedness applicable to non-exempt-use assets	2	
3	Subtract line 2 from line 1d.	3	
4	Cash deemed held for exempt use. Enter 0.015 of line 3 (for greater amount, see instructions).	4	
5	Net value of non-exempt-use assets (subtract line 4 from line 3)	5	
6	Multiply line 5 by 0.035.	6	
7	Recoveries of prior-year distributions	7	
8	Minimum Asset Amount (add line 7 to line 6)	8	

Section C - Distributable Amount			Current Year
1	Adjusted net income for prior year (from Section A, line 8, column A)	1	
2	Enter 0.85 of line 1.	2	
3	Minimum asset amount for prior year (from Section B, line 8, column A)	3	
4	Enter greater of line 2 or line 3.	4	
5	Income tax imposed in prior year	5	
6	Distributable Amount. Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions).	6	
7	<input type="checkbox"/> Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see instructions).		

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	1
2	Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	2
3	Administrative expenses paid to accomplish exempt purposes of supported organizations	3
4	Amounts paid to acquire exempt-use assets	4
5	Qualified set-aside amounts (prior IRS approval required - <i>provide details in Part VI</i>)	5
6	Other distributions (<i>describe in Part VI</i>). See instructions.	6
7	Total annual distributions. Add lines 1 through 6.	7
8	Distributions to attentive supported organizations to which the organization is responsive (<i>provide details in Part VI</i>). See instructions.	8
9	Distributable amount for 2020 from Section C, line 6	9
10	Line 8 amount divided by line 9 amount	10

Section E - Distribution Allocations (see instructions)		(i) Excess Distributions	(ii) Underdistributions Pre-2020	(iii) Distributable Amount for 2020
1	Distributable amount for 2020 from Section C, line 6			
2	Underdistributions, if any, for years prior to 2020 (reasonable cause required - <i>explain in Part VI</i>). See instructions.			
3	Excess distributions carryover, if any, to 2020			
a	From 2015			
b	From 2016			
c	From 2017			
d	From 2018			
e	From 2019			
f	Total of lines 3a through 3e			
g	Applied to underdistributions of prior years			
h	Applied to 2020 distributable amount			
i	Carryover from 2015 not applied (see instructions)			
j	Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
4	Distributions for 2020 from Section D, line 7: \$			
a	Applied to underdistributions of prior years			
b	Applied to 2020 distributable amount			
c	Remainder. Subtract lines 4a and 4b from line 4.			
5	Remaining underdistributions for years prior to 2020, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, <i>explain in Part VI</i> . See instructions.			
6	Remaining underdistributions for 2020. Subtract lines 3h and 4b from line 1. For result greater than zero, <i>explain in Part VI</i> . See instructions.			
7	Excess distributions carryover to 2021. Add lines 3j and 4c.			
8	Breakdown of line 7:			
a	Excess from 2016			
b	Excess from 2017			
c	Excess from 2018			
d	Excess from 2019			
e	Excess from 2020			

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.)

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

Schedule of Contributors

OMB No. 1545-0047

2020

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

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

Organization type (check one):

Filers of:

Section:

Form 990 or 990-EZ

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

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

527 political organization

Form 990-PF

501(c)(3) exempt private foundation

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

501(c)(3) taxable private foundation

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

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

General Rule

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

Special Rules

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

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

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

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

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

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	\$ 100,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
2	J ALEXANDER 3398 HARBOUR POINT PARKWAY GAINSVILLE, GA 30506	\$ 105,200.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
3	MR JOHNNY MCCRANIE HOLIDAY PROPERTIES VALDOSTA, GA 31604	\$ 20,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
4	FIBROCELL SCIENCE 405 EAGLEVIEW BLVD EXTON, PA 19341	\$ 110,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
5	FACEBOOK 1601 WILLOW RD MENLO PARK, CA 94025	\$ 32,997.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
6	KRYSTAL BIOTECH INC 2100 WHARTON ST, SUITE 701 PITTSBURGH, PA 15203	\$ 25,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)

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

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
7	ABEONA THERAPEUTICS INC 333 LEE PARKWAY, SUITE 600 DALLAS, TX 75219	\$ 25,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
8	MOLNLYCKE & OTHERS 5445 TRIANGLE PARKWAY PEACHTREE CORNERS, GA 30092	\$ 464,342.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input checked="" type="checkbox"/> (Complete Part II for noncash contributions.)
_____	_____ _____ _____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
_____	_____ _____ _____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
_____	_____ _____ _____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
_____	_____ _____ _____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)

Name of organization DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA	Employer identification number 11-2519726
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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
1	DONATED MEDICAL SUPPLIES AND BANDAGES _____ _____ _____	\$ 464,342.	12/01/2020
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____

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

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

2020

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 total number at end of year, aggregate value of contributions, grants, and end of year, and two Yes/No questions regarding donor advisement.

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 purpose(s) of conservation easements, total number of easements, acreage, and number of easements on certified historic structures.

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 whether organization elected to report in revenue statement and balance sheet works of art, historical treasures, or other similar assets.

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.

Table with 3 columns: (a) Description of security or category, (b) Book value, (c) Method of valuation. Includes rows for Financial derivatives, Closely held equity interests, and Other (A) PREFERRED STOCK.

Part VIII Investments - Program Related.

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

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

Part IX Other Assets.

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

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

Part X Other Liabilities.

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

Table with 2 columns: (a) Description of liability, (b) Book value. Includes rows for Federal income taxes and AGENCY FUNDS HELD FOR OTHERS.

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 1,875,849.

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 1,628,961.

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

Part XIII Supplemental Information *(continued)*

**SCHEDULE F
(Form 990)**

Statement of Activities Outside the United States

OMB No. 1545-0047

2020

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 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)					
3a Subtotal					
b Total from continuation sheets to Part I					
c Totals (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	53,454.	CASH TRANSFE		NONE	FMV
(2)			CENT. AMERICA/CARIBBEAN	TO FUND INTE	27,000.	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 a tax exempt 501(c)(3) organization 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).

SCHEDULE G
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Supplemental Information Regarding Fundraising or Gaming Activities

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

▶ Attach to Form 990 or Form 990-EZ.

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

OMB No. 1545-0047

2020

Open to Public Inspection

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.

a <input type="checkbox"/> Mail solicitations	e <input type="checkbox"/> Solicitation of non-government grants
b <input type="checkbox"/> Internet and email solicitations	f <input type="checkbox"/> Solicitation of government grants
c <input type="checkbox"/> Phone solicitations	g <input type="checkbox"/> Special fundraising events
d <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						
Total						

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

Part II Fundraising Events. Complete if the organization answered "Yes" 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	
		OTHER EVENTS			(add col. (a) through col. (c))	
		(event type)	(event type)	(total number)		
Revenue	1	Gross receipts	1,032,492.		1,032,492.	
	2	Less: Contributions	25,000.		25,000.	
	3	Gross income (line 1 minus line 2)	1,007,492.		1,007,492.	
Direct Expenses	4	Cash prizes				
	5	Noncash prizes				
	6	Rent/facility costs				
	7	Food and beverages				
	8	Entertainment				
	9	Other direct expenses	99,635.		99,635.	
	10	Direct expense summary. Add lines 4 through 9 in column (d) ▶				99,635.
	11	Net income summary. Subtract line 10 from line 3, column (d) ▶				907,857.

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	13a	%
b An outside facility	13b	%

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

Name ▶ _____

Address ▶ _____

- 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).

**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.

2020

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.

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

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

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.

- | | |
|--------------------------------------------------------------|--------------------------------------------------------------------------|
| <input checked="" type="checkbox"/> Compensation committee | <input type="checkbox"/> Written employment contract |
| <input type="checkbox"/> Independent compensation consultant | <input type="checkbox"/> Compensation survey or study |
| <input type="checkbox"/> Form 990 of other organizations | <input type="checkbox"/> Approval by the board or compensation committee |

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

- a** Receive a severance payment or change-of-control payment? **4a** **X**
- b** Participate in or receive payment from a supplemental nonqualified retirement plan? **4b** **X**
- c** Participate in or receive payment from an equity-based compensation arrangement? **4c** **X**
- If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.

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

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

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

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

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

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

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

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

	Yes	No
1a		
1b		
2		
3		
4a		X
4b		X
4c		X
5a		X
5b		X
6a		X
6b		X
7		X
8		X
9		X

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

Schedule J (Form 990) 2020

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				
BRETT KOPELAN	(i)	0.	0.	0.				
EXECUTIVE DIRECTOR	(ii)	261,529.	0.	0.		261,529.		
2	(i)							
	(ii)							
3	(i)							
	(ii)							
4	(i)							
	(ii)							
5	(i)							
	(ii)							
6	(i)							
	(ii)							
7	(i)							
	(ii)							
8	(i)							
	(ii)							
9	(i)							
	(ii)							
10	(i)							
	(ii)							
11	(i)							
	(ii)							
12	(i)							
	(ii)							
13	(i)							
	(ii)							
14	(i)							
	(ii)							
15	(i)							
	(ii)							
16	(i)							
	(ii)							

Part III Supplemental Information

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

**SCHEDULE M
(Form 990)**

Department of the Treasury
Internal Revenue Service

Noncash Contributions

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

OMB No. 1545-0047

2020

**Open to Public
Inspection**

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

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.	464,342.	FMV
21 Taxidermy				
22 Historical artifacts.				
23 Scientific specimens				
24 Archeological artifacts				
25 Other ▶ (LEGAL SERVICES)	X	1.	31,263.	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 V, Donee Acknowledgement **29**

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

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.

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

▶ Attach to Form 990 or 990-EZ.

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

OMB No. 1545-0047

2020**Open to Public
Inspection**Name of the organization
RESEARCH ASSOCIATION OF AMERICA
DYSTROPHIC EPIDERMOLYSIS BULLOSAEmployer 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		131,160.	
	TOTALS	<u>131,160.</u>	

ATTACHMENT 3

FORM 990, PART X - PREPAID EXPENSES AND DEFERRED CHARGES

<u>DESCRIPTION</u>	<u>ENDING BOOK VALUE</u>
PREPAID EXPENSES	58,958.
	TOTALS <u>58,958.</u>

Schedule O (Form 990 or 990-EZ) 2020

Page **2**Name of the organization DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICAEmployer identification number
11-2519726ATTACHMENT 4FORM 990, PART X - INVESTMENTS - PUBLICLY TRADED SECURITIES

<u>DESCRIPTION</u>	<u>ENDING BOOK VALUE</u>	<u>COST OR FMV</u>
MUTUAL FUNDS	833,049.	FMV
TOTALS	<u>833,049.</u>	

Form **4562**

Depreciation and Amortization
(Including Information on Listed Property)

OMB No. 1545-0172

2020

Department of the Treasury
Internal Revenue Service (99)

▶ Attach to your tax return.

▶ Go to 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 2019 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 2021. 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	2,968.

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 2020	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 2020 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 2020 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	Total. 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	2,968.
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 (2020)

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
(a) Type of property (list vehicles first) (b) Date placed in service (c) Business/investment use percentage (d) Cost or other basis (e) Basis for depreciation (business/investment use only) (f) Recovery period (g) Method/Convention (h) Depreciation deduction (i) Elected section 179 cost
25 Special depreciation allowance for qualified listed property placed in service during the tax year and used more than 50% in a qualified business use. See instructions 25
26 Property used more than 50% in a qualified business use:
27 Property used 50% or less in a qualified business use:
28 Add amounts in column (h), lines 25 through 27. Enter here and on line 21, page 1. 28
29 Add amounts in column (i), line 26. Enter here and on line 7, page 1. 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.

30 Total business/investment miles driven during the year (don't include commuting miles)
31 Total commuting miles driven during the year
32 Total other personal (noncommuting) miles driven
33 Total miles driven during the year. Add lines 30 through 32
34 Was the vehicle available for personal use during off-duty hours?
35 Was the vehicle used primarily by a more than 5% owner or related person?
36 Is another vehicle available for personal use?
(a) Vehicle 1 (b) Vehicle 2 (c) Vehicle 3 (d) Vehicle 4 (e) Vehicle 5 (f) Vehicle 6

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.

37 Do you maintain a written policy statement that prohibits all personal use of vehicles, including commuting, by your employees? Yes No
38 Do you maintain a written policy statement that prohibits personal use of vehicles, except commuting, by your employees? See the instructions for vehicles used by corporate officers, directors, or 1% or more owners
39 Do you treat all use of vehicles by employees as personal use?
40 Do you provide more than five vehicles to your employees, obtain information from your employees about the use of the vehicles, and retain the information received?
41 Do you meet the requirements concerning qualified automobile demonstration use? See instructions
Note: If your answer to 37, 38, 39, 40, or 41 is "Yes," don't complete Section B for the covered vehicles.

Part VI Amortization

(a) Description of costs (b) Date amortization begins (c) Amortizable amount (d) Code section (e) Amortization period or percentage (f) Amortization for this year
42 Amortization of costs that begins during your 2020 tax year (see instructions):
43 Amortization of costs that began before your 2020 tax year 43
44 Total. Add amounts in column (f). See the instructions for where to report 44

2020

DYSTROPHIC EPIDERMOLYSIS BULLOSA

Description of Property
GENERAL DEPRECIATION

DEPRECIATION

Asset description	Date placed in service	Unadjusted Cost or basis	Bus. %	179 exp. reduction in basis	Basis Reduction	Basis for depreciation	Beginning Accumulated depreciation	Ending Accumulated depreciation	Method	Conv.	Life	ACRS class	MA CRS class	Current-year 179 expense	Current-year depreciation
OTHER	01/01/2010	-901.	100.000				-901.	-901.	SL		5.000				
DELL COMPUTER	04/01/2011	1,420.	100.000			1,420.	1,420.	1,420.	SL		3.000				
COMPUTER	01/10/2012	2,162.	100.000			2,162.	2,162.	2,162.	SL		3.000				
COMPUTER	04/27/2012	640.	100.000			640.	640.	640.	SL		3.000				
COMPUTER	05/04/2012	594.	100.000			594.	594.	594.	SL		3.000				
FURNITURE	12/19/2012	2,279.	100.000			2,279.	2,279.	2,279.	SL		5.000				
SWITCH	01/07/2013	430.	100.000			430.	430.	430.	SL		3.000				
LENOVO LAPTOP	04/30/2013	1,555.	100.000			1,555.	1,555.	1,555.	SL		3.000				
FIREWALL	11/07/2013	500.	100.000			500.	500.	500.	SL		3.000				
SWITCH	11/07/2013	320.	100.000			320.	320.	320.	SL		3.000				
FURNITURE	08/20/2013	19,567.	100.000			19,567.	19,567.	19,567.	SL		5.000				
REFRIGERATOR	10/01/2013	1,734.	100.000			1,734.	1,734.	1,734.	SL		5.000				
SHELVES	10/15/2013	468.	100.000			468.	468.	468.	SL		3.000				
DELL COMPUTER	03/10/2014	1,861.	100.000			1,861.	1,861.	1,861.	SL		3.000				
DELL COMPUTER	06/02/2015	1,858.	100.000			1,858.	1,858.	1,858.	SL		3.000				
DELL COMPUTER	11/10/2019	5,253.	100.000			5,253.	292.	2,043.	SL		3.000				1,751.
DELL COMPUTER	12/10/2019	3,156.	100.000			3,156.	88.	1,140.	SL		3.000				1,052.
DELL COMPUTER	08/10/2020	1,186.	100.000			1,186.		165.	SL		3.000				165.
Less: Retired Assets															
Subtotals		44,082.				44,983.	34,867.	37,835.							2,968.

Listed Property

Less: Retired Assets															
Subtotals															
TOTALS		44,082.				44,983.	34,867.	37,835.							2,968.

AMORTIZATION

Asset description	Date placed in service	Cost or basis	Accumulated amortization	Ending Accumulated amortization	Code	Life	Current-year amortization
TOTALS							

*Assets Retired
JSA
OX9024 1.000