

Form **990**

Return of Organization Exempt From Income Tax

OMB No. 1545-0047

2021

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.

Open to Public Inspection

A For the 2021 calendar year, or tax year beginning and ending

B Check if applicable:
 Address change
 Name change
 Initial return
 Final return/terminated
 Amended return
 Application pending

C Name of organization DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA
Doing business as
Number and street (or P.O. box if mail is not delivered to street address) Room/suite
 75 BROAD ST SUITE 300
City or town, state or province, country, and ZIP or foreign postal code
 NEW YORK, NY 10004

D Employer identification number
11-2519726

E Telephone number
(212) 868-1573

F Name and address of principal officer: BRETT KOPELAN
75 BROAD ST 300, NEW YORK, NY 10004

G Gross receipts \$ 1,859,467.

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

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

J Website: WWW.DEBRA.ORG

K Form of organization: Corporation Trust Association Other ▶

L Year of formation: 1979 **M State of legal domicile:** NY

H(c) Group exemption number ▶

Part I Summary		Prior Year	Current Year
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 2021 (Part V, line 2a)	5	12
	6 Total number of volunteers (estimate if necessary)	6	
	7a Total unrelated business revenue from Part VIII, column (C), line 12	7a	
b Net unrelated business taxable income from Form 990-T, Part I, line 11	7b		
Revenue	8 Contributions and grants (Part VIII, line 1h)	936,305.	1,003,636.
	9 Program service revenue (Part VIII, line 2g)	NONE	NONE
	10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)	1,046.	787.
	11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	938,498.	105,366.
	12 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	1,875,849.	1,109,789.
Expenses	13 Grants and similar amounts paid (Part IX, column (A), lines 1-3)	80,454.	9,000.
	14 Benefits paid to or for members (Part IX, column (A), line 4)	NONE	NONE
	15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	1,020,960.	1,092,260.
	16a Professional fundraising fees (Part IX, column (A), line 11e)	NONE	NONE
	b Total fundraising expenses (Part IX, column (D), line 25) ▶ 161,229.		
	17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	527,547.	571,423.
	18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	1,628,961.	1,672,683.
19 Revenue less expenses. Subtract line 18 from line 12	246,888.	-562,894.	
Net Assets or Fund Balances	20 Total assets (Part X, line 16)	Beginning of Current Year 2,976,485.	End of Year 2,216,777.
	21 Total liabilities (Part X, line 26)	321,584.	359,056.
	22 Net assets or fund balances. Subtract line 21 from line 20	2,654,901.	1,857,721.

Part II Signature Block

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

Sign Here
 Signature of officer: BRETT KOPELAN Date: 03/15/2022
 Type or print name and title: BRETT KOPELAN EXECUTIVE DIRECTOR

Paid Preparer Use Only
 Print/Type preparer's name: Brian White Preparer's signature: Brian White Date: 03/15/2022
 Check if self-employed PTIN: P00058320
 Firm's name: NANAVATY DAVENPORT STUDLEY WHITE Firm's EIN: 06-1402749
 Firm's address: 123 SOUTH MAIN ST., SUITE 140 NEWTOWN, CT 06470 Phone no.: 203-426-8500

May the IRS discuss this return with the preparer shown above? See instructions Yes No

For Paperwork Reduction Act Notice, see the separate instructions. Form **990** (2021)

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:

SEE SCHEDULE O

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 \$ 322,459. including grants of \$) (Revenue \$)

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

4b (Code:) (Expenses \$ 898,782. 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 \$ 48,368. 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.) SEE SCHEDULE O

(Expenses \$ 161,229. including grants of \$) (Revenue \$)

4e Total program service expenses 1,430,838.

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 number, Question text, Yes, No. Rows 22-38 covering various organizational requirements.

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 number, Question text, 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)		Yes	No
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return. 12		
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns? Note: If the sum of lines 1a and 2a is greater than 250, you may be required to e-file. See instructions.	X	
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?		X
b	If "Yes," has it filed a Form 990-T for this year? <i>If "No" to line 3b, provide an explanation on Schedule O</i>		
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?		X
b	If "Yes," enter the name of the foreign country ▶ _____ See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).		
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?		X
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?		X
c	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?		
6a	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions?		X
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?		
7	Organizations that may receive deductible contributions under section 170(c).		
a	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?	X	
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?	X	
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?		
d	If "Yes," indicate the number of Forms 8282 filed during the year 7d		
e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?		
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?		
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?		
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?		
8	Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?		
9	Sponsoring organizations maintaining donor advised funds.		
a	Did the sponsoring organization make any taxable distributions under section 4966?		
b	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?		
10	Section 501(c)(7) organizations. Enter:		
a	Initiation fees and capital contributions included on Part VIII, line 12 10a		
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities 10b		
11	Section 501(c)(12) organizations. Enter:		
a	Gross income from members or shareholders 11a		
b	Gross income from other sources. (Do not net amounts due or paid to other sources against amounts due or received from them.) 11b		
12a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041? 12a		
b	If "Yes," enter the amount of tax-exempt interest received or accrued during the year 12b		
13	Section 501(c)(29) qualified nonprofit health insurance issuers.		
a	Is the organization licensed to issue qualified health plans in more than one state? 13a Note: See the instructions for additional information the organization must report on Schedule O.		
b	Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans 13b		
c	Enter the amount of reserves on hand 13c		
14a	Did the organization receive any payments for indoor tanning services during the tax year? 14a		X
b	If "Yes," has it filed a Form 720 to report these payments? <i>If "No," provide an explanation on Schedule O</i> 14b		
15	Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or excess parachute payment(s) during the year? 15 If "Yes," see the instructions and file Form 4720, Schedule N.		X
16	Is the organization an educational institution subject to the section 4968 excise tax on net investment income? If "Yes," complete Form 4720, Schedule O. 16		X
17	Section 501(c)(21) organizations. Did the trust, any disqualified person, or mine operator engage in any activities that would result in the imposition of an excise tax under section 4951, 4952 or 4953? 17 If "Yes," complete Form 6069.		

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

BRETT KOPELAN 75 BROAD STREET, SUITE 300 NEW YORK, NY 10004
212-868-1573

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 the 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, Form 1099-MISC, and/or box 1 of Form 1099-NEC) 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 the 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/ 1099-NEC)	(E) Reportable compensation from related organizations (W-2/ 1099-MISC/ 1099-NEC)	(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 NONE				X		260,758.	NONE	NONE	
(2) J ALEC ALEXANDER TREASURER	1.00 NONE	X		X			NONE	NONE	NONE	
(3) ANDREW TAVANI CHAIR	1.00 NONE	X		X			NONE	NONE	NONE	
(4) RICHARD GALLAGHER CHAIR EMERITUS	1.00 NONE	X					NONE	NONE	NONE	
(5) ROBERT RYAN PH. D. DIRECTOR	1.00 NONE	X					NONE	NONE	NONE	
(6) JOHN LEE SECRETARY	1.00 NONE	X		X			NONE	NONE	NONE	
(7) WILLIAM CORNMAN DIRECTOR	1.00 NONE	X					NONE	NONE	NONE	
(8) JAMES WETRICH DIRECTOR	1.00 NONE	X					NONE	NONE	NONE	
(9) LESLIE RADER DIRECTOR	1.00 NONE	X					NONE	NONE	NONE	
(10) JOUI UITTO MD, PH.D DIRECTOR	1.00 NONE	X					NONE	NONE	NONE	
(11) ANGELA CHRISTIANO PH.D. DIRECTOR	1.00 NONE	X					NONE	NONE	NONE	
(12) THOMAS TRIMARCHI DIRECTOR	1.00 NONE	X					NONE	NONE	NONE	
(13)										
(14)										

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	164,990.					
	f All other contributions, gifts, grants, and similar amounts not included above .	1f	838,646.					
	g Noncash contributions included in lines 1a-1f	1g	\$					
	h Total. Add lines 1a-1f			1,003,636.				
	Program Service Revenue				Business Code			
2a _____								
b _____								
c _____								
d _____								
e _____								
f All other program service revenue								
g Total. Add lines 2a-2f			NONE					
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts).			787.	787.			
	4 Income from investment of tax-exempt bond proceeds .			NONE				
	5 Royalties			NONE				
	6a Gross rents	6a	(i) Real	(ii) Personal				
			b Less: rental expenses	6b				
			c Rental income or (loss)	6c	NONE	NONE		
	d Net rental income or (loss)				NONE			
	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)				NONE			
	8a Gross income from fundraising events (not including \$ _____ of contributions reported on line 1c). See Part IV, line 18	8a			849,094.			
			b Less: direct expenses	8b	749,678.			
			c Net income or (loss) from fundraising events			99,416.		99,416.
	9a Gross income from gaming activities. See Part IV, line 19	9a			NONE			
b Less: direct expenses			9b	NONE				
c Net income or (loss) from gaming activities					NONE			
10a Gross sales of inventory, less returns and allowances	10a			NONE				
		b Less: cost of goods sold	10b	NONE				
		c Net income or (loss) from sales of inventory			NONE			
Miscellaneous Revenue				Business Code				
	11a MISCELLANEOUS INCOME		900099	5,950.	5,950.			
	b _____							
	c _____							
	d All other revenue							
e Total. Add lines 11a-11d				5,950.				
12 Total revenue. See instructions				1,109,789.	6,737.		99,416.	

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	NONE			
2 Grants and other assistance to domestic individuals. See Part IV, line 22	NONE			
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16	9,000.	9,000.		
4 Benefits paid to or for members	NONE			
5 Compensation of current officers, directors, trustees, and key employees	260,758.	225,758.	10,000.	25,000.
6 Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)	NONE			
7 Other salaries and wages	614,544.	518,249.	33,765.	62,530.
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	NONE			
9 Other employee benefits	141,368.	120,163.	7,068.	14,137.
10 Payroll taxes	75,590.	64,252.	3,779.	7,559.
11 Fees for services (nonemployees):				
a Management	NONE			
b Legal	NONE			
c Accounting	NONE			
d Lobbying	NONE			
e Professional fundraising services. See Part IV, line 17	NONE			
f Investment management fees	NONE			
g Other. (If line 11g amount exceeds 10% of line 25, column (A), amount, list line 11g expenses on Schedule O.)	109,398.	92,988.	5,470.	10,940.
12 Advertising and promotion	41,117.	34,949.	2,056.	4,112.
13 Office expenses	52,392.	44,533.	2,620.	5,239.
14 Information technology	NONE			
15 Royalties	NONE			
16 Occupancy	98,031.	83,327.	4,901.	9,803.
17 Travel	76,940.	65,399.	3,847.	7,694.
18 Payments of travel or entertainment expenses for any federal, state, or local public officials	NONE			
19 Conferences, conventions, and meetings	NONE			
20 Interest	NONE			
21 Payments to affiliates	NONE			
22 Depreciation, depletion, and amortization	3,198.	2,718.	160.	320.
23 Insurance	67,742.	57,581.	3,387.	6,774.
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	51,388.	51,388.		
b DUES & SUBSCRIPTIONS	12,156.	10,332.	608.	1,216.
c TELEPHONE	25,982.	22,085.	1,299.	2,598.
d EQUIPMENT	8,243.	7,007.	412.	824.
e All other expenses	24,836.	21,109.	1,244.	2,483.
25 Total functional expenses. Add lines 1 through 24e	1,672,683.	1,430,838.	80,616.	161,229.
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here <input type="checkbox"/> if following SOP 98-2 (ASC 958-720)				

Part X Balance Sheet

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

Table with columns (A) Beginning of year, (B) End of year. Rows include Assets (1-16) and Liabilities (17-26). Net Assets or Fund Balances (27-33) include sections for FASB ASC 958 and non-FASB ASC 958 organizations.

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	1,109,789.
2	Total expenses (must equal Part IX, column (A), line 25)	2	1,672,683.
3	Revenue less expenses. Subtract line 2 from line 1	3	-562,894.
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	2,654,901.
5	Net unrealized gains (losses) on investments	5	-115,821.
6	Donated services and use of facilities	6	-118,565.
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain on Schedule O)	9	100.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B))	10	1,857,721.

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 on 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)**

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support

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

▶ Attach to Form 990 or Form 990-EZ.

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

OMB No. 1545-0047

2021

**Open to Public
Inspection**

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).)
- 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 on 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) 2017, (b) 2018, (c) 2019, (d) 2020, (e) 2021, (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) 2017, (b) 2018, (c) 2019, (d) 2020, (e) 2021, (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. Do not include gain or loss from the sale of capital assets; 11 Total support. Add lines 7 through 10; 12 Gross receipts from related activities, etc.; 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 2021 (line 6, column (f), divided by line 11, column (f)) 99.83%; 15 Public support percentage from 2020 Schedule A, Part II, line 14 99.84%; 16a 33 1/3% support test - 2021. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization. [X]; 16b 33 1/3% support test - 2020. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization; 17a 10%-facts-and-circumstances test - 2021. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the facts-and-circumstances test, check this box and stop here. Explain in Part VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization; 17b 10%-facts-and-circumstances test - 2020. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the facts-and-circumstances test, check this box and stop here. Explain in Part VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization; 18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions.

Part 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) 2017, (b) 2018, (c) 2019, (d) 2020, (e) 2021, (f) Total. Rows include: 1 Gifts, grants, contributions, and membership fees received; 2 Gross receipts from admissions, merchandise sold or services performed; 3 Gross receipts from activities that are not an unrelated trade or business; 4 Tax revenues levied for the organization's benefit; 5 The value of services or facilities furnished by a governmental unit; 6 Total. Add lines 1 through 5; 7a Amounts included on lines 1, 2, and 3 received from disqualified persons; 7b Amounts included on lines 2 and 3 received from other than disqualified persons; 7c Add lines 7a and 7b; 8 Public support. (Subtract line 7c from line 6.)

Section B. Total Support

Table with 7 columns: (a) 2017, (b) 2018, (c) 2019, (d) 2020, (e) 2021, (f) Total. Rows include: 9 Amounts from line 6; 10a Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources; 10b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975; 10c Add lines 10a and 10b; 11 Net income from unrelated business activities not included in line 10b; 12 Other income. Do not include gain or loss from the sale of capital assets; 13 Total support. (Add lines 9, 10c, 11, and 12.)

14 First 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 3 columns: Description, Line number, Percentage. Rows: 15 Public support percentage for 2021 (line 8, column (f), divided by line 13, column (f)); 16 Public support percentage from 2020 Schedule A, Part III, line 15.

Section D. Computation of Investment Income Percentage

Table with 3 columns: Description, Line number, Percentage. Rows: 17 Investment income percentage for 2021 (line 10c, column (f), divided by line 13, column (f)); 18 Investment income percentage from 2020 Schedule A, Part III, line 17.

19a 33 1/3% support tests - 2021. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization.

19b 33 1/3% support tests - 2020. 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).</i>		
8 Did the organization make a loan to a disqualified person (as defined in section 4958) not described on line 7? <i>If "Yes," complete Part I of Schedule L (Form 990).</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 on 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 on 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)

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

Section B. Type I Supporting Organizations

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

Section C. Type II Supporting Organizations

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

Section D. All Type III Supporting Organizations

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

Section E. Type III Functionally Integrated Supporting Organizations

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

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>):		
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 2021 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-2021	(iii) Distributable Amount for 2021
1	Distributable amount for 2021 from Section C, line 6		
2	Underdistributions, if any, for years prior to 2021 (reasonable cause required - <i>explain in Part VI</i>). See instructions.		
3	Excess distributions carryover, if any, to 2021		
a	From 2016		
b	From 2017		
c	From 2018		
d	From 2019		
e	From 2020		
f	Total of lines 3a through 3e		
g	Applied to underdistributions of prior years		
h	Applied to 2021 distributable amount		
i	Carryover from 2016 not applied (see instructions)		
j	Remainder. Subtract lines 3g, 3h, and 3i from line 3f.		
4	Distributions for 2021 from Section D, line 7: \$		
a	Applied to underdistributions of prior years		
b	Applied to 2021 distributable amount		
c	Remainder. Subtract lines 4a and 4b from line 4.		
5	Remaining underdistributions for years prior to 2021, 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 2021. 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 2022. Add lines 3j and 4c.		
8	Breakdown of line 7:		
a	Excess from 2017		
b	Excess from 2018		
c	Excess from 2019		
d	Excess from 2020		
e	Excess from 2021		

**Schedule B
(Form 990)**

Department of the Treasury
Internal Revenue Service

Schedule of Contributors

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

OMB No. 1545-0047

2021

Name of the organization DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA	Employer identification number 11-2519726
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Organization type (check one):

Filers of:

Section:

Form 990 or 990-EZ

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

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

527 political organization

Form 990-PF

501(c)(3) exempt private foundation

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

501(c)(3) taxable private foundation

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

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

General Rule

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

Special Rules

For an organization described in section 501(c)(3) filing Form 990 or 990-EZ that met the 33 1/3% support test of the regulations under sections 509(a)(1) and 170(b)(1)(A)(vi), that checked Schedule A (Form 990), 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), 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).

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

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
1	KATHLEEN MARQUARDT 23 TARIFF ST SAYVILLE, NY 11782	\$ 37,707.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
2	RICHARD J GALLAGHER 150 BOARDMAN CT LAKE BLUFF, IL 60044	\$ 22,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
3	DEBORAH GALLAGHER 150 BOARDMAN CT LAKE BLUFF, IL 60044	\$ 35,174.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
	_____ _____ _____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
	_____ _____ _____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
	_____ _____ _____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)

Name of organization <u>DYSTROPHIC EPIDERMOLYSIS BULLOSA</u>	Employer identification number <u>11-2519726</u>
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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
<u>1</u>	<u>DONATED MEDICAL SUPPLIES & BANDAGES</u> _____ _____	\$ <u>971,221.</u>	<u>12/01/2020</u>
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____

SCHEDULE D (Form 990)

Supplemental Financial Statements

OMB No. 1545-0047

2021

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 3 columns: Question, (a) Donor advised funds, (b) Funds and other accounts. Rows include total number at end of year, aggregate values, and yes/no questions about donor advisement.

Part II Conservation Easements.

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

Table with 3 columns: Question, (a) Donor advised funds, (b) Funds and other accounts. Rows include purpose of easements, total number, acreage, and monitoring expenses.

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 3 columns: Question, (a) Donor advised funds, (b) Funds and other accounts. Rows include art collection reporting requirements and amounts.

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 2 columns: Description, Amount. Rows: 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: 1a-1g (Beginning of year balance, Contributions, Net investment earnings, Grants or scholarships, Other expenditures, Administrative expenses, 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: 1a Land, b Buildings, c Leasehold improvements, d Equipment, e Other, Total.

Part VII Investments - Other Securities.

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

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

Part VIII Investments - Program Related.

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

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

Part IX Other Assets.

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

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

Part X Other Liabilities.

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

1. (a) Description of liability	(b) Book value
(1) Federal income taxes	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (Column (b) must equal Form 990, Part X, col. (B) line 25.) ▶	

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 XIII Supplemental Information *(continued)*

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.

**SCHEDULE F
(Form 990)**

Statement of Activities Outside the United States

OMB No. 1545-0047

2021

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)			CENT. AMERICA/CARIBBEAN	TO FUND INTE	9,000.	CASH TRANSFE		NONE	FMV
(2)									
(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

**SCHEDULE G
(Form 990)**

Supplemental Information Regarding Fundraising or Gaming Activities

OMB No. 1545-0047

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

2021

Department of the Treasury
Internal Revenue Service

▶ Attach to Form 990 or Form 990-EZ.

Open to Public Inspection

▶ 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 Fundraising Activities. Complete if the organization answered "Yes" on Form 990, Part IV, line 17. Form 990-EZ filers are not required to complete this part.

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

(i) Name and address of individual or entity (fundraiser)	(ii) Activity	(iii) Did fundraiser have custody or control of contributions?		(iv) Gross receipts from activity	(v) Amount paid to (or retained by) fundraiser listed in 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
		WALKS/ RUNS (event type)	(event type)	NONE (total number)	(add col. (a) through col. (c))
Revenue	1 Gross receipts	849,094.			849,094.
	2 Less: Contributions				
	3 Gross income (line 1 minus line 2)	849,094.			849,094.
Direct Expenses	4 Cash prizes				
	5 Noncash prizes				
	6 Rent/facility costs				
	7 Food and beverages				
	8 Entertainment				
	9 Other direct expenses	749,678.			749,678.
	10 Direct expense summary. Add lines 4 through 9 in column (d) ▶				749,678.
11 Net income summary. Subtract line 10 from line 3, column (d) ▶				99,416.	

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).

- 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)**

Department of the Treasury
Internal Revenue Service

Compensation Information

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

- ▶ Complete if the organization answered "Yes" on Form 990, Part IV, line 23.
- ▶ Attach to Form 990.
- ▶ Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

2021

Open to Public Inspection

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**
 - b** Participate in or receive payment from a supplemental nonqualified retirement plan? **4b**
 - c** Participate in or receive payment from an equity-based compensation arrangement? **4c**
- 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**
 - b** Any related organization? **5b**
- 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**
 - b** Any related organization? **6b**
- If "Yes" on line 6a or 6b, describe in Part III.

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

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

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

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

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

Schedule J (Form 990) 2021

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 and/or 1099-NEC 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)	260,758.					260,758.	
1 EXECUTIVE DIRECTOR	(ii)							
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)							

**SCHEDULE M
(Form 990)**

Noncash Contributions

OMB No. 1545-0047

2021

**Open to Public
Inspection**

Department of the Treasury
Internal Revenue Service

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

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

	(a) Check if applicable	(b) Number of contributions or items contributed	(c) Noncash contribution amounts reported on Form 990, Part VIII, line 1g	(d) Method of determining noncash contribution amounts
1 Art - Works of art				
2 Art - Historical treasures				
3 Art - Fractional interests				
4 Books and publications				
5 Clothing and household goods				
6 Cars and other vehicles.				
7 Boats and planes				
8 Intellectual property				
9 Securities - Publicly traded				
10 Securities - Closely held stock				
11 Securities - Partnership, LLC, or trust interests				
12 Securities - Miscellaneous				
13 Qualified conservation contribution - Historic structures				
14 Qualified conservation contribution - Other				
15 Real estate - Residential				
16 Real estate - Commercial				
17 Real estate - Other				
18 Collectibles				
19 Food inventory				
20 Drugs and medical supplies	X	2,500	971,221.	FMV
21 Taxidermy				
22 Historical artifacts				
23 Scientific specimens				
24 Archeological artifacts				
25 Other ▶ (<u>LEGAL SERVICES</u>)	X	1	13,495.	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?	30a		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?	31		X
32a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash contributions?	32a		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.			

**SCHEDULE O
(Form 990 or 990-EZ)**Department of the Treasury
Internal Revenue Service

Name of the organization

DYSTROPHIC EPIDERMOLYSIS BULLOSA

Supplemental Information to Form 990 or 990-EZComplete 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

2021**Open to Public
Inspection**

Employer 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

MISCELLANEOUS ADJUSTMENT

Name of the organization

Employer identification number

DYSTROPHIC EPIDERMOLYSIS BULLOSA

11-2519726

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 GENETIC MUTATION. TODAY, THERE IS NO CURE OR TREATMENT FOR EB, EXCEPT DAILY WOUND CARE AND BANDAGING. GENETIC RESEARCH IS MAKING PROGRESS TOWARDS TREATMENTS AND A CURE.

Name of the organization

Employer identification number

DYSTROPHIC EPIDERMOLYSIS BULLOSA

11-2519726

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

DESCRIPTION	GRANTS	EXPENSES	REVENUE
RESEARCH		161,229.	
TOTALS		161,229.	

Name of the organization

Employer identification number

DYSTROPHIC EPIDERMOLYSIS BULLOSA

11-2519726

FORM 990, PART X - PREPAID EXPENSES AND DEFERRED CHARGES
=====

DESCRIPTION -----	ENDING BOOK VALUE -----
PREPAID EXPENSES	8,056.
TOTALS	----- 8,056. =====

Name of the organization

Employer identification number

DYSTROPHIC EPIDERMOLYSIS BULLOSA

11-2519726

FORM 990, PART X - INVESTMENTS - PUBLICLY TRADED SECURITIES

=====

DESCRIPTION -----	ENDING BOOK VALUE -----	COST OR FMV -----
MUTUAL FUNDS	736,140.	FMV
TOTALS	----- 736,140. =====	

Form **4562**

Depreciation and Amortization
(Including Information on Listed Property)

OMB No. 1545-0172

2021

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

Identifying number
11-2519726

DYSTROPHIC EPIDERMOLYSIS BULLOSA

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 2020 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 2022. 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	3,198.

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 2021	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 2021 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	
			27.5 yrs.	MM	S/L	
i Nonresidential real property			39 yrs.	MM	S/L	
				MM	S/L	

Section C - Assets Placed in Service During 2021 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	3,198.
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	

Form 4562 (2021)

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

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

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

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

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

Section B - Information on Use of Vehicles

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

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

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

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

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

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

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

2021

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.	2,043.	3,794.	SL		3.000				1,751.
DELL COMPUTER	12/10/2019	3,156.	100.000			3,156.	1,140.	2,192.	SL		3.000				1,052.
DELL COMPUTER	08/10/2020	1,186.	100.000			1,186.	165.	560.	SL		3.000				395.
Less: Retired Assets															
Subtotals		44,082.				44,983.	37,835.	41,033.							3,198.

Listed Property

Less: Retired Assets															
Subtotals															
TOTALS		44,082.				44,983.	37,835.	41,033.							3,198.

AMORTIZATION

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

*Assets Retired
JSA
1X9024 1.000

DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA
Instructions for Filing
Form CHAR500
New York State Annual Filing for Charitable Organizations
For the year ended December 31, 2021

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

File the signed return by May 16, 2022 with:

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

A check or money order payable to "Department of Law" in the amount of \$25 should be attached to the return. Be sure to include the federal EIN and "2021 Form CHAR500" on the check.

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

CHAR500NYS Annual Filing for Charitable Organizations
www.CharitiesNYS.comSend with fee and attachments to:
NYS Office of the Attorney General
Charities Bureau Registration Section
28 Liberty Street
New York, NY 10005**2021**
Open to Public
Inspection**1. General Information**For Fiscal Year Beginning (mm/dd/yyyy) 01 / 01 / **2021** and Ending (mm/dd/yyyy) 12 / 31 / 2021

Check if Applicable: <input type="checkbox"/> Address Change <input type="checkbox"/> Name Change <input type="checkbox"/> Initial Filing <input type="checkbox"/> Final Filing <input type="checkbox"/> Amended Filing <input type="checkbox"/> Reg ID Pending	Name of Organization: DYSTROPHIC EPIDERMOLYSIS BULLOS RESEARCH ASSOCIATION OF AMERICA	Employer Identification Number (EIN): 11-2519726
	Mailing Address: 75 BROAD ST SUITE 300	NY Registration Number:
	City / State / Zip: NEW YORK, NY 10004	Telephone: (212) 868-1573
	Website:	Email: STAFF@DEBRA.ORG

 Check your organization's registration category: 7A only EPTL only DUAL (7A & EPTL) EXEMPT* Confirm your Registration Category in the Charities Registry at www.CharitiesNYS.com.
2. Certification

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

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

President or Authorized Officer:	Signature _____	Print Name and Title _____	Date _____
Chief Financial Officer or Treasurer:	Signature _____	Print Name and Title _____	Date _____

3. Annual Reporting Exemption

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

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

4. Schedules and Attachments

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

5. Fee

See the checklist on the next page to calculate your fee(s). Indicate fee(s) you are submitting here:	7A filing fee: \$ <u>25.</u>	EPTL filing fee: \$ _____	Total fee: \$ <u>25.</u>	Make a single check or money order payable to: "Department of Law"
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CHAR500 Annual Filing for Charitable Organizations (Updated January 2022)

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

Page 1

CHAR500

Annual Filing Checklist

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

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

Checklist of Schedules and Attachments

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

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

Check the financial attachments you must submit with your CHAR500:

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

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

- Review Report if you received total revenue and support greater than \$250,000 and up to \$1,000,000
- Audit Report if you received total revenue and support greater than \$1,000,000 and the fiscal year begins on or after July 1, 2021. If the fiscal year begins before that date, an Audit Report is required if total revenue and support is greater than \$750,000
- No Review Report or Audit Report is required because total revenue and support is less than \$250,000
- We are a DUAL filer and checked box 3a, no Review Report or Audit Report is required

Calculate Your Fee

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

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

For EPTL and DUAL filers, calculate the EPTL fee:

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

Send Your Filing

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

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

Need Assistance?

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

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

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

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

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

DUAL filers are registered under both 7A and EPTL.

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

Confirm your Registration Category and learn more about NY law at www.CharitiesNYS.com.

Where do I find my organization's NET WORTH?

NET WORTH for fee purposes is calculated on:

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

CHAR500Schedule 4a: Professional Fund Raisers, Fund Raising Counsels, Commercial Co-Venturers
www.CharitiesNYS.com**2021**
Open to Public
Inspection

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

Definitions

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

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

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

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

1. Organization Information

Name of Organization: DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA	NY Registration Number:
--	-------------------------

2. Professional Fund Raiser, Fund Raising Counsel, Commercial Co-Venturer Information

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

3. Contract Information

Contract Start Date:	Contract End Date:
----------------------	--------------------

4. Description of Services

Services provided by FRP:

5. Description of Compensation

Compensation arrangement with FRP:	Amount Paid to FRP:
------------------------------------	---------------------

6. Commercial Co-Venturer (CCV) Report

<input type="checkbox"/> Yes <input type="checkbox"/> No	If services were provided by a CCV, did the CCV provide the charitable organization with the interim or closing report(s) required by Section 173(a) part 3 of the Executive Law Article 7A?
--	--



**Department of
Taxation and Finance**

Office of Processing and Taxpayer Services
W A Harriman Campus, Albany NY 12227

Taxpayer ID:

Taxpayer name:

You must file this New York State corporation tax return electronically.

Individual taxpayers and paid preparers who use software to prepare their returns or their clients' returns, but file on paper, are subject to penalties.

E-filing has many advantages:

- It is fast, easy, and secure.
- There are no additional costs. Once you've paid for your New York State tax preparation software, you can e-file your New York State return for **free**.

90% of New Yorkers enjoy the benefits of e-filing.

If you are a corporation:

Because you prepared this New York State tax return using software, you **must** file it electronically.

If you are a paid preparer:

Because you prepared this return using software, you must e-file it. If you file a paper New York State tax return, you will be in violation of New York State law and subject to penalties.

If you are a corporation that used a paid preparer:

Since your preparer used software to prepare this return, it must be e-filed. If your tax return preparer gave you a paper New York State tax return with instructions to mail it, contact them and request that they file it electronically.

There is no charge for e-filing:

New York State Tax Law prohibits your tax preparer from charging you a separate or additional fee for e-filing your New York State tax return.

If you cannot e-file you must include Form CT-2:

If an individual corporation or a paid preparer does not meet the requirements to e-file, a software-generated Form CT-2, *Corporation Tax Return Summary*, **must** be included with the paper return to ensure the return is considered processible.

Questions?

Visit our website for more information about New York's e-file mandate.