Form **990**

Return of Organization Exempt From Income Tax

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

Inspection

OMB No. 1545-0047

Department of the Treasury Internal Revenue Service

▶ Do not enter social security numbers on this form as it may be made public.

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

Tac-cowerpt status	A F	or th	e 2021	calendar year, or tax year beginning	and ending			
RESEARCH ASSOCIATION OF AMERICA 11-25:9726	_			C Name of organization DYSTROPHIC EPIDERMOLYSIS BULLOS.	A	D Employer ide	entificati	on number
Documents and part of the property of the property of the part of the pa	В с	heck if a	applicable:	RESEARCH ASSOCIATION OF AMERICA				
Number and street (or P.O. Dox if mail is not delivered to street address) Roam/suite ETelephone number (212) 868 – 1573				Doing business as		11-251	9726	
City or town, state or province, country, and ZiP or foreign postal code City or town, state or province, country, and ZiP or foreign postal code City or town, state or province, country, and ZiP or foreign postal code City or town, and continued City or town, and c		7	•	Number and street (or P.O. box if mail is not delivered to street address)	Room/suite	E Telephone n	umber	
Ref Second Seco		Initia	l return	75 BROAD ST SHITE 300		(212)8	168 – 1	573
NEN YORK, NY 10004		Final	return/			(212)0	700 1	313
Fame and address of principal effect SRETT KOPELAN H(a) is this agreed mature for very very very very very very very ver						G Gross receip	te \$	1 050 167
Tax-exempt status X Soft(c)(3) Soft(c) X (insert no.) 4947(a)(1) or S27 M(b) are insectional reactions Yes M(c) Group exemption member Yes Yes M(c) Group exemption member Yes Ye	-			-				. — —
Take-opering stations X Solicio Solicio		pend	ling			subordinate	s?	
WebSite:		_						
Name					or 527			
Briefly describe the organization's mission or most significant activities: DEBRA IS DEDICATED TO FINDING A CURE FOR EB THRU RESEARCH					1.			
Briefly describe the organization's mission or most significant activities: DEBRA IS DEDICATED TO FINDING A CURE FOR EB THRU RESEARCH					L Year of	formation: 1979 M	State o	f legal domicile: NY
DEBRA IS DEDICATED TO FINDING A CURE FOR EB THRU RESEARCH	Pa			· ·				
A Number of independent voting members of the governing body (Part VI, line 1b). 5 Total number of volunteers (estimate if necessary). 6 Total number of volunteers (estimate if necessary). 6 Total unrelated business revenue from Part VIII, column (C), line 12. 7a Total unrelated business taxable income from Form 990-T, Part I, line 11. 7b Net unrelated business taxable income from Form 990-T, Part I, line 11. 7b None None None None None None None None		1	Briefly	y describe the organization's mission or most significant activities:				
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Sign Here D83046E0A7DF445 Date	Und	der pe	nalties	of plantifier that I have examined this return, including accompanying schedul	les and statem	nents, and to the best of	of my kn	owledge and belief, it is
Sign Here Date BRETT KOPELAN Type or print name and title Print/Bype or print name and title Preparer Use Only Firm's name Date Date EXECUTIVE DIRECTOR Date Check if PTIN P00058320 P00058320 Firm's name NANAVATY DAVENPORT STUDLEY WHITE Date 03/15/2022 03/15/2022 03/15/2022 03/15/2022 03/15/2022 Firm's name 03/15/2022 03/15/2022 03/15/2022 03/15/2022	tiuc	, соп	oct, and	BREET LAND THE POPULATION OF WHICE THAN ONICE IS BASED ON AN INFORMATION OF WHICE	ii preparei nas	s any knowledge.		
Signature of officer BRETT KOPELAN Type or print name and title Paid Preparer Use Only Firm's name Signature of officer Date EXECUTIVE DIRECTOR Date Check if PTIN 9FB27ABB63D84DA 03/15/2022 self-employed P00058320 Firm's name NANAVATY DAVENPORT STUDLEY WHITE Firm's slin O6-1402749	٠.					03/	15/2	022
BRETT KOPELAN EXECUTIVE DIRECTOR	_		5	Signature of officer		Date		
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Use Only			Firm's	<u> </u>				
Firm's address 123 SOUTH MAIN ST., SUITE 140 NEWTOWN, CT 06470 Phone no. 203-426-8500	use	Only				Phone no.		3-426-8500
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11-2519726

Form 990 (2021) Page 2 Part III **Statement of Program Service Accomplishments** Check if Schedule O contains a response or note to any line in this Part III 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? 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 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 \$ PATIENT & FAMILY SERVICES - PROVIDE SERVICES FOR THE PEOPLE WITH EB AND THEIR FAMILIES THROUGH NEWSLETTERS, COUNSELING, PEER SUPPORT SERVICES, CONFERENCES AND SEMINARS) (Expenses \$) (Revenue \$ 4c (Code: 48,368. including grants of \$ 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

1,430,83

Form 990 (2021) Page **3**

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

DYSTROPHIC EPIDERMOLYSIS BULLOSA

Page 4
Part IV Checklist of Required Schedules (continued)

Par	Checklist of Required Schedules (continued)			
			Yes	No
22	Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? If "Yes," complete Schedule I, Parts I and III	22		Х
00				
23	Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5, about compensation of the			
	organization's current and former officers, directors, trustees, key employees, and highest compensated			
	employees? If "Yes," complete Schedule J	23	X	
24 a	Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than			
	\$100,000 as of the last day of the year, that was issued after December 31, 2002? If "Yes," answer lines 24b			
	through 24d and complete Schedule K. If "No," go to line 25a	24a		Χ
b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		
	Did the organization maintain an escrow account other than a refunding escrow at any time during the year			
	to defease any tax-exempt bonds?	24c		
Ч	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d		
	Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit	274		
25 a		25-		3.7
	transaction with a disqualified person during the year? If "Yes," complete Schedule L, Part I	25a		X
D	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior			
	year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ?			
	If "Yes," complete Schedule L, Part I	25b		X
26	Did the organization report any amount on Part X, line 5 or 22, for receivables from or payables to any current			
	or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35%			
	controlled entity or family member of any of these persons? If "Yes," complete Schedule L, Part II	26		Χ
27	Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key			
	employee, creator or founder, substantial contributor or employee thereof, a grant selection committee			
	member, or to a 35% controlled entity (including an employee thereof) or family member of any of these			
	persons? If "Yes," complete Schedule L, Part III	27		Х
28	Was the organization a party to a business transaction with one of the following parties (see the Schedule L,			21
20				
_	Part IV instructions, for applicable filing thresholds, conditions, and exceptions):			
а	A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? If			
_	"Yes," complete Schedule L, Part IV	28a		X
	A family member of any individual described in line 28a? If "Yes," complete Schedule L, Part IV	28b		X
С	A 35% controlled entity of one or more individuals and/or organizations described in line 28a or 28b? If			
	"Yes," complete Schedule L, Part IV	28c		X
29	Did the organization receive more than \$25,000 in non-cash contributions? If "Yes," complete Schedule M	29	Χ	
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified			
	conservation contributions? If "Yes," complete Schedule M	30		Χ
31	Did the organization liquidate, terminate, or dissolve and cease operations? If "Yes," complete Schedule N, Part I	31		X
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If "Yes,"			
	complete Schedule N, Part II.	32		Х
33	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations			
00	sections 301.7701-2 and 301.7701-3? If "Yes," complete Schedule R, Part I	33		v
24	·	JJ		X
34	Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Part II, III,			
o =	or IV, and Part V, line 1	34		_X_
	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a		X
b	If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a			
	controlled entity within the meaning of section 512(b)(13)? If "Yes," complete Schedule R, Part V, line 2	35b		X
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable			
	related organization? If "Yes," complete Schedule R, Part V, line 2	36		X
37	Did the organization conduct more than 5% of its activities through an entity that is not a related organization			
	and that is treated as a partnership for federal income tax purposes? If "Yes," complete Schedule R, Part VI	37		Χ
38	Did the organization complete Schedule O and provide explanations on Schedule O for Part VI, lines 11b and			
	19? Note : All Form 990 filers are required to complete Schedule O	38	Х	
Part				
	Check if Schedule O contains a response or note to any line in this Part V			
	Should be defined to be thanked to top of the total to diffy life in this talk v		Yes	No
4	Enter the number reported in box 3 of Form 1096. Enter -0- if not applicable		. 55	
	Enter the number of Forms W-2G included on line 1a. Enter -0- if not applicable			
С	Did the organization comply with backup withholding rules for reportable payments to vendors and			
	reportable gaming (gambling) winnings to prize winners?	1c		

	990 (2021)			age 3
Par	t 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 2a 12			
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	2b	X	
	Note: If the sum of lines 1a and 2a is greater than 250, you may be required to <i>e-file</i> . See instructions.			
	Did the organization have unrelated business gross income of \$1,000 or more during the year?	3a		X
	If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation on Schedule O	3b		
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over,	4.		3.7
	a financial account in a foreign country (such as a bank account, securities account, or other financial account)?	4a		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).	E o		v
	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5a 5b		X
	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5c		
	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?	30		
оa	organization solicit any contributions that were not tax deductible as charitable contributions?	6a		Х
h	If "Yes," did the organization include with every solicitation an express statement that such contributions or	- ou		21
b	gifts were not tax deductible?	6b		
7	Organizations that may receive deductible contributions under section 170(c).			
	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods			
u	and services provided to the payor?	7a	Х	
h	If "Yes," did the organization notify the donor of the value of the goods or services provided?	7b	X	
	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was			
Ŭ	required to file Form 8282?	7c		
d	If "Yes," indicate the number of Forms 8282 filed during the year			
	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	7e		
	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7f		
	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	7g		
_	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?.	7h		
8	Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the			
	sponsoring organization have excess business holdings at any time during the year?	8		
9	Sponsoring organizations maintaining donor advised funds.			
а	Did the sponsoring organization make any taxable distributions under section 4966?	9a		
b	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?	9b		
10	Section 501(c)(7) organizations. Enter:			
а	Initiation fees and capital contributions included on Part VIII, line 12			
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities			
11	(/ /)			
	Gross income from members or shareholders			
b	Gross income from other sources. (Do not net amounts due or paid to other sources			
	against amounts due or received from them.)	120		
	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?	12a		
	If "Yes," enter the amount of tax-exempt interest received or accrued during the year			
13	Section 501(c)(29) qualified nonprofit health insurance issuers.	13a		
а	Is the organization licensed to issue qualified health plans in more than one state? Note: See the instructions for additional information the organization must report on Schedule O.	104		
h	Enter the amount of reserves the organization is required to maintain by the states in which			
D	the organization is licensed to issue qualified health plans			
	Enter the amount of reserves on hand			
	Did the organization receive any payments for indoor tanning services during the tax year?	14a		Х
	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		Х
	If "Yes," see the instructions and file Form 4720, Schedule N.			
16	Is the organization an educational institution subject to the section 4968 excise tax on net investment income?	16		Х
-	If "Yes," complete Form 4720, Schedule O.			
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.			

DYSTROPHIC EPIDERMOLYSIS BULLOSA Page 6 Form 990 (2021) Part VI Governance, Management, and Disclosure. For each "Yes" response to lines 2 through 7b below, and for a response to line 8a, 8b, or 10b below, describe the circumstances, processes, or changes on Schedule O. See instructions. Check if Schedule O contains a response or note to any line in this Part VI Section A. Governing Body and Management No 1a 11 1a Enter the number of voting members of the governing body at the end of the tax year If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain on Schedule O. 11 Enter the number of voting members included on line 1a, above, who are independent Did any officer, director, trustee, or key employee have a family relationship or a business relationship with 2 Χ 3 Did the organization delegate control over management duties customarily performed by or under the direct 3 Χ supervision of officers, directors, trustees, or key employees to a management company or other person?.... 4 Χ 4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed? 5 Χ 5 Did the organization become aware during the year of a significant diversion of the organization's assets?.... 6 Χ 6 7a Did the organization have members, stockholders, or other persons who had the power to elect or appoint 7a Χ b Are any governance decisions of the organization reserved to (or subject to approval by) members, 7b Χ Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following: 8a Χ a The governing body?...... Χ Each committee with authority to act on behalf of the governing body?................ Is there any officer, director, trustee, or key employee listed in Part VII. Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses on Schedule O. 9 Section B. Policies (This Section B requests information about policies not required by the Internal Revenue Code.) No Yes 10a Χ b If "Yes," did the organization have written policies and procedures governing the activities of such chapters, 10b affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes? . . . 11a Χ Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? . b Describe on Schedule O the process, if any, used by the organization to review this Form 990. 12a Χ Were officers, directors, or trustees, and key employees required to disclose annually interests that could give 12b Χ c Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," 12c 13 Χ 13 14 Χ 14 Did the organization have a written document retention and destruction policy?............. Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision? 15a Χ 15b If "Yes" to line 15a or 15b, describe the process on Schedule O. See instructions. 16a Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement 16a Χ b If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements? Section C. Disclosure List the states with which a copy of this Form 990 is required to be filed ▶ CA, MA, MI, NJ, NY, 17 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.

- Another's website X Upon request Other (explain on Schedule O)
- Describe on Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, 19 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 Form **990** (2021) rm 990 (2021) DYSTROPHIC EPIDERMOLYSIS BULLOSA 11-2519726 Page

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

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.s
- 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.

X 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)	box, office or direct	not ch unles	Pos neck ss pe	rson	e than or highest compensated employee	an	(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
(1) BRETT KOPELAN	40.00									
EXECUTIVE DIRECTOR	NONE				Х			260,758.	NONE	NONE
(2) J ALEC ALEXANDER	1.00									
TREASURER	NONE	X		Χ				NONE	NONE	NONE
(3) ANDREW TAVANI	1.00									
CHAIR	NONE	X		Χ				NONE	NONE	NONE
(4) RICHARD GALLAGHER	1.00									
CHAIR EMERITUS	NONE	X						NONE	NONE	NONE
(5) ROBERT RYAN PH. D.	1.00									
DIRECTOR	NONE	X						NONE	NONE	NONE
(6) JOHN LEE	1.00									
SECRETARY	NONE	X		Χ				NONE	NONE	NONE
(7) WILLIAM CORNMAN	1.00									
DIRECTOR	NONE	Х						NONE	NONE	NONE
(8) JAMES WETRICH	1.00									
DIRECTOR	NONE	X						NONE	NONE	NONE
(9) LESLIE RADER	1.00									
DIRECTOR	NONE	X						NONE	NONE	NONE
(10) JOUI UITTO MD, PH.D	1.00									
DIRECTOR	NONE	Х						NONE	NONE	NONE
(11) ANGELA CHRISTIANO PH.D.	1.00									
DIRECTOR	NONE	Х						NONE	NONE	NONE
(12) THOMAS TRIMARCHI	1.00									_
DIRECTOR	NONE	Х						NONE	NONE	NONE
<u>(13)</u>										
<u>(14)</u>										

Form **990** (2021)

Form 990 (2021)

Page 8

Page

Рa	Section A. Officers, Directors, 1rt	ustees, Ke	y En	ıpıc	ye	es,	and F	ııgı	nest Compensat	ea Emplo	yees (d	continue	(d)	
	(A) Name and title	(B) Average hours per week (list any hours for related organizations	box,	unles	Pos neck ss pe	erson	e than of is both cor/trust	an	(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reporta compensati relate organiza (W-2/1099	on from d tions	am com fro	timated to the count of the cou	f ion
		below dotted line)	Individual trustee or director	Institutional trustee	9r	Key employee	Highest compensated employee	er	(W-2/1033-MIGG)			l	d related Inization	
			-											
			-											
			-											
С	Sub-total Total from continuation sheets to Part VII, Solution (add lines 1b and 1c)	ection A						> > >	260,758. NONE 260,758.		NONE NONE			NONE NONE
	Total number of individuals (including but not reportable compensation from the organization	limited to t						re		\$100,000				NONE
3	Did the organization list any former officemployee on line 1a? If "Yes," complete Schedu	er, directo	or, or	tru <i>ivid</i> u	ıste ual	e,	key e	mp	loyee, or highes	t compens	ated	3	Yes	No X
4	For any individual listed on line 1a, is the sorganization and related organizations graindividual	eater than	\$15	0,0	00?	. If	"Yes	," (4	X	
5	Did any person listed on line 1a receive or for services rendered to the organization? If "Ye											5		X
Se	ction B. Independent Contractors													
1	Complete this table for your five highest com compensation from the organization. Report c year.													
	(A) Name and business add	dress							(B) Description of se	rvices	C	(C) Compens	ation	
								-						
_														
2	Total number of independent contractors (in more than \$100,000 in compensation from the				nite	d to	thos		sted above) who	received				

11-2519726

Form 990 (2021)

Part VIII Statement of Revenue

		Check if Schedule O contains a respon	se or note to an	y line in this Part V	/III		
		·		(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512-514
its, Grants r Amounts	1a b c	Federated campaigns 1a Membership dues 1b Fundraising events 1c Related organizations 1d					
Program Service Contributions, Gifts, Grants Revenue and Other Similar Amounts	e f	Government grants (contributions) 1e All other contributions, gifts, grants, and similar amounts not included above . 1f	164,990. 838,646.				
Contri and Ot	g h	Noncash contributions included in lines 1a-1f		1,003,636.			
ervice ue	2a b		Business Code				
rogram S Reven	c d e						
<u> </u>	f g 3	All other program service revenue Total. Add lines 2a-2f		NONE			
	4 5	other similar amounts)	proceeds ►	787. NONE NONE	787.		
	6a b c	Gross rents 6a Less: rental expenses 6b Rental income or (loss) 6c NONE	(II) Feisural				
	d 7a	Net rental income or (loss)	(ii) Other	NONE			
Revenue	b	ther than inventory 7a Less: cost or other basis and sales expenses 7b					
Other Re	d 8a	Gain or (loss)	▶	NONE			
0	_	events (not including \$ of contributions reported on line 1c). See Part IV, line 18	849,094. 749,678.				
	b c 9a			99,416.			99,416.
		activities. See Part IV, line 19 9a Less: direct expenses 9b	NONE NONE	MONE			
	10a	Net income or (loss) from fundraising events					
S				NONE			
Miscellaneous Revenue	11a b	MISCELLANEOUS INCOME		5,950.	5,950.		
Misc	c d e	All other revenue		5,950.			
	40	Tatal variance Can instructions	▶	1 100 700	6 505		1 00 44.5

11-2519726

Form 990 (2021)

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 (C) Management and (A) Total expenses (B) Program service (**D**) Fundraising Do not include amounts reported on lines 6b. 7b. 8b. 9b. and 10b of Part VIII. expenses general expenses expenses 1 Grants and other assistance to domestic organizations NONE and domestic governments. See Part IV, line 21 2 Grants and other assistance to domestic NONE individuals. See Part IV, line 22 3 Grants and other assistance to foreign organizations, foreign governments, 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. NONE 8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions) 141,368 120,163. 7,068 14,137. 75,590. 64,252. 3,779. 7,559. 11 Fees for services (nonemployees): NONE a Management NONE NONE **c** Accounting NONE d Lobbying NONE e Professional fundraising services. See Part IV, line 17. NONE f Investment management fees 9 Other. (If line 11g amount exceeds 10% of line 25, column 109,398. 92,988. 10,940. 5,470. (A), amount, list line 11g expenses on Schedule O.) 12 Advertising and promotion 41,117 34,949. 2,056. 4,112. 52**,**392. 44,533. 2,620. 5,239. 13 Office expenses NONE 14 Information technology NONE 15 Royalties 83,327. 4,901. 98,031. 9,803. 16 76,940. 65,399. 3,847. 7,694. 17 Travel Payments of travel or entertainment expenses NONE for any federal, state, or local public officials Conferences, conventions, and meetings NONE 19 NONE Interest NONE 21 Payments to affiliates Depreciation, depletion, and amortization 3,198 2,718. 160 320. 22 67,742. <u>3</u>,387. <u>6,7</u>74. 57,581. 23 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. 10,332. DUES & SUBSCRIPTIONS 12,156. 608. 1,216. TELEPHONE 25,982 22,085. 1,299. 2,598. d EQUIPMENT 8,243 7,007. 412. 824. 24,836. 21,109. 1,244. 2,483. e All other expenses 1,672,683. 25 Total functional expenses. Add lines 1 through 24e 1,430,838. 80,616. 161,229. 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 following SOP 98-2 (ASC 958-720)

Form 990 (2021) Page **11**

Part X Balance Sheet

		Check if Schedule O contains a response of	or not	e to any line in this Pa	art X		X
					(A) Beginning of year		(B) End of year
	1	Cash - non-interest-bearing			651,965.	1	451,231.
	2	Savings and temporary cash investments			NONE	2	NONE
	3	Pledges and grants receivable, net			NONE	3	NONE
	4	Accounts receivable, net			527 , 541.	4	262,765.
	5	Loans and other receivables from any current of	or forr	ner officer, director,			
		trustee, key employee, creator or founder, subst	antial	contributor, or 35%			
		controlled entity or family member of any of these	e pers	ons	NONE	5	NONE
	6	Loans and other receivables from other disqua	lified	persons (as defined			
		under section 4958(f)(1)), and persons described	in sec	ction 4958(c)(3)(B)	NONE	6	NONE
ts	7	Notes and loans receivable, net			NONE	7	NONE
Assets	8	Inventories for sale or use		648,724.	8	505,536.	
ĕ	9	Prepaid expenses and deferred charges SEE.	SCHI	EDULE O	58 , 958.	9	8,056.
	10 a	Land, buildings, and equipment: cost or other					
		basis. Complete Part VI of Schedule D	10a	44,082.			
	b	Less: accumulated depreciation	10b	41,033.	6,248.	10c	3,049.
	11	Investments - publicly traded securities SEE	SCHI	EDULE O	833,049.	11	736,140.
	12	Investments - other securities. See Part IV, line 11	250,000.	12	250,000.		
	13	Investments - program-related. See Part IV, line 1		NONE	13	NONE	
	14	Intangible assets		NONE	14	NONE	
	15	Other assets. See Part IV, line 11			NONE	15	NONE
	16	Total assets. Add lines 1 through 15 (must equal			2,976,485.	16	2,216,777.
	17	Accounts payable and accrued expenses			321,584.	17	359,056.
	18	Grants payable			NONE	18	NONE
	19	Deferred revenue		NONE	19	NONE	
	20	Tax-exempt bond liabilities	NONE	20	NONE		
	21	Escrow or custodial account liability. Complete Pa	of Schedule D	NONE	21	NONE	
S	22	Loans and other payables to any current or					
Liabilities		trustee, key employee, creator or founder, subst					
abi		controlled entity or family member of any of these			NONE	22	NONE
Ë	23	Secured mortgages and notes payable to unrelat			NONE	23	NONE
	24	Unsecured notes and loans payable to unrelated		· -	NONE	24	NONE
	25	Other liabilities (including federal income tax,					
		parties, and other liabilities not included on lines					
		of Schedule D			NONE	25	NONE
	26	Total liabilities. Add lines 17 through 25			321,584.	26	359,056.
seo		Organizations that follow FASB ASC 958, check and complete lines 27, 28, 32, and 33.			·		
ılar	27	Net assets without donor restrictions			2,107,054.	27	1,306,145.
B	28	Net assets with donor restrictions			547,847.	28	551,576.
Net Assets or Fund Balances		Organizations that do not follow FASB ASC 958 and complete lines 29 through 33.			. ,		, , ,
ō	29	Capital stock or trust principal, or current funds				29	
ets	30	Paid-in or capital surplus, or land, building, or equ				30	
SS	31	Retained earnings, endowment, accumulated inc	-			31	
ĭΑ	32	Total net assets or fund balances			2,654,901.	32	1,857,721.
Ž	33	Total liabilities and net assets/fund balances			2,976,485.	33	2,216,777.
	100	Total habilities and het assets/fulla balances, , ,			4, 510, 403.	55	5 990 (0004)

Form **990** (2021)

DYSTROPHIC EPIDERMOLYSIS BULLOSA

Page **12** Form 990 (2021) Part XI **Reconciliation of Net Assets** Check if Schedule O contains a response or note to any line in this Part XI 109,789. 1 1,672,683. 2 3 -562,894. 3 Revenue less expenses. Subtract line 2 from line 1........... 2,654,901. 4 Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A)) 4 5 -115,821. 5 -118,565.6 6 7 7 8 8 100. 9 9 10 Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 1,857,721 10 Part XII Financial Statements and Reporting Yes No Accounting method used to prepare the Form 990: Cash X Accrual Other If the organization changed its method of accounting from a prior year or checked "Other," explain on Schedule O. 2a Χ 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 2b Χ **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: X 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 2c Χ 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 3a Χ 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 . . .

Form **990** (2021)

SCHEDULE A (Form 990)

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.

► 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

Department of the Treasury Internal Revenue Service

Name of the organization DYSTROPHIC EPIDERMOLYSIS BULLOSA

Employer identification number

RE	SEAI	RCH ASSOCIATION OF A	AMERICA				11-2	519726
Рa	rt I	Reason for Public Cha	rity Status. (All o	organizations must	complet	te this p	art.) See instructions	S.
The	orga	anization is not a private fou	ndation because it	is: (For lines 1 through	gh 12, ch	eck only	one box.)	
1		A church, convention of chu	urches, or associa	tion of churches desci	ribed in s	ection 1	70(b)(1)(A)(i).	
2		A school described in secti	on 170(b)(1)(A)(ii)	. (Attach Schedule E	(Form 99	90).)		
3		A hospital or a cooperative	•	•				
4		A medical research organiz	zation operated in	conjunction with a hos	spital de	scribed ir	n section 170(b)(1)(A)	(iii). Enter the
		hospital's name, city, and st						
5		An organization operated		a college or universit	y owne	d or ope	rated by a governme	ntal unit described in
		section 170(b)(1)(A)(iv). (C						
6		A federal, state, or local go	•			•		
7	X	An organization that norma			pport fr	om a go	vernmental unit or fro	om the general public
_		described in section 170(b)			D (!!)			
8	\vdash	A community trust describe					l in	land mank sallana
9		An agricultural research org	-				=	
		or university or a non-land-	grant college of ag	inculture (see instruct	ions). E	nter the i	name, city, and state o	The college of
10		university: An organization that norma	Ily receives (1) mo	are than 331/2 % of its	cupport	from cor	atributions membersh	in fees, and gross
10		receipts from activities rela	ted to its exempt f	unctions, subject to c	ertain ex	ceptions	s; and (2) no more than	331/3 % of its
		support from gross investmacquired by the organization	nent income and ui	nrelated business tax 975 See section 509	able inco (a)(2) ((ome (less Complete	s section 511 tax) from Part III \	businesses
11		An organization organized						
12		An organization organized a	•	•	-			ry out the purposes of
		one or more publicly suppo	rted organizations (described in section 5	09(a)(1)	or secti	on 509(a)(2). See sec	tion 509(a)(3). Check
		the box on lines 12a throug	h 12d that describ	es the type of suppor	ting orga	anization	and complete lines 1	2e, 12f, and 12g.
а		$\overline{}$ Type I. A supporting orga	anization operated	, supervised, or contr	olled by	its supp	orted organization(s),	typically by giving
		the supported organization	on(s) the power to	regularly appoint or e	lect a m	ajority of	the directors or truste	es of the
		_ supporting organization. \	You must complet	e Part IV, Sections A	and B.			
b		$oxedsymbol{oxed}$ Type II. A supporting org	anization supervise	ed or controlled in co	nnection	with its	supported organization	on(s), by having
		control or management of	•	•	the sam	e persor	s that control or man	age the supported
		$_{_}$ organization(s). You must						
С		Type III functionally integrated						ly integrated with,
_		its supported organization		•				
d		☐ Type III non-functionally			-			
		that is not functionally into	-		-			d an attentiveness
_		requirement (see instruct	•	•				I. Tumo III
е		Check this box if the orga functionally integrated, or					• • • • • • • • • • • • • • • • • • • •	і, туре ііі
f	Fn	ter the number of supported	<i>-</i> 1	, ,	porting	Jigariizai	ion.	
a		ovide the following information						
		ame of supported organization	(ii) EIN	(iii) Type of organization		organization	(v) Amount of monetary	(vi) Amount of
				(described on lines 1-10 above (see instructions))		ur governing ment?	support (see instructions)	other support (see instructions)
				above (see ilistructions))	Yes	No	instructions)	ilistructions)
(A)								
(<u>^</u>)								
(B)								
(0)								
(C)								
(D)								
(E)								
Tota	al							

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.)

Sec	tion A. Public Support								
Cale	ndar year (or fiscal year beginning in)	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total		
1	Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	SEE SUPP PAGE 662,523.	602,587.	705,872.	723,260.	838,646.	3,532,888.		
2	Tax revenues levied for the organization's benefit and either paid to or expended on its behalf	002,323.	0027307.	7037072.	7237200.	0307010.	NONE		
3	The value of services or facilities furnished by a governmental unit to the organization without charge						NONE		
4	Total. Add lines 1 through 3	662,523.	602,587.	705,872.	723,260.	838,646.	3,532,888.		
5	The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount						VOVE		
c	shown on line 11, column (f)						NONE		
6							3,532,888.		
	tion B. Total Support	(-) 0047	(h) 0040	(-) 0040	(-1) 0000	(-) 0004	(D. T-+-I		
Cale	ndar year (or fiscal year beginning in)	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total		
7 8	Amounts from line 4 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources	662,523. 554.	602,587. 1,956.	705,872. 1,696.	723,260.	838,646. 787.	3,532,888.		
9	Net income from unrelated business activities, whether or not the business is regularly carried on						NONE		
10	Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						NONE		
11	Total support. Add lines 7 through 10						3,538,927.		
12	Gross receipts from related activities, etc. (s	see instructions)				12			
13	First 5 years. If the Form 990 is for organization, check this box and stop here	<u> </u>							
Sec	tion C. Computation of Public Sup	•							
14	Public support percentage for 2021 (li		-			14	99.83 %		
15	Public support percentage from 2020	Schedule A, Pa	rt II, line 14			15	99.84 %		
	331/3% support test - 2021. If the organization q	ualifies as a pub	licly supported	organization			▶ X		
	33 1/3 % support test - 2020. If the org this box and stop here. The organization	on qualifies as a	publicly suppor	ted organizatior	ı		▶ 🔲		
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.								
b 18	10%-facts-and-circumstances test - 2 15 is 10% or more, and if the organizin Part VI how the organization meets organization	zation meets the sthe facts-and	e facts-and-circu	umstances test, est. The organi	check this box zation qualifies	and stop here. as a publicly su	Explain pported		
10	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.)

	<u>'</u>						
	tion A. Public Support						
Caler	ndar year (or fiscal year beginning in) 🕨	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total
1	Gifts, grants, contributions, and membership fees						
	received. (Do not include any "unusual grants.")						<u> </u>
2	Gross receipts from admissions, merchandise						
	sold or services performed, or facilities						
	furnished in any activity that is related to the						
	organization's tax-exempt purpose						
3	Gross receipts from activities that are not an						
	unrelated trade or business under section 513						
4	Tax revenues levied for the						
	organization's benefit and either paid to						
_	or expended on its behalf						
5	The value of services or facilities						
	furnished by a governmental unit to the						
_	organization without charge						
6	Total. Add lines 1 through 5						
7 a	Amounts included on lines 1, 2, and 3						
h	received from disqualified persons Amounts included on lines 2 and 3						
	received from other than disqualified						
	persons that exceed the greater of \$5,000						
	or 1% of the amount on line 13 for the year		+				
С 8	Add lines 7a and 7b						
٠	line 6.)						
Sec	tion B. Total Support						
	ndar year (or fiscal year beginning in)	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total
9	Amounts from line 6						
	Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources						
h	Unrelated business taxable income (less						
~	section 511 taxes) from businesses						
	acquired after June 30, 1975						
c	Add lines 10a and 10b						
11	Net income from unrelated business						
	activities not included in line 10b, whether						
	or not the business is regularly carried on.						
12	Other income. Do not include gain or						
12	loss from the sale of capital assets						
	(Explain in Part VI.)						
13	Total support. (Add lines 9, 10c, 11,						
	and 12.)						1
14	First 5 years. If the Form 990 is for	the organizati	ion's first, secon	d, third, fourth,	or fifth tax ye	ear as a section	501(c)(3)
	organization, check this box and stop here .						▶ 🗌
Sec	tion C. Computation of Public Supp						
15	Public support percentage for 2021 (line 8,	column (f), divid	ded by line 13, colu	mn (f))		15	%
16	Public support percentage from 2020 Sche	dule A, Part III, lir	ne 15			16	%
Sec	tion D. Computation of Investment	Income Per	centage				
17	Investment income percentage for 2021 (lir	ne 10c, column ((f), divided by line	13, column (f))		17	%
18	Investment income percentage from 2020					18	%
19 a	331/3% support tests - 2021. If the or					ore than 331/3 %	, and line
	17 is not more than 331/3 %, check this	-					
b	331/3% support tests - 2020. If the orga		_				
	line 18 is not more than 331/3 %, check						
20	Private foundation. If the organization of		•	•			

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

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

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	W Supporting Organizations (continued)			age 🗸
Part	Supporting Organizations (continued)		Yos	No
11	Has the organization accepted a gift or contribution from any of the following persons?		163	140
	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?	11a		
b	A family member of a person described on line 11a above?	11b		
C	A 35% controlled entity of a person described on line 11a or 11b above? <i>If "Yes" to line 11a, 11b, or 11c,</i>			
	provide detail in Part VI .	11c		
Secti	on 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? 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.	1		
2	Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised, or controlled the supporting organization.	2		
Secti	on C. Type II Supporting Organizations			
			Yes	No
1	Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)? If "No," describe in Part VI how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s).	1		
Secti	on D. All Type III Supporting Organizations			
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		Yes	No
_	provided?	1		
2	Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported organization(s) or (ii) serving on the governing body of a supported organization? If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).	2		
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? If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.	3		
Secti	on 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 in	structi	ons).	
а	The organization satisfied the Activities Test. Complete line 2 below.		/	
b	The organization is the parent of each of its supported organizations. Complete line 3 below.			
С	The organization supported a governmental entity. Describe in Part VI how you supported a governmental entity (se	ee instr	uction	s).
2	Activities Test. Answer lines 2a and 2b below.		Yes	No
a	Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.	2a		
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? 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.	2b		
3 a	Parent of Supported Organizations. <i>Answer lines 3a and 3b below.</i> 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</i> "Yes" or "No," provide details in Part VI .	3a		
b	Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? If "Yes," describe in Part VI the role played by the organization in this regard.	3b		

-	3446 - (, 5446 - 6			. age e
Pa	Type III Non-Functionally Integrated 509(a)(3) Supporting Orga			
1	Check here if the organization satisfied the Integral Part Test as a qualifyin			
	instructions. All other Type III non-functionally integrated supporting organi	izations n	nust complete Section	_
Se	ction 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		
Se	ection 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):			
_	Average monthly value of securities	1a		
	Average monthly value of securities Average monthly cash balances	1b		
	Fair market value of other non-exempt-use assets	1c		
	Total (add lines 1a, 1b, and 1c)	1d		
_	Discount claimed for blockage or other factors	Iu		
·	(explain in detail in Part VI):			
	Acquisition indebtedness applicable to non-exempt-use assets	2		
3	Subtract line 2 from line 1d.	3		
	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		7		
8	Minimum Asset Amount (add line 7 to line 6)	8		
_	ection 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	Check here if the current year is the organization's first as a non-functional	lly integra	ted Type III supporting	g organization
	(see instructions).	, ,	, , , , , , , , , , , , , , , , , , ,	

Schedule A (Form 990) 2021

Part V

11-2519726

Schedule A (Form 990) 2021 Page 7 Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations (continued)

Secti	Section D - Distributions Current Year						
1	Amounts paid to supported organizations to accomplish ex	xempt purposes		1			
2	Amounts paid to perform activity that directly furthers exer	npt purposes of support	ed				
	organizations, in excess of income from activity			2			
3	Administrative expenses paid to accomplish exempt purpo	ses of supported organiz	zations	3			
4	Amounts paid to acquire exempt-use assets			4			
5	Qualified set-aside amounts (prior IRS approval required - p	rovide details in Part VI)		5			
6	Other distributions (describe in Part VI). See instructions.			6			
7	Total annual distributions. Add lines 1 through 6.			7			
8	Distributions to attentive supported organizations to which	the organization is resp	onsive				
	(provide details in Part VI). See instructions.			8			
9	Distributable amount for 2021 from Section C, line 6			9			
10	Line 8 amount divided by line 9 amount			10			
Secti	on E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2021	S	(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 - explain in Part VI). See						
	instructions.						
3	Excess distributions carryover, if any, to 2021						
a	From 2016						
b	From 2017						
C	From 2018						
d	From 2019						
е	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)						
<u>j</u>	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, explain in Part VI . See instructions.						
6	Remaining underdistributions for 2021. Subtract lines 3h						
	and 4b from line 1. For result greater than zero, explain in						
	Part VI. 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						

Schedule A (Form 990) 2021

c Excess from 2019 d Excess from 2020 Excess from 2021

Schedule B (Form 990)

Schedule of Contributors

Attach to Form 990 or Form 990-PF.

OMB No. 1545-0047

2021

Department of the Treasury Internal Revenue Service

► Attach to Form 990 or Form 990-PF.

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

Name of the organization

DYSTROPHIC EPIDERMOLYSIS BULLOSA

RESEARCH ASSOCIATION OF AMERICA

11-2519726

RESEARCH ASSOCIATION	OF AMERICA	11-2519726					
Organization type (check one):							
Filers of:	Section:						
Form 990 or 990-EZ	∑ 501(c)(³) (enter number) organization						
	4947(a)(1) nonexempt charitable trust not treated as a private four	ndation					
	527 political organization						
Form 990-PF	501(c)(3) exempt private foundation						
	4947(a)(1) nonexempt charitable trust treated as a private foundate	tion					
	501(c)(3) taxable private foundation						
Check if your organization is co	vered by the General Rule or a Special Rule.						
	ction: 501(c)(3						
General Rule							
_	property) from any one contributor. Complete Parts I and II. See instructio	_					
Special Rules							
regulations under sec 16b, and that receive	tions 509(a)(1) and 170(b)(1)(A)(vi), that checked Schedule A (Form 990) d from any one contributor, during the year, total contributions of the grea), Part II, line 13, 16a, or ter of (1) \$5,000; or					
contributor, during the literary, or educational	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.						
contributor, during the contributions totaled r during the year for an General Rule applies	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	Employer identification number
DYSTROPHIC EPIDERMOLYSIS BULLOSA	11-2519726

Part I	Contributors (see instructions).	Use duplicate copies of P	art I if additional space is ne	eded.

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

Schedule B (Form 990) (2021)	Page 3
Name of organization	Employer identification number
DYSTROPHIC EPIDERMOLYSIS BULLOSA	11-2519726

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

(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
1	DONATED MEDICAL SUPPLIES & BANDAGES	-	
		\$ 971,221.	12/01/2020
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
		-	
		\$	
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
		-	
		- - \$	
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
		-	
		\$	
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
		-	
		\$	
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
		-	
		. \$	

SCHEDULE D (Form 990)

Department of the Treasury

Supplemental Financial Statements
► Complete if the organization answered "Yes" on Form 990,

Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b.

► Attach to Form 990.

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

OMB No. 1545-0047

Open to Public Inspection

Internal Revenue Service Name of the organization Employer identification number DYSTROPHIC EPIDERMOLYSIS BULLOSA

	EARCH ASSOCIATION OF AMERICA		<u> </u>			11-25197	26	
Pa					Acco	unts.		
	Complete if the organization answered					\		
		(a) Donor advi	sed fu	unds	(b) Funds and	other account	ts ———
1	Total number at end of year							
2	Aggregate value of contributions to (during year)							
3	Aggregate value of grants from (during year)							
4	Aggregate value at end of year							
5	Did the organization inform all donors and dono	_						
	funds are the organization's property, subject to the	_		•			Yes	No
6	Did the organization inform all grantees, donors,							
	only for charitable purposes and not for the bene							
	conferring impermissible private benefit?						Yes	No
Pa	rt Conservation Easements.							
	Complete if the organization answered							
1	Purpose(s) of conservation easements held by the	- '	that	apply).				
	Preservation of land for public use (for example	e, recreation or education)	Щ	Preservation				area
	Protection of natural habitat			Preservation	of a ce	rtified histor	ic structure	
	Preservation of open space							
2	Complete lines 2a through 2d if the organization h	eld a qualified conserv	ation	contribution in	the for			
	easement on the last day of the tax year.					Held at the	End of the Ta	ax Year
а	Total number of conservation easements				2a			
b	Total acreage restricted by conservation easement	s			2b			
С	Number of conservation easements on a certified	historic structure include	led in	ı (a)	2c			
d	Number of conservation easements included in (c) acquired after 7/25/	06, a	and not on a				
	historic structure listed in the National Register				2d			
3	Number of conservation easements modified, tra	ansferred, released, ext	ingui	ished, or termi	inated	by the orga	nization du	ring the
	tax year 🕨							
4	Number of states where property subject to conse	ervation easement is loc	ated	>				
5	Does the organization have a written policy re	garding the periodic i	moni	toring, inspect	ion, ha	andling of		
	violations, and enforcement of the conservation ea	sements it holds?					Yes	Ш No
6	Staff and volunteer hours devoted to monitoring, insp	pecting, handling of viola	itions,	, and enforcing	conserv	vation easeme	ents during	the year
	>							
7	Amount of expenses incurred in monitoring, inspec	cting, handling of violation	ons, a	and enforcing co	onserva	ation easeme	ents during	the year
	▶ \$							
8	Does each conservation easement reported on line	2(d) above satisfy the re	equire	ements of secti	on 170((h)(4)(B)(i)		
	and section 170(h)(4)(B)(ii)?						Yes	Ш No
9	In Part XIII, describe how the organization reports						t and	
	balance sheet, and include, if applicable, the text	of the footnote to the o	rgani	ization's financi	ial state	ements that o	lescribes the	е
	organization's accounting for conservation easeme	ents.						
Pa	rt III Organizations Maintaining Collection				r Simil	lar Assets.		
	Complete if the organization answered	I "Yes" on Form 990,	Part	IV, line 8.				
1a	If the organization elected, as permitted under F.	ASB ASC 958, not to	repor	t in its revenue	e state	ment and b	alance shee	et works
	of art, historical treasures, or other similar assesservice, provide in Part XIII the text of the footnote	ets held for public ext	nibitio	on, education, hat describes th	or res	earch in fur	therance o	of public
b	If the organization elected, as permitted under F						nca shaat i	works of
D	art, historical treasures, or other similar assets he	eld for public exhibition						
	provide the following amounts relating to these ite					• •		
	(i) Revenue included on Form 990, Part VIII, line	1				5		
	(ii) Assets included in Form 990, Part X							
2	If the organization received or held works of a				assets	ior iinancia	ı gaın, pro	viae tne
_	following amounts required to be reported under F					▶ ♠		
a h	Revenue included on Form 990, Part VIII, line 1. Assets included in Form 990, Part X					> \$		

DocuSign Envelope ID: 8D7AF153-E5F8-4510-9670-D3980B0D0873 Schedule D (Form 990) 2021 Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets (continued) 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): Public exhibition Loan or exchange program а Scholarly research b Preservation for future generations C Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part 4 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? No **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. Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X? No If "Yes," explain the arrangement in Part XIII and complete the following table: Amount 1c Distributions during the year f Ending balance 2a Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability? No b If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided on Part XIII **Endowment Funds.** Part V Complete if the organization answered "Yes" on Form 990, Part IV, line 10. (a) Current year (b) Prior year (c) Two years back (d) Three years back (e) Four years back Beginning of year balance **c** Net investment earnings, gains, and losses d Grants or scholarships Other expenditures for facilities f Administrative expenses g End of year balance.... Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as: a Board designated or quasi-endowment Permanent endowment > 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 Yes No organization by: 3a(i) 3a(ii) b If "Yes" on line 3a(ii), are the related organizations listed as required on Schedule R?......... Describe in Part XIII the intended uses of the organization's endowment funds. Land, Buildings, and Equipment. Part VI Complete if the organization answered "Yes" on Form 990, Part IV, line 11a. See Form 990, Part X, line 10. Description of property (a) Cost or other basis (b) Cost or other basis (c) Accumulated (d) Book value depreciation (investment) (other)

44,983.

41,934

3,049

3,049

1a Land............ c Leasehold improvements

d Equipment

Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10c.)

Schedule D (Form 990) 2021 11-2519726 Page 3

Part VII Investments - Other Securities. Complete if the organization answered	l "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 valuat Cost or end-of-year mark	tion:
(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)	0.5.0.00		
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 valuar Cost or end-of-year mark	
(1)			
(2)			
(3)			
(4)			
(5)			
<u>(6)</u>			
(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	I "Yes" on Form 990	, Part IV, line 11d. See Form 990	, Part X, line 15.
	SCIPUOII		(b) Book value
<u>(1)</u>			
<u>(2)</u> (3)			
(4)			
(5)			
(6)			
(7)			
(8)			
(9)			
Total. (Column (b) must equal Form 990, Part X, col. (B) II	ine 15.)		
Part X Other Liabilities. Complete if the organization answered line 25.	l "Yes" on Form 990	, Part IV, line 11e or 11f. See For	m 990, Part X,
1. (a) Descrip	tion 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 .

Schedule D (Form 990) 2021 Page 4 11 - 2519726Reconciliation of Revenue per Audited Financial Statements With Revenue per Return. Part XI Complete if the organization answered "Yes" on Form 990, Part IV, line 12a. 1,978,684. 1 2 Amounts included on line 1 but not on Form 990, Part VIII, line 12: -115,821. a Net unrealized gains (losses) on investments 984,716. 2c c Recoveries of prior year grants d Other (Describe in Part XIII.) 2e 868,895. e Add lines 2a through 2d 1,109,789. 3 3 Amounts included on Form 990, Part VIII, line 12, but not on line 1: a Investment expenses not included on Form 990, Part VIII, line 7b 4b Other (Describe in Part XIII.) Add lines 4a and 4b 4c Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.) 1,109,789. Reconciliation of Expenses per Audited Financial Statements With Expenses per Return. Part XII Complete if the organization answered "Yes" on Form 990, Part IV, line 12a. 2,775,863. Total expenses and losses per audited financial statements 1 Amounts included on line 1 but not on Form 990. Part IX. line 25: 2 1,103,180. a Donated services and use of facilities 2c d Other (Describe in Part XIII.) 2e 1,103,180. 1,672,683. 3 Amounts included on Form 990, Part IX, line 25, but not on line 1: 4a a Investment expenses not included on Form 990, Part VIII, line 7b **b** Other (Describe in Part XIII.) 4c Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.). 1,672,683. Part XIII Supplemental Information. Provide the descriptions required for Part II, lines 3, 5, and 9; Part III, lines 1a and 4; Part IV, lines 1b and 2b; Part V, line 4; Part X, line 2; Part XI, lines 2d and 4b; and Part XII, lines 2d and 4b. Also complete this part to provide any additional information. SEE SUPPLEMENTAL PAGE

Schedule D (Form 990) 2021 11-2519726 Page **5**

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

► 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.

OMB No. 1545-0047

2021

Open to Public Inspection

Department of the Treasury Internal Revenue Service

Name	of the organization <code>DYSTROPHIC E</code>	PIDERMOLYS	IS BULLOSA	4		Employer identifica	ition number
	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 employees, agents, and independent contractors in the region in the region (by type) (such as, show the region (b) the region						
Part			Outside the	United States. Comple	ete if the	organization a	nswered "Yes" or
1			ntain records	to substantiate the amou	int of its	grants and	
1 2 3 (1) (2) (3)	other assistance, the grantees'	eligibility for t	the grants or	assistance, and the selec	tion crite	ria used to	
	award the grants or assistance?						Yes No
	_	Part V the org	anization's pro	ocedures for monitoring t	he use o	of its grants and	d other assistance
3	Activities per Region. (The follov	ving Part I, line	3 table can be	duplicated if additional sp	ace is ne	eded.)	
	(a) Region	of offices in	employees, agents, and independent contractors	region (by type) (such as, fundraising, program services, investments, grants to recipients	a pro describ	ogram service, oe specific type of	expenditures for and investments
(1)							
(2)							
(3)							
(4)							
(5)							
(6)							
(7)							
(8)							
(9)							
(10)							
(11)							
(12)							
(13)							
(14)							
(15)							
(16)							
(17)							
3 a							
b	Total from continuation sheets to Part I						

c Totals (add lines 3a and 3b)

Schedule F (Form 990) 2021

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, othe
(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)									

Schedule F (Form 990) 2021

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)							
<u>(7)</u>							
(8)							
(9)							
(10)							
(11)							
(12)							
(13)							
(14)							
(15)							
(16)							
(17)							
(18)							edule F (Form 990) 2021

Schedule F (Form 990) 2021

Part	V 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	s X 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	s X 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	s X 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	s X 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	s X 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	s X No

Schedule F (Form 990) 2021

Page 4

SCHEDULE G (Form 990)

Supplemental Information Regarding Fundraising or Gaming Activities

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

► Attach to Form 990 or Form 990-EZ.

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

OMB No. 1545-0047

2021

Open to Public Inspection

Department of the Treasury Internal Revenue Service

ver identification number

Name of the	e organization DYSTROPHIC E	PIDERMOLYSIS	BULLOSA	A		Employer identification	on number	
RESEAR	CH ASSOCIATION OF AMERI					11-251972		
Part I	Fundraising Activities. Com				Yes" on Form 99	90, Part IV, line 1	7.	
	Form 990-EZ filers are not re							
1 Ind	licate whether the organization ra	ised funds through	any of the	following	activities. Check a	all that apply.		
a	Mail solicitations	е	Solid	citation of i	non-government g	grants		
b	Internet and email solicitations	f	Solid	citation of	government grant	s		
c	Phone solicitations	g	ı	cial fundra	ising events			
d	In-person solicitations							
2a Dic	d the organization have a written o	or oral agreement v	with any ind	dividual (in	cluding officers, o	lirectors, trustees,		
	key employees listed in Form 990						Yes No	
	Yes," list the 10 highest paid ind		(fundraise	rs) pursua	nt to agreements	under which the	fundraiser is to be	
cor	mpensated at least \$5,000 by the	organization.						
			(iii) Did fundraiser have			(v) Amount paid to	(vi) Amount paid to	
((i) Name and address of individual or entity (fundraiser)	(ii) Activity	custody o	or control of	(iv) Gross receipts from activity	(or retained by) fundraiser listed in	(or retained by)	
				outions?		col. (i)	organization	
4			Yes	No				
1								
2								
3								
4								
5								
6								
7								
8								
9								
10								
T . 4 . 1								
Total	A all adades to subtable discountries			1 4 11 . 14				
	t all states in which the organizagistration or licensing.	ation is registered	or licensed	i to solicit	contributions or	nas been notified	it is exempt from	
109	distration of licensing.							

Page 2 Schedule G (Form 990) 2021 11-2519726

	gross receipts greater than \$5,0	(a) Event #1	(b) Event #2	(c) Other events	(d) Total events
		WALKS/ RUNS		NONE	(aḋd col. (a) through
a)		(event type)	(event type)	(total number)	col. (c))
Revenue	1 Gross receipts	849,094.			849,094.
ш	2 Less: Contributions				
	3 Gross income (line 1 minus line 2)				849,094.
	4 Cash prizes				
	5 Noncash prizes				
Direct Expenses	6 Rent/facility costs				
t Exp	7 Food and beverages				
Direc	8 Entertainment				
	9 Other direct expenses	749,678.			749,678.
	10 Direct expense summary. Add li11 Net income summary. Subtract	nes 4 through 9 in colu line 10 from line 3. colu	mn (d)		749,678. 99,416.
	art III Gaming. Complete if the or				
		~	ies on ronn 990, r	art iv, line 19, or	reported more than
	\$15,000 on Form 990-EZ, li	ne 6a. □		rait iv, line 19, or	
venue	\$15,000 on Form 990-EZ, II	ne 6a. (a) Bingo	(b) Pull tabs/instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col. (a) through col. (c))
Revenue	\$15,000 on Form 990-E2, II 1 Gross revenue	ne 6a. (a) Bingo	(b) Pull tabs/instant		(d) Total gaming (add
		ne 6a. (a) Bingo	(b) Pull tabs/instant		(d) Total gaming (add
Expenses Revenue	1 Gross revenue	ne 6a. (a) Bingo	(b) Pull tabs/instant		(d) Total gaming (add
Expenses	1 Gross revenue	ne 6a. (a) Bingo	(b) Pull tabs/instant		(d) Total gaming (add
	1 Gross revenue	ne 6a. (a) Bingo	(b) Pull tabs/instant		(d) Total gaming (add
Expenses	1 Gross revenue	ne 6a. (a) Bingo	(b) Pull tabs/instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add
Expenses	1 Gross revenue	ne 6a. (a) Bingo Yes % No	(b) Pull tabs/instant bingo/progressive bingo Yes% No	(c) Other gaming Yes% No	(d) Total gaming (add
Expenses	1 Gross revenue	Yes % No nes 2 through 5 in columns	(b) Pull tabs/instant bingo/progressive bingo Yes% No mn (d)	(c) Other gaming Yes% No	(d) Total gaming (add
Direct Expenses	1 Gross revenue	Yes % No No No The Subtract line 7 from line ganization conducts ganduct gaming activities	Yes% No nn (d) 1, column (d) ming activities: in each of these state	(c) Other gaming Yes% No Services:	(d) Total gaming (add col. (a) through col. (c))
Direct Expenses	1 Gross revenue	Yes % No No Subtract line 7 from line	Yes% No nn (d) 1, column (d) ming activities: in each of these state	(c) Other gaming Yes% No Services:	(d) Total gaming (add col. (a) through col. (c))

Sched	dule G (Form 990 or 990-EZ) 2021 11-2519726	Page 3
11	Does the organization conduct gaming activities with nonmembers?	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?	No
13	Indicate the percentage of gaming activity conducted in:	
а	The organization's facility	%
b		%
14	Enter the name and address of the person who prepares the organization's gaming/special events books and records:	
	Name ▶	
	Address ▶	
15 a	Does the organization have a contract with a third party from whom the organization receives gaming	
	revenue?	No
b		
	amount of gaming revenue retained by the third party ▶ \$	
С	Tame and the second sec	
	Name ▶	
	Address ▶	
16	Gaming manager information:	
	Name ▶	
	Gaming manager compensation ▶ \$	
	Description of services provided ▶	
	Director/officer Employee Independent contractor	
17	Mandatory distributions:	
а		
	retain the state gaming license?	No
b	Enter the amount of distributions required under state law to be distributed to other exempt organizations	
Daw	or spent in the organization's own exempt activities during the tax year > \$	
Par	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).	

Sched	dule G (Form 990 or 990-EZ) 2021 11-2519726	Page 3
11	Does the organization conduct gaming activities with nonmembers?	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?	No
13	Indicate the percentage of gaming activity conducted in:	
а	The organization's facility	%
b		%
14	Enter the name and address of the person who prepares the organization's gaming/special events books and records:	
	Name ▶	
	Address ▶	
15 a	Does the organization have a contract with a third party from whom the organization receives gaming	
	revenue?	No
b		
	amount of gaming revenue retained by the third party ▶ \$	
С	Tame and the second sec	
	Name ▶	
	Address ▶	
16	Gaming manager information:	
	Name ▶	
	Gaming manager compensation ▶ \$	
	Description of services provided ▶	
	Director/officer Employee Independent contractor	
17	Mandatory distributions:	
а		
	retain the state gaming license?	No
b	Enter the amount of distributions required under state law to be distributed to other exempt organizations	
Daw	or spent in the organization's own exempt activities during the tax year > \$	
Par	Supplemental Information. Provide the explanation required by Part I, line 2b, columns (iii) and (v), and Part III, lines 9, 9b, 10b, 15b, 15c, 16, and 17b, as applicable. Also provide any additional information (see instructions).	

SCHEDULE J (Form 990)

Compensation InformationFor 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. **Open to Public** Inspection

OMB No. 1545-0047

Department of the Treasury Internal Revenue Service Name of the organization

DYSTROPHIC EPIDERMOLYSIS BULLOSA

Employer identification number 11-2519726

RESEARCH ASSOCIATION OF AMERICA Part I Questions Regarding Compensation

	a data and the grant and a company of the grant and the gr			
1.	Check the appropriate boy(ee) if the organization provided any of the following to or far a parent listed on Form		Yes	No
ıa	Check the appropriate box(es) if the organization provided any of the following to or for a person listed on Form 990, Part VII, Section A, line 1a. Complete Part III to provide any relevant information regarding these items.			
	First-class or charter travel Housing allowance or residence for personal use			
	Travel for companions Payments for business use of personal residence			
	Tax indemnification and gross-up payments Health or social club dues or initiation fees			
	Discretionary spending account Personal services (such as maid, chauffeur, chef)			
b	If any of the boxes on line 1a are checked, did the organization follow a written policy regarding payment or reimbursement or provision of all of the expenses described above? If "No," complete Part III to	1b		
2	explain	10		
_	directors, trustees, and officers, including the CEO/Executive Director, regarding the items checked on line			
	1a?	2		
2	Indicate which, if any, of the following the organization used to establish the compensation of the	_		
3	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.			
	X Compensation committee Written employment contract			
	Independent compensation consultant Compensation survey or study			
	Form 990 of other organizations Approval by the board or compensation committee			
4	During the year, did any person listed on Form 990, Part VII, Section A, line 1a, with respect to the filing organization or a related organization:			
а		4a		Х
b	Participate in or receive payment from a supplemental nonqualified retirement plan?	4b		Х
С	Participate in or receive payment from an equity-based compensation arrangement?	4c		Х
	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:			
а	The organization?	5a		Х
b	Any related organization?	5b		Х
	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:			
а	The organization?	6a		Χ
b	Any related organization?	6b		Χ
	If "Yes" on line 6a or 6b, describe in Part III.			
7	For persons listed on Form 990, Part VII, Section A, line 1a, did the organization provide any nonfixed			
	payments not described on lines 5 and 6? If "Yes," describe in Part III.	7		X
8	Were any amounts reported on Form 990, Part VII, paid or accrued pursuant to a contract that was subject			
	to the initial contract exception described in Regulations section 53.4958-4(a)(3)? If "Yes," describe			
_	in Part III	8		X
9	If "Yes" on line 8, did the organization also follow the rebuttable presumption procedure described in			
	Regulations section 53.4958-6(c)?	9		

Schedule J (Form 990) 2021 11-2519726 Page **2**

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 a	ind/or 1099-MISC and/or	1099-NEC compensation	(C) Retirement and	(D) Nontaxable	(E) Total of columns	(F) Compensation
		(i) Base compensation	(ii) Bonus & incentive compensation	(iii) Other reportable compensation	other deferred compensation	benefits	(B)(i)-(D)	in column (B) reported as deferred on prior Form 990
BRETT KOPELAN	(i)	260,758.					260,758.	
1 EXECUTIVE DIRECTOR	(ii)							
	(i)							
2	(ii)							
	(i)							
3	(ii)							
	(i)							
4	(ii)							
	(i)							
5	(ii)							
	(i)							
6	(ii)							
	(i)							
7	(ii)							
	(i)							
8	(ii)							
	(i)							
9	(ii)							
	(i)							
10	(ii)							
	(i)							
11	(ii)							
	(i)							
12	(ii)							
	(i)							
13	(ii)							
	(i)							
14	(ii)							
	(i)							
15	(ii)							
	(i)							
16	(ii)							

SCHEDULE M (Form 990)

Noncash Contributions

► Complete if the organizations answered "Yes" on Form 990, Part IV, lines 29 or 30.

► Attach to Form 990.

Open to Public Inspection

OMB No. 1545-0047

Department of the Treasury Internal Revenue Service

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

DYSTROPHIC EPIDERMOLYSIS BULLOSA

Employer identification number 11-2519726

RESEARCH ASSOCIATION OF AMERICA Part I Types of Property

	,, , ,			(-)	
		(a) Check if applicable	(b) Number of contributions or items contributed	(c) Noncash contribution amounts reported on Form 990, Part VIII, line 1g	(d) Method of determining noncash contribution amounts
1	Art - Works of art				
2	Art - Historical treasures				
3	Art - Fractional interests				
4	Books and publications				
5	Clothing and household				
3	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		2,500	971,221.	FMV
21	Taxidermy			, , _ ,	
22	Historical artifacts				
23	Scientific specimens				
24	Archeological artifacts				
25	Other ▶ (LEGAL SERVICES)		1	13,495.	FMV
26	Other ►()			.,	
27	Other ►()				
28	Other ►(
29	Number of Forms 8283 received	by the ora	anization during the tax ve	ear for contributions for	
	which the organization completed I		•		29
	· ·	•	,		Yes No
30a	During the year, did the organizat	ion receive	by contribution any prope	rty reported in Part I, line	s 1 through
	28, that it must hold for at least the	hree years f	rom the date of the initial	contribution, and which is	sn't required
	to be used for exempt purposes for	the entire h	olding period?		30a X
b	If "Yes," describe the arrangement i	n Part II.			
31	Does the organization have a		tance policy that require	s the review of any	nonstandard
	contributions?				
32a	Does the organization hire or use				
	contributions?				
b	If "Yes," describe in Part II.				
33	If the organization didn't report an	amount in c	column (c) for a type of pro	perty for which column (a)) is checked,
	describe in Part II.				

SCHEDULE O (Form 990 or 990-EZ)

Supplemental Information to Form 990 or 990-EZ

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

▶ Attach to Form 990 or 990-EZ.

OMB No. 1545-0047

2021

Open to Public Inspection

Department of the Treasury Internal Revenue Service Name of the organization

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

Employer identification number 11-2519726

DYSTROPHIC EPIDERMOLYSIS BULLOSA

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-PROIFT 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

Schedule O (Form 990 or 990-EZ) 2021 Page **2**

Name of the organization

DYSTROPHIC EPIDERMOLYSIS BULLOSA

Employer identification number

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.

Schedule O (Form 990 or 990-EZ) 2021 Page 2 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. ==========

Schedule O (Form 990 or 990-EZ) 2021 Page 2 Name of the organization Employer identification number DYSTROPHIC EPIDERMOLYSIS BULLOSA 11-2519726 FORM 990, PART X - PREPAID EXPENSES AND DEFERRED CHARGS _____ ENDING DESCRIPTION BOOK VALUE PREPAID EXPENSES 8,056. _____ TOTALS 8,056. =========

Schedule O (Form 990 or 990-EZ) 2021 Page 2 Name of the organization Employer identification number DYSTROPHIC EPIDERMOLYSIS BULLOSA 11-2519726 FORM 990, PART X - INVESTMENTS - PUBLICLY TRADED SECURITIES ______ ENDING COST DESCRIPTION BOOK VALUE OR FMV ----------MUTUAL FUNDS 736,140. FMV _____

736,140.

==========

TOTALS

Form 4562

Depreciation and Amortization

(Including Information on Listed Property)

► Attach to your tax return.

OMB No. 1545-0172

Attachment Sequence No. 179

Department of the Treasury Internal Revenue Service Name(s) shown on return

► Go to www.irs.gov/Form4562 for instructions and the latest information.

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. Maximum amount (see instructions) Total cost of section 179 property placed in service (see instructions) 2 Threshold cost of section 179 property before reduction in limitation (see instructions) 3 Reduction in limitation. Subtract line 3 from line 2. If zero or less, enter -0-4 Dollar limitation for tax year. Subtract line 4 from line 1. If zero or less, enter -0-. If married filing separately, see instructions 6 (a) Description of property Listed property. Enter the amount from line 29 Total elected cost of section 179 property. Add amounts in column (c), lines 6 and 7 Tentative deduction. Enter the **smaller** of line 5 or line 8 9 Carryover of disallowed deduction from line 13 of your 2020 Form 4562 10 10 11 Business income limitation. Enter the smaller of business income (not less than zero) or line 5. See instructions 11 Section 179 expense deduction. Add lines 9 and 10, but don't enter more than line 11 Carryover of disallowed deduction to 2022. Add lines 9 and 10, less line 12 Note: Don't use Part II or Part III below for listed property. Instead, use Part V. Part | Special Depreciation Allowance and Other Depreciation (Don't include listed property. See instructions.) Special depreciation allowance for qualified property (other than listed property) placed in service during the tax year. See instructions 14 15 Other depreciation (including ACRS) 16 3,198 Part | MACRS Depreciation (Don't include listed property. See instructions.) Section A 17 If you are electing to group any assets placed in service during the tax year into one or more general asset accounts, check here Section B - Assets Placed in Service During 2021 Tax Year Using the General Depreciation System (b) Month and year (c) Basis for depreciation (d) Recovery (a) Classification of property (business/investment use (e) Convention (f) Method (g) Depreciation deduction placed in only - see instructions) service 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 vrs S/I 27.5 yrs. MMS/L h Residential rental ММ S/L 27.5 yrs. property 39 yrs. MMS/L i Nonresidential real ММ property Section C - Assets Placed in Service During 2021 Tax Year Using the Alternative Depreciation System 20a Class life **b** 12-year 12 yrs. S/I **c** 30-year 30 yrs MMS/L MM d 40-year 40 yrs S/I Part IV Summary (See instructions.) Listed property. Enter amount from line 28 21 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

For assets shown above and placed in service during the current year, enter the portion of the basis attributable to section 263A costs

3,198

11-2519726

	n 4562 (2021) rt V Listed Pro	perty (Include	automob	iles	certair	01	ther	vel	hicle	s (certa	in air	craft	and	nroner	tv use	Page 2 ed fo
Га	entertainme	ent, récrèation, o	r amuseme	ent.)									ŕ			•	
	24b, column	ny vehicle for whi s (a) through (c) of	Section A,	all of S	Section E	3, and	d Se	ction	C if a	applic	able.						ly 24a
		Depreciation and						-									
24a	Do you have evidenc			ent use	e claimed?	Щ	Yes	$\overline{}$	No	_		∕es," is t		nce writt	en?	_ Yes	No
	(a) Type of property (list vehicles first)	(b) Date placed in service	(c) Business/ investment use percentage	e Cost	(d) or other ba		(busine		eciation estment	Red	(f) covery eriod	Met	g) hod/ ention	Depre	h) eciation uction	Elected so	ection 179
25	Special depreciation																
	the tax year and us					e. Se	e ins	truct	ions				. 25				
26	Property used mor	e than 50% in a qւ			se:							1					
				%													
				% %						+							
27	Property used 50%	or less in a qualifi															
	1 Toperty asea 50 %	or icos irra quaiir		% d3C.								S/L -					
				%								S/L -				_	
				%								S/L -					
28	Add amounts in co	lumn (h), lines 25 t	through 27.	Enter	here an	d on	line	21, p	age '	1			_ 28				
29	Add amounts in co	lumn (i), line 26. E	nter here a	nd on	line 7, pa	ige 1									. 29		
			Sectio	nB-	Informa	ition	n on	Use	of V	ehic	les						
	plete this section fo															rovided	vehicle
to y	our employees, first an	swer the questions in	Section C to			an ex		on to	comp		g this			T .	_		
					(a) nicle 1	V	(b) 'ehicle	2	v	(c) /ehicle	3		d) icle 4		e) icle 5	(1 Vehi	
30	Total business/inve	estment miles drive	en during														
31	Total commuting m																
	•	ersonal (nonco															
-	miles driven	•	٠,														
33	Total miles drive																
	lines 30 through 32																
34	Was the vehicle	available for pers	sonal	Yes	No	Yes	s	No	Yes	s	No	Yes	No	Yes	No	Yes	No
	use during off-duty	hours?															
35	Was the vehicle																
	than 5% owner or r	elated person?															
	la amathan wahiala																
36	Is another vehicle		-	nlovo	ro Mha	Dro	ida	. Val	hiolo	o for	Llos	by Th	oir Em	nlovo			
Λnc	wer these question	ction C - Questions if										-				who a	ron't
	re than 5% owners o		•		eption t	5 60	пріс	ung	Jeci	IOII L	101	vernoles	s useu	by em	pioyees	wiio ai	en t
	Do you maintain a				ohihite a	all na	ersor	nal II	se o	f vet	nicles	includ	lina co	mmutir	na hv	Yes	No
01	your employees?											, 1110140	g 00		ig, by		
38	Do you maintain	a written policy s	tatement tl	hat pr	ohibits	pers	onal	use	of ve	ehicle	es, e	xcept c	commu	ting, by	your		
	employees? See th																
	Do you treat all use																
40	Do you provide m																
	use of the vehicles,	and retain the info	ormation red	ceived'	?												
41	Do you meet the re																
Pa	Note: If your answ rt VI Amortizati		0,014118	1 C S, (uon i col	пріе	رد عو	JUIJ	טו פוו	n tile	COVE	area ver	IIUICS.				
ı u	Amortizati	1011	4.										(е)			
	(a)		(b) Date amorti	zation			(c)			_	(d)		Amorti	zation		(f)	
	Description o	T COSTS	begins		Am	ortıza	ble an	ount		С	ode se	ction	perio percei		Amortiza	ation for th	is year
42	Amortization of cos	sts that begins duri	ng your 202	21 tax	year (se	e ins	truct	ions)	:								
	Amortization of cos													43			
44	Total. Add amount	ts in column (f). Se	ee the instru	<u>ict</u> ions	for whe	re to	repo	ort .						44			

2021 DYSTROPHIC EPIDERMOLYSIS BULLOSA 11-2519726

Description of Property

GENERAL DEPRECIATION

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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	Me-	Conv.	Life	ACRS	MA CRS class	Current-year 179 expense	Current-year depreciation
OTHER	01/01/2010	-901.	100.000			шоргоонино	-901.	-901.	SL		5.000	Glado			<u> </u>
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.			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														1	
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															

JSA 1X9024 1.000

DocuSign Envelope ID: 8D7AF153-E5F8-4510-9670-D3980B0D0873 port Studley & White, LLP 123 South Main St., Suite 140 Newtown, CT 06470

Fax: 203-426-7174

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.

CHAR500

NYS Annual Filing for Charitable Organizations www.CharitiesNYS.com

Send with fee and attachments to: NYS Office of the Attorney General Charities Bureau Registration Section 28 Liberty Street New York, NY 10005 2021
Open to Public Inspection

1. General Information

For Fiscal Vear Beginn	ning (mm/dd/yyyy)01	/ 01 / 2021 and Fr	nding (mm/dd/www)	12_/_31/_2021					
Check if Applicable:	Name of Organization: D	YSTROPHIC EPIDERM	OLYSIS BULLOS	Employer Identification Number (EIN):					
Address Change	_	ATION OF AMERICA		11-2519726					
Name Change	Mailing Address: NY Registration Number:								
Initial Filing	75 BROAD ST SUITE 300								
Final Filing	City / State / Zip: Telephone:								
Amended Filing	NEW YORK, NY 10								
Reg ID Pending	Website:	004		Email:					
Compared to reliable				STAFF@DEBRA.ORG					
Check your organization's registration category:	Check your organization's Confirm your Registration Category in the								
2. Certification									
See instructions for certif signatories.	ication requirements. Improp	er certification is a violation	of law that may be subject	to penalties. The certification requires two					
	er penalties of perjury that we re are true, correct and complete			best of our knowledge and belief, oplicable 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 Repor	ting Exemption								
categories (DUAL filers)	that apply to your registration, . If you cannot claim an exem	complete only parts 1, 2, a	nd 3, and submit the certifie	ory (7A or EPTL only filers) or both d Char500. No fee, schedules, or additional n, you must file applicable schedules and					
-	-	_	_	ent agencies, etc. did not exceed \$25,000 olicit contributions during the fiscal year.					
3b. EPTL filling 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	for a checklist of Yes X No for fund raising activity in NV State2. If yes, complete Schedule 4a.								
attachments to complete your filing.	attachments to Yes Y No. 4b Did the organization receive government grants? If yes, complete Schedule 4b								
5. Fee									
See the checklist on the next page to calculate you	7A filing fee:	EPTL filing fee:	Total fee:	Make a single check or money order					
next page to calculate your fee(s). Indicate fee(s) you are submitting here: \$ \$									

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.

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

Chec	k 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								
Chec	k the financial attachments you must submit with your CHAR500:								
X	IRS Form 990, 990-EZ, or 990-PF, and 990-T if applicable								
X	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 reven filing year. We have included an IRS Form 990-EZ for state purposes only.	ue exceeded \$25,000 and/or our assets exceeded \$25,000 in the							
If you	are a 7A only or DUAL filer, submit the applicable independent Certified Public A	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							
X	Audit Report if you received total revenue and support greater than \$1,000,000 lf the fiscal year begins before that date, an Audit Report is required if total revenue.								
	No Review Report or Audit Report is required because total revenue and support	t is less than \$250,000							
	We are a DUAL filer and checked box 3a, no Review Report or Audit Report is re-	quired							
Cal	culate Your Fee								
		Is my Registration Category 7A, EPTL, DUAL or EXEMPT?							
	Culate Your Fee A and DUAL filers, calculate the 7A fee: \$0, if you checked the 7A exemption in Part 3a	Is my Registration Category 7A, EPTL, DUAL or EXEMPT? Organizations are assigned a Registration Category upon registration with the NY Charities Bureau:							
	A and DUAL filers, calculate the 7A fee:	Organizations are assigned a Registration Category upon							
For 7	A and DUAL filers, calculate the 7A fee: \$0, if you checked the 7A exemption in Part 3a	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")							
For 7	A 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	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							
For 7	A 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 PTL and DUAL filers, calculate the EPTL fee:	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							
For 7	A 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 PTL and DUAL filers, calculate the EPTL fee: \$0, if you checked the EPTL exemption in Part 3b	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							
For 7	A 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 PTL and DUAL filers, calculate the EPTL fee: \$0, if you checked the EPTL exemption in Part 3b	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.							
For 7	A 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 PTL 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	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							
For 7	A 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 PTL 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	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							
For 7	A 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 PTL 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	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							

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

Where do I find my organization's NET WORTH?

NET WORTH for fee purposes is calculated on:

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

CHAR500

2021

Schedule 4a: Professional Fund Raisers, Fund Raising Counsels, Commercial Co-Venturers www.CharitiesNYS.com

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.

draft applications for funding from	n a government agency or tax exempt org	anization.
1. Organization Inform	nation	
Name of Organization:		NY Registration Number:
-	RMOLYSIS BULLOSA	
RESEARCH ASSOCIA		
2. Professional Fund R	aiser, Fund Raising Couns	sel, Commercial Co-Venturer Information
	Name of FRP:	NY Registration Number:
Fund Raising Professional type:		
Professional Fund Raiser	Mailing Address:	Telephone:
Found Baising Command		
Fund Raising Counsel	City / State / Zip:	
Commercial Co-Venturer	· ·	
	_	
0. 0 4 4 6 4		
3. Contract Information		
Contract Start Date:	Contract End Date:	
4. Description of Servi	ices	
Services provided by FRP:		
5. Description of Com	pensation	
Compensation arrangement with F	RP:	Amount Paid to FRP:
6. Commercial Co-Ven	turer (CCV) Report	
If services	were provided by a CCV_did the CCV p	rovide the charitable organization with the interim or closing report(s) required by
	3(a) part 3 of the Executive Law Article 7	



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.