Form **990** 

Department of the Treasury

# **Return of Organization Exempt From Income Tax**

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

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

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

OMB No. 1545-0047

Form **990** (2020)

Inter	nal Reve	enue Serv	rice		► Go to w	ww.irs.gov/Fo	rm990 for i	nstructions	and the	e latest info	rmation.			Inspec	ction
A	For th	e 2020	calend	ar year, or tax	year beginning	l		, 2020	, and e	nding	_		, 2	20	
			C Name	e of organization	DYSTROPHI	C EPIDERI	MOLYSIS	BULLOSA	A		D Employer ide	ntifica	ation nun	nber	
В	Check if a	applicable:	RES	SEARCH ASS	SOCIATION	OF AMERI	CA				11-251	972	6		
	Addr chan		Doing	business as											
	7	e change	Num	per and street (or	P.O. box if mail is	s not delivered to	street addre	ess)	Room/	suite	E Telephone n	umber			
	Initia	l return	75	BROAD ST	SUITE 300	)					(212) 868-1573				
		return/ inated	City	or town, state or p	province, country,	and ZIP or fore	ign postal cod	de							
		nded	NEV	YORK, NY	7 10004						<b>G</b> Gross receip	ts\$	1	,975	5,484
		ication	F Name	e and address of	principal officer:	BRETT	KOPELA	N			H(a) Is this a gro	oup retu	ırn for	Yes	X N
	pend	g	75	BROAD ST	300, NEW	YORK, NY	10004				subordinate <b>H(b)</b> Are all subor		ncluded?	Yes	□ N
$\overline{\Gamma}$	Tax-ex	cempt sta	atus:	X 501(c)(3)	501(c) (	) <b>《</b> (ins	sert no.)	4947(a)(1)	or	527	If "No,"	attach a	list. See in	 istructions	 s
J	Webs	ite: 🕨	WWW.	DEBRA.ORG		, ,	,				H(c) Group exer	nption n	number	<b>&gt;</b>	
K	Form	of organ	ization:	X Corporation	Trust	Association	Other	<b>&gt;</b>	L	Year of form	ation: 1979 M	State	of legal of	domicile:	NY
Р	art I	Su	mmary	<u>,                                     </u>			l		I		<u> </u>				
	1			oe the organiza	tion's mission	or most sianifi	cant activitie	es:					-		-
ø		•		DEDICATE		•			RESI	EARCH					-
and		EB Z	AFFEC	TS 1 OUT	OF EVERY	50,000 L	IVE BIF	RTHS IN	THE U	J.S.					-
Activities & Governance	2	Check	this bo	x ▶ if the	e organization	discontinued	its operatio	ns or dispos	ed of m	ore than 25	% of its net asse	ts.	-		-
õ	3			ting members	ū		•	•				3			11.
≪	4			dependent votir								4			11.
ties	5			of individuals								5			11.
ξ	6			of volunteers (e								6			0.
Ac	7a			ed business reve								7a			0.
				business taxal								7b			
						.,	,				Prior Year	1.4	Cu	ırrent Y	/ear
4	8	Contri	butions	and grants (Pa	rt VIII. line 1h)						705,8	72.		936	,305.
nue	9			ice revenue (Pa								0.			0 .
Revenue	10			come (Part VIII							1,6	96.		1	,046.
Ř	11			e (Part VIII, col							853,7			,498.	
	12			- add lines 8 t							1,561,2	1,875,849.			
	13			milar amounts							50,7				,454.
	14			to or for memb										0 .	
"	4.5			er compensation							945,728.			,020	,960.
Expenses	16a			fundraising fees								0.			0 .
e d	b			ing expenses (I						• • •					
û	17			es (Part IX, col							469,2	17.	527,547.		
				es. Add lines 13							1,465,6	95.	1	,628	,961.
	19			expenses. Sub							95,6				,888.
o s				•							inning of Current	Year	Er	nd of Ye	ar
Net Assets or Fund Balances	20	Total a	assets (	Part X, line 16)							2,407,0	30.	2	,976	,485.
Ass	21	Total I	iabilitie	s (Part X, line 26	6)						311,6	82.		321	,584.
Per	22			fund balances							2,095,3	98.	2	,654	,901.
	art II	Sig	gnature	Block											
Un	der pe	nalties c	of perjury	igned by declare that I	have examined t	his return, inclu	iding accom	panying sched	lules and	statements,	and to the best of	of my l	knowledg	je and b	elief, it is
tru	e, corre	ect, and	complete DK 7	Declaration of c	reparer (other tha	an officer) is bas	sed on all info	rmation of wh	iich prep	arer nas any	knowledge.				
				6E0A7DF445	V						03/2	27/2	021		
Siç	-	S	Signature	of officer							Date				
He	BRETT KOPELAN						EXECUTIVE DIRECTOR								
_				rint name and title	)	DocuSig	ned by:								
D		Brint/	Type pre	parer's name		Preparer's si			Dat		Check	if F	PTIN		
Pai		L				bewlut			5/	3/2021	self-emplo			05832	20
	parer Only	Firm's	name	NANAVAT	Y DAVENPO	RT SŤUĎĹ	EY WHIT	E			Firm's EIN	ე6-1	40274	19	
_	Ciliy		address	▶123 SOUTH M	MAIN ST., SUIT	re 140 NEWTO	WN, CT 064	70			Phone no.	203-	-426-8		
Ma	y the	IRS d	iscuss	this return wit	th the prepare	er shown abo	ove? (see	instructions	)				. X	Yes	No

For Paperwork Reduction Act Notice, see the separate instructions.

DYSTROPHIC EPIDERMOLYSIS BULLOSA 11-2519726

Forr	m 990 (2020)	Page 2
Pa	Statement of Program Service Accomplishments	$\overline{}$
1	Check if Schedule O contains a response or note to any line in this Part III  Briefly describe the organization's mission:	X
'	ATTACHMENT 1	
2	· · · · · · · · · · · · · · · · · · ·	No
3	If "Yes," describe these new services on Schedule O.  Did the organization cease conducting, or make significant changes in how it conducts, any program	_
	services?	∐ No
4	Describe the organization's program service accomplishments for each of its three largest program services, as measured to the organization of the	ed by
	expenses. Section $501(c)(3)$ and $501(c)(4)$ organizations are required to report the amount of grants and allocations to the total expenses, and revenue, if any, for each program service reported.	
4a	(Code: ) (Expenses \$ 262,323. including grants of \$ ) (Revenue \$ 5,641. )	
	PUBLIC AND PROFESSIONAL EDUCATION - EDUCATE THE PUBLIC & HEALTH	
	PROFESSIONALS ABOUT DYSTROPHIC EPIDERMOLYSIS BULLOSA "EB"	
4b	(Code:) (Expenses \$999,391. including grants of \$) (Revenue \$)	
	PATIENT & FAMILY SERVICES - PROVIDE SERVICES FOR THE PEOPLE WITH	
	EB AND THEIR FAMILIES THROUGH NEWSLETTERS, COUNSELING, PEER SUPPORT SERVICES, CONFERENCES AND SEMINARS	
	SUPPORT SERVICES, CONFERENCES AND SEMINARS	
4c	(Code:) (Expenses \$39,349. including grants of \$) (Revenue \$)	
	ADVOCACY - NETWORK WITH OTHER PROFESSIONAL ORGANIZATIONS AND MEET	
	KEY LEGISLATORS TO INFORM THEM OF EB AND SECURE RESEARCH FUNDS	
4d	Other program services (Describe on Schedule O.) ATTACHMENT 2	
_	(Expenses \$ 131,160. including grants of \$ ) (Revenue \$ )	

**4e** Total program service expenses ► JSA 0E1020 1.000 1,432,223. Form 990 (2020) Page **3** 

Par	IV Checklist of Required Schedules			
			Yes	No
1	Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? If "Yes,"			
_	complete Schedule A	1	X	
2	Is the organization required to complete Schedule B, Schedule of Contributors See instructions?	2	Х	
3	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to			Х
	candidates for public office? If "Yes," complete Schedule C, Part I	3		
4	Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h)	,		Х
5	election in effect during the tax year? If "Yes," complete Schedule C, Part II	4		
5	assessments, or similar amounts as defined in Revenue Procedure 98-19? If "Yes," complete Schedule C, Part III	5		Х
6	Did the organization maintain any donor advised funds or any similar funds or accounts for which donors			
Ū	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		Х
7	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	7		Х
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes,"			
	complete Schedule D, Part III	8		X
9	Did the organization report an amount in Part X, line 21, for escrow or custodial account liability, serve as a			
	custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or			
	debt negotiation services? If "Yes," complete Schedule D, Part IV	9		X
10	Did the organization, directly or through a related organization, hold assets in donor-restricted endowments			
	or in quasi endowments? If "Yes," complete Schedule D, Part V	10		X
11	If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI,			
	VII, VIII, IX, or X as applicable.			
а	Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes,"		v	
	complete Schedule D, Part VI	11a	Х	
D	Did the organization report an amount for investments-other securities in Part X, line 12, that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VII	11b	х	
_	Did the organization report an amount for investments-program related in Part X, line 13, that is 5% or more	110	- 21	
C	of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VIII	11c		Х
d	Did the organization report an amount for other assets in Part X, line 15, that is 5% or more of its total assets	110		
-	reported in Part X, line 16? If "Yes," complete Schedule D, Part IX	11d		Х
е	Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X	11e		Х
	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	Х	
12 a	Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete			
	Schedule D, Parts XI and XII	12a	Х	
b	Was the organization included in consolidated, independent audited financial statements for the tax year? If			
	"Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional	12b		X
13	Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E	13		X
	Did the organization maintain an office, employees, or agents outside of the United States?	14a		X
b	Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking,			
	fundraising, business, investment, and program service activities outside the United States, or aggregate	4.46		Х
15	foreign investments valued at \$100,000 or more? If "Yes," complete Schedule F, Parts I and IV	14b		
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	Х	
16	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other	13		
	assistance to or for foreign individuals? If "Yes," complete Schedule F, Parts III and IV	16		Х
17	Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on			
	Part IX, column (A), lines 6 and 11e? If "Yes," complete Schedule G, Part I See instructions	17		Х
18	Did the organization report more than \$15,000 total of fundraising event gross income and contributions on			
	Part VIII, lines 1c and 8a? If "Yes," complete Schedule G, Part II	18	Х	
19	Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a?			
	If "Yes," complete Schedule G, Part III	19		Х
20 a	Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H	20a		Х
b	If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?	20b		
21	Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or			
	domestic government on Part IX, column (A), line 1? If "Yes," complete Schedule I, Parts I and II	21		X

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Part	Checklist of Required Schedules (continued)		V	Na
			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		X
23	Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the			
	organization's current and former officers, directors, trustees, key employees, and highest compensated			
	employees? 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		Х
h	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			
·		24c		
	to defease any tax-exempt bonds?			
	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d		
25 a	Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit			3.7
	transaction with a disqualified person during the year? If "Yes," complete Schedule L, Part I	25a		X
b	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior			
	year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ?			
	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		X
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			
		27		Х
00	persons? If "Yes," complete Schedule L, Part III	27		71
28	Was the organization a party to a business transaction with one of the following parties (see Schedule L,			
	Part IV instructions, for applicable filing thresholds, conditions, and exceptions):			
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 lines 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	X	
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified			
	conservation contributions? If "Yes," complete Schedule M	30		Х
31	Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>	31		X
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If</i> "Yes,"	<u> </u>		
32		22		Х
	complete Schedule N, Part II.	32		- 21
33	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations			37
	sections 301.7701-2 and 301.7701-3? If "Yes," complete Schedule R, Part I.	33		X
34	Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Part II, III,			
	or IV, and Part V, line 1	34		X
35 a	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		
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		Х
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and	ļ .		
50	19? <b>Note:</b> All Form 990 filers are required to complete Schedule O.	38	Х	
Part		30	21	<u> </u>
Part				
	Check if Schedule O contains a response or note to any line in this Part V			
			Yes	No
	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable			
	Enter the number of Forms W-2G included in 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		

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Part V Statements Regarding Other IRS Filings and Tax Compliance (continued) No 2a Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax 11 Statements, filed for the calendar year ending with or within the year covered by this return. . 2b b If at least one is reported on line 2a, did the organization file all required federal employment tax returns? Note: If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)...... Χ 3a Did the organization have unrelated business gross income of \$1,000 or more during the year?...... b 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, Χ 4a a financial account in a foreign country (such as a bank account, securities account, or other financial account)?... **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). Χ 5a **5a** Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?..... X b Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction? c If "Yes" to line 5a or 5b, did the organization file Form 8886-T? 6a Does the organization have annual gross receipts that are normally greater than \$100,000, and did the Χ b If "Yes," did the organization include with every solicitation an express statement that such contributions or 6b Organizations that may receive deductible contributions under section 170(c). a Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods 7a X Χ **b** If "Yes," did the organization notify the donor of the value of the goods or services provided? c Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was 7e e Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract? 7f f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract? 7g g If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required? h If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?... Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the 8 Sponsoring organizations maintaining donor advised funds. 9a 9b **b** Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?...... 10 Section 501(c)(7) organizations. Enter: 10a a Initiation fees and capital contributions included on Part VIII, line 12 . . . . . . . . . b Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities . . . . Section 501(c)(12) organizations. Enter: **b** Gross income from other sources (Do not net amounts due or paid to other sources 12a 12a Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041? b If "Yes," enter the amount of tax-exempt interest received or accrued during the year . . . . . 12b Section 501(c)(29) qualified nonprofit health insurance issuers. 13a a Is the organization licensed to issue qualified health plans in more than one state? Note: See the instructions for additional information the organization must report on Schedule O. **b** Enter the amount of reserves the organization is required to maintain by the states in which Χ b If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation on Schedule O Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or Χ excess parachute payment(s) during the year?............. 15 If "Yes," see instructions and file Form 4720, Schedule N. Χ Is the organization an educational institution subject to the section 4968 excise tax on net investment income? If "Yes," complete Form 4720, Schedule O.

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Part VI

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

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

	Check if Schedule O contains a response of note to any line in this Part VI			Λ
Sect	ion A. Governing Body and Management			
			Yes	No
1a	Enter the number of voting members of the governing body at the end of the tax year	_		
b	Enter the number of voting members included on line 1a, above, who are independent 1b 11			
2	Did any officer, director, trustee, or key employee have a family relationship or a business relationship with			
	any other officer, director, trustee, or key employee?	2		X
3	Did the organization delegate control over management duties customarily performed by or under the direct			
	supervision of officers, directors, trustees, or key employees to a management company or other person?	3		X
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?	4		Х
5	Did the organization become aware during the year of a significant diversion of the organization's assets?	5		Х
6	Did the organization have members or stockholders?	6		X
7a	Did the organization have members, stockholders, or other persons who had the power to elect or appoint			
·u	one or more members of the governing body?	7a		X
b	Are any governance decisions of the organization reserved to (or subject to approval by) members,			
D	stockholders, or persons other than the governing body?	7b		X
8	Did the organization contemporaneously document the meetings held or written actions undertaken during			
Ū	the year by the following:			
а	The governing body?	8a	Х	
b	Each committee with authority to act on behalf of the governing body?	8b	Х	
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at			
•	the organization's mailing address? If "Yes," provide the names and addresses on Schedule O	9		X
Secti	on B. Policies (This Section B requests information about policies not required by the Internal Revenue	Code	.)	
			Yes	No
10a	Did the organization have local chapters, branches, or affiliates?	10a		Х
	If "Yes," did the organization have written policies and procedures governing the activities of such chapters,			
	affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes?	10b		
11a	Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?	11a	Х	
b	Describe in Schedule O the process, if any, used by the organization to review this Form 990.			
12a	Did the organization have a written conflict of interest policy? <i>If "No," go to line 13 </i>	12a	X	
b	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give			
-	rise to conflicts?	12b	X	
С	Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes,"			
•	describe in Schedule O how this was done	12c	X	
13	Did the organization have a written whistleblower policy?	13	Х	
14	Did the organization have a written document retention and destruction policy?	14	Х	
15	Did the process for determining compensation of the following persons include a review and approval by			
	independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision?			
а	The organization's CEO, Executive Director, or top management official	15a	X	
b	Other officers or key employees of the organization	15b		
-	If "Yes" to line 15a or 15b, describe the process in Schedule O (see instructions).			
16a	Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement			
	with a taxable entity during the year?	16a		X
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?	16b		
Secti	on C. Disclosure			
17	List the states with which a copy of this Form 990 is required to be filed ► CA, MA, MI, NJ, NY,			
18	Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, and 990-7	(Sec	tion 5	01(c)
	(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.	•		. ,
	Own website Another's website X Upon request Other (explain on Schedule O)			
19	Describe on Schedule O whether (and if so, how) the organization made its governing documents, conflict of	f inter	est p	oolicy,
	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 record BRETT KOPELAN 75 BROAD STREET, SUITE 300 NEW YORK, NY 10004 212-868-1573	ls ▶		

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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 instructions for definition of "key employee."
- List the organization's five **current** highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations.
- List all of the organization's **former** officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations. See instructions for the order in which to list the persons above.

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

hours for related organizations below dotted line)	Individual trustee or director	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee) Former  Key employee Officer Officer Officer Officer Officer Officer		compensation from the organization (W-2/1099-MISC)	compensation from related organizations (W-2/1099-MISC)	of other compensation from the organization and related organizations			
					Δ.				
							_		_
				X			0.	261,529.	0.
							_	_	_
	X		X				0.	0.	0.
	Х		X				0.	0.	0.
	X						0.	0.	0.
							_	_	_
	X						0.	0.	0.
	X		X				0.	0.	0.
	Х						0.	0.	0.
	X						0.	0.	0.
	X						0.	0.	0.
	X						0.	0.	0.
	X						0.	0.	0.
0.	X						0.	0.	0.
	related organizations below dotted line)  40.00 0. 1.00 0. 1.00 0. 1.00 0. 1.00 0. 1.00 0. 1.00 0. 1.00 0. 1.00 0. 1.00 0. 1.00 0. 1.00 0. 1.00 0. 1.00 0. 1.00	Nours for related organizations below dotted line)	Nours for related organizations below dotted line)	Nours for related organizations below dotted line)	Nours for related organizations below dotted line)	Nours for related organizations below dotted line   Nours for related organizations   Nours for related organizati	Nours for related organizations below dotted line)	Nours for related organizations below dotted line)   Notice   No	Nours for related organizations below dotted line   Nours for related organizations   Nours for related organization

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Part VII Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees (continued) (A) (C) (D) (E) (B) Name and title Position Reportable Reportable Estimated Average (do not check more than one compensation hours per compensation from amount of week (list any box, unless person is both an other from related officer and a director/trustee) compensation hours for the organizations Highest compensated employee Individual trustee or director Institutional trustee related (W-2/1099-MISC) from the organization organizations organization employee (W-2/1099-MISC) and related below dotted organizations 0. 261,529. 0. 1b Sub-total 0. 0. 0. c Total from continuation sheets to Part VII, Section A 0. 261,529. 0. Total number of individuals (including but not limited to those listed above) who received more than \$100,000 of reportable compensation from the organization > Yes No 3 Did the organization list any former officer, director, or trustee, key employee, or highest compensated Χ employee on line 1a? If "Yes," complete Schedule J for such individual 3 For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? If "Yes," complete Schedule J for such 4 X 5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? If "Yes," complete Schedule J for such person Χ **Section B. Independent Contractors** Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax year. (A) (B) (C) Name and business address Description of services Compensation Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 in compensation from the organization ▶

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Part VIII	Statement	of Revenue
-----------	-----------	------------

		Check if Schedule O contains a re	espon	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
ts ts	1a	Federated campaigns	1a					
Contributions, Gifts, Grants and Other Similar Amounts	b	Membership dues	1b					
عَ ق	С	Fundraising events	1c					
r, F,S	d	Related organizations	1d					
ਛੁ≅	e	Government grants (contributions)	1e					
ns,		, , , , , , , , , , , , , , , , , , ,	16					
ξË	f	All other contributions, gifts, grants,	4.	026 205				
be in		and similar amounts not included above	1f	936,305.				
<u></u>	g	Noncash contributions included in		405 605				
25		lines 1a-1f.	1g \$					
	h	Total. Add lines 1a-1f			936,305.			
4			-	Business Code				
<u>ĕ</u>	2a							
ne je	b							
n S	С							
e a	d							
Program Service Revenue	е							
₫	f	All other program service revenue	[					
	g	Total. Add lines 2a-2f		<u> ▶</u>	0.			
	3	Investment income (including divide	ends,	interest, and				
		other similar amounts)		▶	1,046.			1,046.
	4	Income from investment of tax-exempt			0.			
	5	Royalties		•	0.			
		(i) Rea		(ii) Personal				
	6a	Gross rents 6a						
	b	Less: rental expenses 6b						
	C	Rental income or (loss) 6c						
	d	Net rental income or (loss)		<b>•</b>	0.			
	7a	Gross amount from (i) Securit		(ii) Other				
	'a	sales of assets		(,				
4	١	,						
Revenue	b	Less: cost or other basis						
ĕ		and sales expenses 7b						
Re		Gain or (loss)			0.			
er	a	Net gain or (loss)			0.			
Other	8a	Gross income from fundraising						
•		events (not including \$						
		of contributions reported on line						
		1c). See Part IV, line 18	8a	1,032,492.				
	b	Less: direct expenses	8b	99,635.				
	С	Net income or (loss) from fundraising e	vents.	<u></u>	932,857.			932,857.
	9a	Gross income from gaming						
		activities. See Part IV, line 19	9a	0.				
	b	Less: direct expenses	9b	0.				
	С	Net income or (loss) from gaming active	vities	▶	0.			
	10a	Gross sales of inventory, less						
		returns and allowances	10a	0.				
	b	Less: cost of goods sold	10b	0.				
	c	Net income or (loss) from sales of invent		<u>.</u> ▶	0.			
s				Business Code				
og a	11a	MISCELLANEOUS INCOME	ļ	900099	5,641.	5,641.		
ane nu						· · ·		
e ∈	b							
Miscellaneous Revenue	c d	All other revenue						
Ξ		Total. Add lines 11a-11d			5,641.			
	<u>е</u> 12	Total revenue. See instructions			1,875,849.	5,641.		933,903.
	. 4	. J.a. 10 toliao. Occ ilistiacionis			1,0,0,049.	5,041.		, ,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,

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YSIS BULLOSA 11-2

# 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 responsible of the contains a responsible of the contains a responsible of the contains and th	<u> </u>		· · · · · · · · · · · · · · · · · · ·	
Do	not include amounts reported on lines 6b, 7b,	(A)		(C)	(D)
	9b, and 10b of Part VIII.	Total expenses	(B) Program service	Management and	Fundraising
			expenses	general expenses	expenses
1	Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	0.			
2	Grants and other assistance to domestic individuals. See Part IV, line 22	0.			
3	Grants and other assistance to foreign				
	organizations, foreign governments, and				
	foreign individuals. See Part IV, lines 15 and 16	80,454.	80,454.		
4	Benefits paid to or for members	0.			
5	Compensation of current officers, directors,				
	trustees, and key employees	261,529.	222,300.	13,076.	26,153.
6	Compensation not included above to disqualified				
	persons (as defined under section 4958(f)(1)) and				
	persons described in section 4958(c)(3)(B)	0.			
7	Other salaries and wages	590,535.	501,955.	29,527.	59,053.
8	Pension plan accruals and contributions (include				
	section 401(k) and 403(b) employer contributions)	0.			
9	Other employee benefits	100,127.	85,108.	5,006.	10,013.
10	Payroll taxes	68,769.	58,454.	3,438.	6,877.
11	Fees for services (nonemployees):				
а	Management	0.			
	Legal	0.			
c	Accounting	0.			
	Lobbying	0.			
	Professional fundraising services. See Part IV, line 17	0.			
1	f Investment management fees	0.			
Q	Other. (If line 11g amount exceeds 10% of line 25, column				
	(A) amount, list line 11g expenses on Schedule O.)	8,300.	7,055.	415.	830.
12	Advertising and promotion	10,173.	8,647.	509.	1,017.
13	Office expenses	58,905.	50,070.	2,945.	5,890.
14	Information technology	0.			
15	Royalties	0.			
16	Occupancy	103,927.	88,338.	5,196.	10,393.
17	Travel	19,161.	16,287.	958.	1,916.
18	Payments of travel or entertainment expenses				
	for any federal, state, or local public officials	0.			
19	Conferences, conventions, and meetings	14,351.	12,198.	718.	1,435.
20	Interest	0.			
21	Payments to affiliates	0.			
22	Depreciation, depletion, and amortization	2,968.	2,523.	148.	297.
23	Insurance	23,282.	19,790.	1,164.	2,328.
24	Other expenses. Itemize expenses not covered				
	above (List miscellaneous expenses on line 24e. If				
	line 24e amount exceeds 10% of line 25, column				
	(A) amount, list line 24e expenses on Schedule O.)				
•	PATIENT ASSISTANCE	236,900.	236,900.		
-	DUES & SUBSCRIPTIONS	3,306.	2,810.	165.	331.
_	TELEPHONE	17,463.	14,844.	873.	1,746.
c	EQUIPMENT	10,808.	9,187.	540.	1,081.
e	All other expenses	18,003.	15,303.	900.	1,800.
	Total functional expenses. Add lines 1 through 24e	1,628,961.	1,432,223.	65,578.	131,160.
26	Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here if following SOP 98-2 (ASC 958-720)	0.			
_	10.10 ming 001 00 2 (A00 000-120)	0.			- 000 (assa)

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### Part X Balance Sheet

P	art X		ort V		X
		Check if Schedule O contains a response or note to any line in this Pa	(A)	<u></u>	(B)
			Beginning of year		End of year
	1	Cash - non-interest-bearing	972,811.	1	651,965.
	2	Savings and temporary cash investments	0.	2	0.
	3	Pledges and grants receivable, net	0.	3	0.
	4	Accounts receivable, net	5,360.	4	527,541.
	5	Loans and other receivables from any current or former officer, director,			
		trustee, key employee, creator or founder, substantial contributor, or 35%			
		controlled entity or family member of any of these persons	0.	5	0.
	6	Loans and other receivables from other disqualified persons (as defined			
		under section 4958(f)(1)), and persons described in section 4958(c)(3)(B)	0.	6	0.
ts	7	Notes and loans receivable, net	0.	7	0.
Assets	8	Inventories for sale or use	467,518.	8	648,724.
⋖	9	Prepaid expenses and deferred charges	38,570.	9	58,958.
	10 a	Land, buildings, and equipment: cost or other			
		basis. Complete Part VI of Schedule D 10a 44,082.			
	b	Less: accumulated depreciation	8,029.		6,248.
	11	Investments - publicly traded securities	664,792.		833,049.
	12	Investments - other securities. See Part IV, line 11	250,000.		250,000.
	13	Investments - program-related. See Part IV, line 11	0.		0.
	14	Intangible assets	0.	1.7	0.
	15	Other assets. See Part IV, line 11	0.	13	0.
	16	Total assets. Add lines 1 through 15 (must equal line 33)	2,407,080.	16	2,976,485.
	17	Accounts payable and accrued expenses	214,071.	17	321,584.
	18	Grants payable	0.		0.
	19	Deferred revenue.	0.		0.
	20	Tax-exempt bond liabilities	0.		0.
"	21 22	Escrow or custodial account liability. Complete Part IV of Schedule D	0.	21	0.
Liabilities	22	Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35%			
įΪ		controlled entity or family member of any of these persons	0.	22	0.
Lia	23	Secured mortgages and notes payable to unrelated third parties	0.		0.
	24	Unsecured notes and loans payable to unrelated third parties	0.		0.
	25	Other liabilities (including federal income tax, payables to related third			
		parties, and other liabilities not included on lines 17-24). Complete Part X			
		of Schedule D	97,611.	25	0.
	26	Total liabilities. Add lines 17 through 25	311,682.	26	321,584.
seou		Organizations that follow FASB ASC 958, check here ► X and complete lines 27, 28, 32, and 33.			
alar	27	Net assets without donor restrictions	1,283,751.	27	2,107,054.
Ä	28	Net assets with donor restrictions	811,647.	28	547,847.
Fund Balances		Organizations that do not follow FASB ASC 958, check here ▶ and complete lines 29 through 33.			
ō ,	29	Capital stock or trust principal, or current funds		29	
sets	30	Paid-in or capital surplus, or land, building, or equipment fund		30	
ASS	31	Retained earnings, endowment, accumulated income, or other funds		31	
Net Assets or	32	Total net assets or fund balances	2,095,398.	32	2,654,901.
z	33	Total liabilities and net assets/fund balances	2,407,080.	33	2,976,485.
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Page **12** Form 990 (2020) Part XI **Reconciliation of Net Assets** Check if Schedule O contains a response or note to any line in this Part XI 1,875,849. 1 1 1,628,961. 2 246,888. 3 3 2,095,398. 4 Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A)) . . . . . 4 138,689. 5 5 173,926. 6 6 0. 7 7 0. 8 8 0. 9 9 10 Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 2,654,901. 10 Part XII Financial Statements and Reporting Check if Schedule O contains a response or note to any line in this Part XII........... 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 in Schedule O. Χ 2a 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 Χ 2b **b** Were the organization's financial statements audited by an independent accountant? If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both: Separate basis Consolidated basis Both consolidated and separate basis c If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of X 2c 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 . . .

# **SCHEDULE A**

(Form 990 or 990-EZ)

Department of the Treasury Internal Revenue Service

### **Public Charity Status and Public Support**

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust. Attach to Form 990 or Form 990-EZ.

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

OMB No. 1545-0047 Open to Public Inspection

DYSTROPHIC EPIDERMOLYSIS BULLOSA Employer identification number Name of the organization RESEARCH ASSOCIATION OF AMERICA 11-2519726 Part I Reason for Public Charity Status. (All organizations must complete this part.) See instructions. The organization is not a private foundation because it is: (For lines 1 through 12, check only one box.) 1 A church, convention of churches, or association of churches described in section 170(b)(1)(A)(i). 2 A school described in section 170(b)(1)(A)(ii). (Attach Schedule E (Form 990 or 990-EZ).) 3 A hospital or a cooperative hospital service organization described in section 170(b)(1)(A)(iii). 4 A medical research organization operated in conjunction with a hospital described in section 170(b)(1)(A)(iii). Enter the hospital's name, city, and state: 5 An organization operated for the benefit of a college or university owned or operated by a governmental unit described in section 170(b)(1)(A)(iv). (Complete Part II.) A federal, state, or local government or governmental unit described in section 170(b)(1)(A)(y). 6 An organization that normally receives a substantial part of its support from a governmental unit or from the general public 7 described in section 170(b)(1)(A)(vi). (Complete Part II.) 8 A community trust described in section 170(b)(1)(A)(vi). (Complete Part II.) 9 An agricultural research organization described in section 170(b)(1)(A)(ix) operated in conjunction with a land-grant college or university or a non-land-grant college of agriculture (see instructions). Enter the name, city, and state of the college or university: An organization that normally receives (1) more than 331/3% of its support from contributions, membership fees, and gross 10 receipts from activities related to its exempt functions, subject to certain exceptions; and (2) no more than 331/3 % of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See section 509(a)(2). (Complete Part III.) An organization organized and operated exclusively to test for public safety. See section 509(a)(4). 11 An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes 12 of one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2). See section 509(a)(3). Check the box in lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g. Type I. A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization. You must complete Part IV, Sections A and B. Type II. A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s). You must complete Part IV, Sections A and C. Type III functionally integrated. A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions). You must complete Part IV. Sections A. D. and E. d Type III non-functionally integrated. A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions). You must complete Part IV, Sections A and D, and Part V. Check this box if the organization received a written determination from the IRS that it is a Type II, Type III, Type III, functionally integrated, or Type III non-functionally integrated supporting organization. Provide the following information about the supported organization(s). (i) Name of supported organization (ii) EIN (iii) Type of organization (iv) Is the organization (v) Amount of monetary (vi) Amount of (described on lines 1-10 listed in your governing support (see other support (see above (see instructions)) instructions) instructions) document? Yes No (A) (B) (C) (D) (E) Total

Schedule A (Form 990 or 990-EZ) 2020 Page **2** 

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) 2016	<b>(b)</b> 2017	(c) 2018	<b>(d)</b> 2019	(e) 2020	(f) Total
1	Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	749,944.	662,523.	602,587.	705,872.	723,260.	3,444,186.
2	Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						0.
3	The value of services or facilities furnished by a governmental unit to the organization without charge						0.
4	Total. Add lines 1 through 3	749,944.	662,523.	602,587.	705,872.	723,260.	3,444,186.
5	The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f)						0.
6	Public support. Subtract line 5 from line 4						3,444,186.
Sec	tion B. Total Support						<u> </u>
Cale	ndar year (or fiscal year beginning in)	(a) 2016	<b>(b)</b> 2017	(c) 2018	<b>(d)</b> 2019	<b>(e)</b> 2020	(f) Total
7	Amounts from line 4	749,944.	662,523.	602,587.	705,872.	723,260.	3,444,186.
8	Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources	303.	554.	1,956.	1,696.	1,046.	5,555.
9	Net income from unrelated business activities, whether or not the business is regularly carried on						0.
10	Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						0.
11	Total support. Add lines 7 through 10						3,449,741.
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 tion C. Computation of Public Sup	<u> </u>		l, third, fourth,	or fifth tax yea	ar as a section	501(c)(3)
	Public support percentage for 2020 (li	•		11 solumn (f))		14	99.84%
14	Public support percentage for 2020 (iii  Public support percentage from 2019			, ,		15	99.77%
15	331/3% support test - 2020. If the org						
	box and <b>stop here</b> . The organization q <b>33</b> 1/3% <b>support test - 2019</b> . If the org	ualifies as a pub	olicly supported	organization			<b>&gt;</b> X
	this box and <b>stop here.</b> The organization	on qualifies as a	publicly suppor	ted organizatio	n		▶ □
17a	10%-facts-and-circumstances test - 2	<b>2020.</b> If the org	ganization did no	ot check a box	on line 13, 16	a, or 16b, and I	ine 14 is
	10% or more, and if the organization	n meets the fac	cts-and-circumst	ances test, che	eck this box ar	nd <b>stop here.</b> E	xplain in
	Part VI how the organization meets organization						▶ □
b	10%-facts-and-circumstances test - 2						
	15 is 10% or more, and if the organization						•
	in Part VI how the organization meets organization						▶ □
18	<b>Private foundation.</b> If the organization instructions						

Schedule A (Form 990 or 990-EZ) 2020 Page 3

#### Support Schedule for Organizations Described in Section 509(a)(2) Part III

(Complete only if you checked the box on line 10 of Part I or if the organization failed to qualify under Part II.

Sec	tion A. Public Support	any anaon ale	, todio nateu be	Jiow, picase C	ompicio i ait	··· <i>,</i>	
	ndar year (or fiscal year beginning in)	(a) 2016	<b>(b)</b> 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
_		(4) 2010	(3) 2017	(0) 2010	(4) 2013	(3) 2020	(1) 10(a)
1	Gifts, grants, contributions, and membership fees						
2	received. (Do not include any "unusual grants.")  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						
2							
3	Gross receipts from activities that are not an						
4	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		1		+		
7 a	Amounts included on lines 1, 2, and 3						
h	received from disqualified persons		1		+		
D	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						
0							
500	tion B. Total Support						
	ndar year (or fiscal year beginning in)	(a) 2016	<b>(b)</b> 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
	· · · · · · · · · · · ·	(4) 2010	(6) 2017	(6) 2010	(a) 2010	(6) 2020	(i) rotai
9 10 a	Amounts from line 6. Gross income from interest, dividends,						
	payments received on securities loans,						
	rents, royalties, and income from similar						
h	Unrelated business taxable income (less						
Б	section 511 taxes) from businesses						
	acquired after June 30, 1975						
_	Add lines 10a and 10b						
11	Net income from unrelated business						
•••	activities not included in line 10b. whether						
	,						
4.5	or not the business is regularly carried on.		+		+		
12	Other income. Do not include gain or						
	loss from the sale of capital assets						
13	(Explain in Part VI.)  Total support. (Add lines 9, 10c, 11,						
13	and 12.)						
14	First 5 years. If the Form 990 is for	the organizati	ion's first secon	d third fourth	or fifth tay w	ear as a section	501(c)(3)
	organization, check this box and <b>stop here</b> .	~			•		
Sec	tion C. Computation of Public Supp						
15	Public support percentage for 2020 (line 8,		-	ımn (f))		15	%
16	Public support percentage from 2019 Sched		•			16	% %
	tion D. Computation of Investment						70
<u> </u>	Investment income percentage for 2020 (lin			13. column (f))		17	%
18	Investment income percentage for 2020 (iiii						% %
	331/3% support tests - 2020. If the org						
. <i>3</i> a	17 is not more than 331/3%, check this						
h	331/3% support tests - 2019. If the orga	-	-	•			<del></del>
b	line 18 is not more than 331/3%, check						
20	Private foundation. If the organization di		•	•			<del></del>
		,		, , ,			

Schedule A (Form 990 or 990-EZ) 2020 Page **4** 

#### 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

- 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.

  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 or 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 or 990-EZ).
- 8 Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).
- 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 in 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 in 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.
  - 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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DYSTROPHIC EPIDERMOLYSIS BULLOSA 11-2519726 Schedule A (Form 990 or 990-EZ) 2020 Page 5 Part IV **Supporting Organizations** (continued) Yes No Has the organization accepted a gift or contribution from any of the following persons? a A person who directly or indirectly controls, either alone or together with persons described in lines 11b and 11c below, the governing body of a supported organization? 11a 11b **b** A family member of a person described in line 11a above? c A 35% controlled entity of a person described in line 11a or 11b above? If "Yes" to line 11a, 11b, or 11c, provide detail in Part VI. 11c Section B. Type I Supporting Organizations Yes No 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 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 Section C. Type II Supporting Organizations Yes No 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 Section D. All Type III Supporting Organizations Yes No 1 Did the organization provide to each of its supported organizations, by the last day of the fifth month of the organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the organization's governing documents in effect on the date of notification, to the extent not previously provided? 1 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 By reason of the relationship described in 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 Section E. Type III Functionally Integrated Supporting Organizations Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions). The organization satisfied the Activities Test. Complete line 2 below. а b The organization is the parent of each of its supported organizations. Complete line 3 below. The organization supported a governmental entity. Describe in Part VI how you supported a governmental entity (see instructions). C Yes No Activities Test. Answer lines 2a and 2b below. 2 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 in 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 Parent of Supported Organizations. Answer lines 3a and 3b below. a Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? If "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.

Schedule A (Form 990 or 990-EZ) 2020 Page **6** 

Part V Type III Non-Fund	ctionally Integrated 509(a)(3) Supporting Orga	nizations	<u> </u>	. age 🗸
	nization satisfied the Integral Part Test as a qualifyin			in in <b>Part VI</b> ). <b>See</b>
	Type III non-functionally integrated supporting organ			
Section A - Adjusted Net Inco	me		(A) Prior Year	(B) Current Year (optional)
1 Net short-term capital gain		1		
2 Recoveries of prior-year dis	stributions	2		
3 Other gross income (see in	structions)	3		
4 Add lines 1 through 3.		4		
5 Depreciation and depletion		5		
	ses paid or incurred for production or collection of ement, conservation, or maintenance of property ne (see instructions)	6		
7 Other expenses (see instru	·	7		
8 Adjusted Net Income (sub	tract lines 5, 6, and 7 from line 4)	8		
Section B - Minimum Asset Ar	nount		(A) Prior Year	(B) Current Year (optional)
	e of all non-exempt-use assets (see ar or assets held for part of year):			
a Average monthly value of s	ecurities	1a		
<b>b</b> Average monthly cash bala	nces	1b		
c Fair market value of other r	on-exempt-use assets	1c		
d Total (add lines 1a, 1b, and	1c)	1d		
e Discount claimed for block	age or other factors (explain in detail in Part VI):	1e		
2 Acquisition indebtedness a	pplicable to non-exempt-use assets	2		
3 Subtract line 2 from line 1d		3		
4 Cash deemed held for exercise instructions).	mpt use. Enter 0.015 of line 3 (for greater amount,	4		
5 Net value of non-exempt-us	se assets (subtract line 4 from line 3)	5		
6 Multiply line 5 by 0.035.		6		
7 Recoveries of prior-year dis	stributions	7		
8 Minimum Asset Amount (a	add line 7 to line 6)	8		
Section C - Distributable Amo	unt			Current Year
1 Adjusted net income for pr	or 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 lin	• • • • • • • • • • • • • • • • • • • •	4		
5 Income tax imposed in prio	r year	5		
6 Distributable Amount. Sub	tract line 5 from line 4, unless subject to			
emergency temporary redu		6		
7 Check here if the curre	ent year is the organization's first as a non-functional	lly integra	ted Type III supporting	g organization
(see instructions).		-		

Schedule A (Form 990 or 990-EZ) 2020

Schedule A (Form 990 or 990-EZ) 2020 Page **7** 

Part	Type III Non-Functionally Integrated 509(a)(3)	Supporting Organizat	ions (continued)		-
Secti	on D - Distributions				Current Year
1	Amounts paid to supported organizations to accomplish ex	kempt purposes		1	
2	Amounts paid to perform activity that directly furthers exer	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 <b>Part VI</b> )		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 2020 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) Underdistribution Pre-2020	ıs	(iii) Distributable Amount for 2020
1	Distributable amount for 2020 from Section C, line 6				
2	Underdistributions, if any, for years prior to 2020				
	(reasonable cause required - explain in Part VI). See				
	instructions.				
3	Excess distributions carryover, if any, to 2020				
а	From 2015				
b	From 2016				
С	From 2017				
d	From 2018				
е	From 2019				
f	Total of lines 3a through 3e				
g	Applied to underdistributions of prior years				
h	Applied to 2020 distributable amount				
i	Carryover from 2015 not applied (see instructions)				
j	Remainder. Subtract lines 3g, 3h, and 3i from line 3f.				
4	Distributions for 2020 from				
	Section D, line 7: \$				
а	Applied to underdistributions of prior years				
b	Applied to 2020 distributable amount				
С	Remainder. Subtract lines 4a and 4b from line 4.				
5	Remaining underdistributions for years prior to 2020, if				
	any. Subtract lines 3g and 4a from line 2. For result				
	greater than zero, explain in <b>Part VI.</b> See instructions.				
6	Remaining underdistributions for 2020. Subtract lines 3h				
	and 4b from line 1. For result greater than zero, explain in				
	Part VI. See instructions.				
7	Excess distributions carryover to 2021. Add lines 3j				
	and 4c.				
8	Breakdown of line 7:				
а	Excess from 2016				
b	Excess from 2017				
С	Excess from 2018				
d	Excess from 2019				
е	Excess from 2020				

Schedule A (Form 990 or 990-EZ) 2020

DYSTROPHIC EPIDERMOLYSIS BULLOSA

11-2519726

Schedule A (Form 990 or 990-EZ) 2020

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

Schedule A (Form 990 or 990-EZ) 2020

Schedule B (Form 990, 990-EZ, or 990-PF) Department of the Treasury Schedule of Contributors

► Attach to Form 990, Form 990-EZ, or Form 990-PF.

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

OMB No. 1545-0047

**2020** 

Internal Revenue Service **Employer identification number** Name of the organization DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA 11-2519726 Organization type (check one): Filers of: Section: X Form 990 or 990-EZ 501(c)(3 ) (enter number) organization 4947(a)(1) nonexempt charitable trust not treated as a private foundation 527 political organization Form 990-PF 501(c)(3) exempt private foundation 4947(a)(1) nonexempt charitable trust treated as a private foundation 501(c)(3) taxable private foundation Check if your organization is covered by the General Rule or a Special Rule. Note: Only a section 501(c)(7), (8), or (10) organization can check boxes for both the General Rule and a Special Rule. See instructions. **General Rule** For an organization filing Form 990, 990-EZ, or 990-PF that received, during the year, contributions totaling \$5,000 or more (in money or property) from any one contributor. Complete Parts I and II. See instructions for determining a contributor's total contributions. **Special Rules** [X] For an organization described in section 501(c)(3) filing Form 990 or 990-EZ that met the 33 1/3% support test of the regulations under sections 509(a)(1) and 170(b)(1)(A)(vi), that checked Schedule A (Form 990 or 990-EZ), Part II, line 13, 16a, or 16b, and that received from any one contributor, during the year, total contributions of the greater of (1) \$5,000; or (2) 2% of the amount on (i) Form 990, Part VIII, line 1h; or (ii) Form 990-EZ, line 1. Complete Parts I and II. For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, total contributions of more than \$1,000 exclusively for religious, charitable, scientific, literary, or educational purposes, or for the prevention of cruelty to children or animals. Complete Parts I (entering "N/A" in column (b) instead of the contributor name and address), II, and III. For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions exclusively for religious, charitable, etc., purposes, but no such contributions totaled more than \$1,000. If this box is checked, enter here the total contributions that were received during the year for an exclusively religious, charitable, etc., purpose. Don't complete any of the parts unless the General Rule applies to this organization because it received nonexclusively religious, charitable, etc., contributions 

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

Schedule B (Form 990, 990-EZ, or 990-PF) (2020)

Name of organization DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA

Employer identification number 11-2519726

Part I Contributors (see instructions). Use duplicate copies of Part I if additional space is need	ded.
--	------

(a)	(b)	(c) Total contributions	(d) Type of contribution
No.	Name, address, and ZIP + 4	Total contributions	
1	JOHN LEE  555 MONTGOMERY ST SUITE 603	\$	Person X Payroll Noncash
	SAN FRANCISCO, CA 94111		(Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
2	J ALEXANDER		Person X
	3398 HARBOUR POINT PARKWAY	\$105,200.	Payroll Noncash
	GAINSVILLE, GA 30506		(Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
3	MR JOHNNY MCCRANIE		Person X
	HOLIDAY PROPERTIES	\$20,000.	Payroll Noncash
	VALDOSTA, GA 31604		(Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
4	FIBROCELL SCIENCE		Person
	405 EAGLEVIEW BLVD	\$110,000.	Payroll Noncash
	EXTON, PA 19341		(Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
5_	FACEBOOK		Person X
	1601 WILLOW RD	\$32,997.	Payroll Noncash
	MENLO PARK, CA 94025		(Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
6	KRYSTAL BIOTECH INC		Person
	2100 WHARTON ST, SUITE 701	\$\$	Payroll Noncash
	PITTSBURGH, PA 15203		(Complete Part II for noncash contributions.)

Schedule B (Form 990, 990-EZ, or 990-PF) (2020)

Page 2

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

Part I	Contributors (see instructions). Use duplicate copi	ies of Part I if additional space is ne	eeded.
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
7	ABEONA THERAPEUTICS INC  333 LEE PARKWAY, SUITE 600  DALLAS, TX 75219	\$\$	Person Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
8	MOLNLYCKE & OTHERS  5445 TRIANGLE PARKWAY  PEACHTREE CORNERS, GA 30092	\$ \$ 464,342.	Person Payroll Noncash  (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		\$	Person Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		\$	Person Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		\$	Person Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		\$	Person Payroll Noncash (Complete Part II for noncash contributions.)

Schedule B (Form 990, 990-EZ, or 990-PF) (2020)

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

(a) No. from	(b)	(c) FMV (or estimate)	(d)
Part I	Description of noncash property given	(See instructions.)	Date received
	DONATED MEDICAL SUPPLIES AND BANDAGES		
		\$\$	12/01/2020
) No. rom art I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
		\$	
) No. rom art I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
		\$	
) No. rom art I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
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) No. om art I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
		_	
		\$	
) No. rom art I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
		<sub>\$</sub>	

Name of organization DYSTROPHIC EPIDERMOLYSIS BULLOSA

Employer identification number

Schedule B (Form 990, 990-EZ, or 990-PF) (2020)

	RESEARCH ASSOCIATION O	F AMERICA		11-2519726
Part III	(10) that total more than \$1,000 for the following line entry. For organization contributions of \$1,000 or less for the Use duplicate copies of Part III if additional contributions of \$1,000 or less for the Use duplicate copies of Part III if additional contributions of \$1,000 or less for the Use duplicate copies of Part III if additional contributions of \$1,000 or less for the Use duplicate copies of Part III if additional contributions of \$1,000 or less for the Use duplicate copies of Part III if additional contributions of \$1,000 or less for the Use duplicate copies of Part III if additional contributions of \$1,000 or less for the Use duplicate copies of Part III if additional contributions of \$1,000 or less for the Use duplicate copies of Part III if additional contributions of \$1,000 or less for the Use duplicate copies of Part III if additional contributions of \$1,000 or less for the Use duplicate copies of Part III if additional contributions of \$1,000 or less for the Use duplicate copies of Part III if additional contributions of \$1,000 or less for the Use duplicate copies of Part III if additional contributions of \$1,000 or less for the Use duplicate copies of Part III if additional contributions of \$1,000 or less for the Use duplicate copies of Part III if additional contributions of \$1,000 or less for the Use duplicate copies of Part III if additional contributions of \$1,000 or less for the Use duplicate copies of Part III if additional contributions of \$1,000 or less for the Use duplicate copies of Part III if additional contributions of \$1,000 or less for the Use duplicate copies of Part III if additional contributions of \$1,000 or less for the Use duplicate copies of Part III if additional contributions of \$1,000 or less for the Use duplicate copies of Part III if additional contributions of \$1,000 or less for the Use duplicate copies of Part III if additional contributions of \$1,000 or less for the Use duplicate copies of Part III if additional contributions of \$1,000 or less for the Use duplicat	the year from any ions completing Pari e year. (Enter this in	one contributor. Contributor. Contributor. Contributors on the total contributors on the contributors of t	complete columns (a) through (e) and of exclusively religious, charitable, etc.
(a) No. from Part I	(b) Purpose of gift	(c) Use	of gift	(d) Description of how gift is held
	Transferee's name, address, an	(e) Transf	-	ship of transferor to transferee
(a) No. from Part I	(b) Purpose of gift	(c) Use	of gift	(d) Description of how gift is held
	Transferee's name, address, an	(e) Transf nd ZIP + 4	-	ship of transferor to transferee
(a) No. from Part I	(b) Purpose of gift	(c) Use	of gift	(d) Description of how gift is held
	Transferee's name, address, an	(e) Transf nd ZIP + 4		ship of transferor to transferee
(a) No. from Part I	(b) Purpose of gift	(c) Use	of gift	(d) Description of how gift is held
	Transferee's name, address, an	(e) Transf nd ZIP + 4		ship of transferor to transferee
(a) No.	(b) Purpose of gift  Transferee's name, address, an  (b) Purpose of gift	(c) Use  (e) Transf	of gift Relation Relation of gift Relation of gift	(d) Description of how gift is held

# SCHEDULE D (Form 990)

Department of the Treasury Internal Revenue Service

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

► 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

2020

Open to Public Inspection

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

RES	SEARCH ASSOCIATION OF AMERICA		11-2519726
Pa	organizations Maintaining Donor Advised Funds or Other S		or Accounts.
	Complete if the organization answered "Yes" on Form 990, P		
	(a) Donor advise	ed funds	(b) Funds and other accounts
1	Total number at end of year		
2	Aggregate value of contributions to (during year)		
3	Aggregate value of grants from (during year)		
4	Aggregate value at end of year		
5	Did the organization inform all donors and donor advisors in writing that	t the assets held	d in donor advised
	funds are the organization's property, subject to the organization's exclusive	e legal control?	Yes 🔛 No
6	Did the organization inform all grantees, donors, and donor advisors in wi	riting that grant	funds can be used
	only for charitable purposes and not for the benefit of the donor or dono	r advisor, or for	any other purpose
	conferring impermissible private benefit?	<u> </u>	Yes No
Pa	art II Conservation Easements.		
	Complete if the organization answered "Yes" on Form 990, P		
1	Purpose(s) of conservation easements held by the organization (check all the		
	Preservation of land for public use (for example, recreation or education)		n of a historically important land area
	Protection of natural habitat	Preservation	n of a certified historic structure
_	Preservation of open space		
2	Complete lines 2a through 2d if the organization held a qualified conservat	ion contribution i	
	easement on the last day of the tax year.		Held at the End of the Tax Year
а	Total number of conservation easements		2a
b	Total acreage restricted by conservation easements		2b
С.	Number of conservation easements on a certified historic structure include		2c
d	Number of conservation easements included in (c) acquired after 7/25/06		
_	historic structure listed in the National Register		2d
3	Number of conservation easements modified, transferred, released, extin	iguisnea, or tern	ninated by the organization during the
,	tax year ▶ Number of states where property subject to conservation easement is locat	tad N	
4 5	Does the organization have a written policy regarding the periodic me		etion handling of
J	violations, and enforcement of the conservation easements it holds?		-
6	Staff and volunteer hours devoted to monitoring, inspecting, handling of violation		
U	Stair and volunteer nours devoted to monitoring, inspecting, nanding of violatic	Jis, and emorcing	g conservation easements during the year
7	Amount of expenses incurred in monitoring, inspecting, handling of violation	s and enforcing	conservation easements during the year
•	►\$	o, and omoromy	oonoorvation casemonia daning the year
8	Does each conservation easement reported on line 2(d) above satisfy the req	uirements of sec	tion 170(h)(4)(B)(i)
-	and section 170(h)(4)(B)(ii)?		
9	In Part XIII, describe how the organization reports conservation easements		
	balance sheet, and include, if applicable, the text of the footnote to the org		
	organization's accounting for conservation easements.		
Pa	art III Organizations Maintaining Collections of Art, Historical Tre		er Similar Assets.
	Complete if the organization answered "Yes" on Form 990, P	art IV, line 8.	
1a	If the organization elected, as permitted under FASB ASC 958, not to re of art, historical treasures, or other similar assets held for public exhibit	port in its reven	ue statement and balance sheet works
	of art, historical treasures, or other similar assets held for public exhibs service, provide in Part XIII the text of the footnote to its financial statement	oition, education to that describes	, or research in furtherance of public
b	If the organization elected, as permitted under FASB ASC 958, to repor		
	art, historical treasures, or other similar assets held for public exhibition, provide the following amounts relating to these items:	education, or re-	search in furtherance of public service,
	(i) Revenue included on Form 990, Part VIII, line 1		
	(ii) Assets included in Form 990, Part X		▶\$
2	If the organization received or held works of art, historical treasures,		
	following amounts required to be reported under FASB ASC 958 relating to		
а	Revenue included on Form 990, Part VIII, line 1		
b	Assets included in Form 990, Part X		▶ \$

DocuSign Envelope ID: 51BE8100-5268-4A4C-9C0C-8985F053A364 DYSTROPHIC EPIDERMOLYSIS BULLOSA 11-2519726 Schedule D (Form 990) 2020 Page 2 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): а Public exhibition Loan or exchange program 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? . . . . . . Yes 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? Yes No If "Yes," explain the arrangement in Part XIII and complete the following table: Amount 1c Distributions during the year 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. Part V **Endowment Funds.** Complete if the organization answered "Yes" on Form 990, Part IV, line 10. (c) Two years back (a) Current year (b) Prior year (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 **b** 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)

44,082.

37,834.

Schedule D (Form 990) 2020

6,248

6,248.

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) 2020 Page **3** 

Concadio D (1 offil 330) 2020			i age (
Part VII Investments - Other Securities.	"Vos" on Form 000	Part IV line 11h See Form 000	Part V line 12
Complete if the organization answered  (a) Description of security or category	(b) Book value	(c) Method of valuati	
(including name of security)	(b) Book value	Cost or end-of-year market	
(1) Financial derivatives			
(2) Closely held equity interests			
(3) Other	250 000	COCH	
(A) PREFERRED STOCK	250,000.	COST	
(B)			
(C) (D)			
(E)			
(F)			
(G)			
(H)			
Total. (Column (b) must equal Form 990, Part X, col. (B) line 12.)	250,000.		
Part VIII Investments - Program Related. Complete if the organization answered	"Yes" on Form 990	, Part IV, line 11c. See Form 990,	Part X, line 13.
(a) Description of investment	(b) Book value	(c) Method of valuation	
		Cost or end-of-year marke	et value
(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	"Yes" on Form 990	, Part IV, line 11d. See Form 990,	Part X, line 15.
(a) Des	scription		(b) Book value
<u>(1)</u>			
_(2)			
_(3)			
(4)			
(5)			
(6)			
<u>(7)</u>			
(8) (9)			
Total. (Column (b) must equal Form 990, Part X, col. (B) lin	ne 15.)	<b>•</b>	
Part X Other Liabilities. Complete if the organization answered line 25.			m 990, Part X,
1. (a) Descript	tion of liability		(b) Book value
(1) Federal income taxes	· · · · · · · · · · · · · · · · · · ·		
(2) AGENCY FUNDS HELD FOR OTHERS			
(3)			
(4)			
(5)			
(6)			
(7)			
(8)			
(9)			
Total. (Column (b) must equal Form 990, Part X, col. (B) line 25.)		<u></u>	
2 Liability for uncertain tay positions. In Part VIII, provide the	tout of the feetnets to t	the erganization's financial etatements th	at ranaria tha

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) 2020

DYSTROPHIC EPIDERMOLYSIS BULLOSA

Schedule D (Form 990) 2020 Page 4 Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per Return. Complete if the organization answered "Yes" on Form 990, Part IV, line 12a. 2,510,143. 1 2 Amounts included on line 1 but not on Form 990, Part VIII, line 12: 138,689 495,605 2c c Recoveries of prior year grants............ d Other (Describe in Part XIII.) 634,294. 2e 1,875,849. 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 . . . . . . . **b** Other (Describe in Part XIII.) 4c 1,875,849. Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.) . . . . . 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. 1,950,640. 1 2 Amounts included on line 1 but not on Form 990. Part IX. line 25: 321,679 2a 2c c Other losses....... d Other (Describe in Part XIII.) 321,679. 2e 1,628,961. 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.) 1,628,961. Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.). . . . . . Part XIII Supplemental Information. Provide the descriptions required for Part II, lines 3, 5, and 9; Part III, lines 1a and 4; Part IV, lines 1b and 2b; Part V, line 4; Part X, line 2; Part XI, lines 2d and 4b; and Part XII, lines 2d and 4b. Also complete this part to provide any additional information. SCHEDULE D PART X LINE 2 THE ORGANIZATION RECOGNIZES THE EFFECT OF TAX POSITIONS ONLY WHEN THEY ARE MORE LIKELY THAN NOT OF BEING SUSTAINED. MANAGEMENT HAS DETERMINED THAT THE ORGANIZATION HAD NO UNCERTAIN TAX POSITIONS THAT WOULD REQUIRE FINANCIAL STATEMENT RECOGNITION. THE THREE PREVIOUS TAX YEARS REMAIN OPEN TO EXAMINATION BY FEDERAL AND STATE AUTHORITIES.

Schedule D (Form 990) 2020 DYSTROPHIC EPIDERMOLYSIS BULLOSA

11-2519726

Page 5

Part XIII Supplemental Information (continued)

#### **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 Open to Public Inspection

Department of the Treasury Internal Revenue Service Name of the organization

DYSTROPHIC EPIDERMOLYSIS BULLOSA

Employer identification number

RESE	EARCH ASSOCIATION OF A	MERICA	.212 20220		11-25197	26
Part	General Information o	n Activities	Outside the	United States. Comple		
4	Form 990, Part IV, line 14		ntoin rocardo	to outoutinto the amou	unt of its growts and	
	For grantmakers. Does the orgother assistance, the grantees' award the grants or assistance?	eligibility for t	he grants or	assistance, and the selec	ction criteria used to	Yes No
	For grantmakers. Describe in loutside the United States.	Part V the org	anization's pro	ocedures for monitoring t	the use of its grants an	d other assistance
3	Activities per Region. (The follow	ving Part I, line		duplicated if additional sp	ace is needed.)	
	(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in the region	(d) Activities conducted in the region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in the region	(f) Total expenditures for and investments in the region
(1)						
(2)						
(3)						
(4)						
(5)						
(6)						
(7)						
(8)						
(9)						
(10)						
(11)						
(12)						
(13)						
(14)						
(15)						
(16)						
(17)						
3a						
b	Total from continuation sheets to Part I					

Totals (add lines 3a and 3b)

DYSTROPHIC EPIDERMOLYSIS BULLOSA

Schedule F (Form 990) 2020

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, oth
(1)			EUROPE/ICELAND/GREENLAND	TO FUND INTE	53,454.	CASH TRANSFE		NONE	FMV
(2)			CENT. AMERICA/CARIBBEAN	TO FUND INTE	27,000.	CASH TRANSFE		NONE	FMV
(3)									
(4)									
(5)									
(6)									
(7)									
(8)									
(9)									
0)									
1)									
2)									
3)									
4)									
5)									
16)									

DYSTROPHIC EPIDERMOLYSIS BULLOSA

Schedule F (Form 990) 2020

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	<b>(d)</b> 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)							
<b>(7)</b>							
(8)							
(9)							
(10)							
(11)							
(12)							
(13)							
(14)							
(15)							
(16)							
(17)							
(18)							

Schedule F (Form 990) 2020

DYSTROPHIC EPIDERMOLYSIS BULLOSA 11-2519726

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)	<b></b> ,	Yes	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	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			77	
	Certain Foreign Corporations (see Instructions for Form 5471)	Ш '	Yes	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	X	No
	, , , , , , , , , , , , , , , , , , ,		103		
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	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	X	No

Schedule F (Form 990) 2020

Page 4

DYSTROPHIC EPIDERMOLYSIS BULLOSA

Schedule F (Form 990) 2020 Page 5

Part V

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

11-2519726

Schedule F (Form 990) 2020

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

Department of the Treasury

#### 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 Open to Public

Yes

Inspection Internal Revenue Service DYSTROPHIC EPIDERMOLYSIS BULLOSA Employer identification number RESEARCH ASSOCIATION OF AMERICA 11-2519726 Fundraising Activities. Complete if the organization answered "Yes" on Form 990, Part IV, line 17. Form 990-EZ filers are not required to complete this part. 1 Indicate whether the organization raised funds through any of the following activities. Check all that apply. Mail solicitations Solicitation of non-government grants а Internet and email solicitations f Solicitation of government grants Phone solicitations Special fundraising events C In-person solicitations d 2a Did the organization have a written or oral agreement with any individual (including officers, directors, trustees,

b If "Yes," list the 10 highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization.

or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services?

	(i) Name and address of individual or entity (fundraiser)	(ii) Activity	(iii) Did fundraiser have custody or control of contributions?		(iv) Gross receipts from activity	(v) Amount paid to (or retained by) fundraiser listed in col. (i)	(vi) Amount paid to (or retained by) organization
			Yes	No			
1							
2							
3							
4							
5							
6							
7							
8							
9							
10							
Total				▶			
	List all states in which the organiza registration or licensing.	tion is registered o	r licensed	I to solicit	contributions or	has been notified	it is exempt from

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

Schedule G (Form 990 or 990-EZ) 2020

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Pa	irt i	more than \$15,000 of fundra events with gross receipts gre	aising event contributi			
			(a) Event #1 OTHER EVENTS	(b) Event #2	(c) Other events	(d) Total events (add col. (a) through
a)			(event type)	(event type)	(total number)	col. <b>(c)</b> )
Revenue	1	Gross receipts	1,032,492.			1,032,492
ď		Less: Contributions Gross income (line 1 minus	25,000.			25,000
		line 2)	1,007,492.			1,007,492
	4	Cash prizes				
"	5	Noncash prizes				
<b>Direct Expenses</b>	6	Rent/facility costs				
ct Exp	7	Food and beverages				
Dire	8	Entertainment				
	9	Other direct expenses	99,635.			99,635
	10 11	Direct expense summary. Add lin Net income summary. Subtract li	es 4 through 9 in colu ne 10 from line 3, colu	mn (d) ımn (d)		99,635 907,857
Pa	rt	Gaming. Complete if the org \$15,000 on Form 990-EZ, lin		Yes" on Form 990, F	Part IV, line 19, or	reported more than
Φ		\$13,000 0111 01111 330-LZ, 1111		(b) Pull tabs/instant	(-) Othi	(d) Total gaming (add
Revenue			(a) Bingo	bingo/progressive bingo	(c) Other gaming	col. (a) through col. (c))
Şe						
_	1	Gross revenue				
nses	2	Cash prizes				
Expenses	3	Noncash prizes				
Direct	4	Rent/facility costs				
	5	Other direct expenses				
	6	Volunteer labor	Yes % No	Yes% No	Yes% No	
	7	Direct expense summary. Add lin	es 2 through 5 in colu	mn (d)		
	8	Net gaming income summary. Su	ubtract line 7 from line	1, column (d)		
9 8	a D	Enter the state(s) in which the orgalis the organization licensed to con If "No," explain:		in each of these state		Yes No
10a	a )	Were any of the organization's gaming If "Yes," explain:	g licenses revoked, susp			Yes No

### DYSTROPHIC EPIDERMOLYSIS BULLOSA

Sched	lule G (Form 990 or 990-EZ) 2020 Page <b>3</b>											
11	Does the organization conduct gaming activities with nonmembers? Yes No											
12	Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity											
	formed to administer charitable gaming?											
13	Indicate the percentage of gaming activity conducted in:											
а	The organization's facility											
b	An outside facility											
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?											
b	If "Yes," enter the amount of gaming revenue received by the organization ▶ \$ and the											
-	amount of gaming revenue retained by the third party > \$											
С	If "Yes," enter name and address of the third party:											
	Name ▶											
	Address ►											
16	Gaming manager information:											
	Name ▶											
	Gaming manager compensation ▶\$											
	Description of services provided ▶											
	Director/officer Employee Independent contractor											
17	Mandatory distributions:											
а	Is the organization required under state law to make charitable distributions from the gaming proceeds to											
	retain the state gaming license?											
b	Enter the amount of distributions required under state law to be distributed to other exempt organizations											
	or spent in the organization's own exempt activities during the tax year  \$											
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 Information**For certain Officers, Directors, Trustees, Key Employees, and Highest **Compensated Employees** 

► Complete if the organization answered "Yes" on Form 990, Part IV, line 23.

Attach to Form 990. ► Go to www.irs.gov/Form990 for instructions and the latest information. **Open to Public** Inspection

OMB No. 1545-0047

Department of the Treasury Internal Revenue Service Name of the organization

DYSTROPHIC EPIDERMOLYSIS BULLOSA

RESEARCH ASSOCIATION OF AMERICA

Employer identification number 11-2519726

Part	Questions Regarding Compensation			
			Yes	No
1a	Check the appropriate box(es) if the organization provided any of the following to or for a person listed on Form			
	990, Part VII, Section A, line 1a. Complete Part III to provide any relevant information regarding these items.			
	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			
	explain	1b		
2	Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all			
	directors, trustees, and officers, including the CEO/Executive Director, regarding the items checked on line			
	1a?	2		
3	Indicate which, if any, of the following the organization used to establish the compensation of the			
	organization's CEO/Executive Director. Check all that apply. Do not check any boxes for methods used by a related organization to establish compensation of the CEO/Executive Director, but explain in Part III.			
	X   Compensation committee   Written employment contract   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	Receive a severance payment or change-of-control payment?	4a		Х
b	Participate in or receive payment from a supplemental nonqualified retirement plan?	4b		Х
c	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		X
	If "Yes" on line 5a or 5b, describe in Part III.			
6	For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any			
	compensation contingent on the net earnings of:			
а	The organization?	6a		X
b	Any related organization?	6b		Х
	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	_		v
	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			Х
9	in Part III	8		Λ
3	Regulations section 53.4958-6(c)?	9		
	109616410110001000100000(0).	J		

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

Schedule J (Form 990) 2020

11-2519726

Schedule J (Form 990) 2020

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.

		(B) Breakdown of	f W-2 and/or 1099-MI	SC compensation	(C) Retirement and	(D) Nontaxable	(E) Total of columns	(F) Compensation in column (B) reported
(A) Name and Title		(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)	0.	0.					
1EXECUTIVE DIRECTOR	(ii)	261,529.	0.	0.			261,529.	
	(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)							
								adula 1/Farm 000) 2020

DYSTROPHIC EPIDERMOLYSIS BULLOSA 11-2519726

Schedule J (Form 990) 2020

# Part III Supplemental Information

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

# SCHEDULE M (Form 990)

**Noncash Contributions** 

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

Attach to Form 990.

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

OMB No. 1545-0047

2020

Open to Public Inspection

Department of the Treasury Internal Revenue Service

Name of the organization

DYSTROPHIC EPIDERMOLYSIS BULLOSA

Employer identification number

11-2519726

RESEARCH ASSOCIATION OF AMERICA

**Types of Property** (c) (a) (b) (d) Noncash contribution Check if Number of contributions or Method of determining amounts reported on Form 990, Part VIII, line 1g applicable items contributed noncash contribution amounts Art - Works of art 1 Art - Historical treasures 3 Art - Fractional interests Books and publications 5 Clothing and household goods . . . . . . . . . . . . . . . . . 6 Cars and other vehicles 7 Boats and planes Intellectual property Securities - Publicly traded 10 Securities - Closely held stock Securities - Partnership, LLC, 11 or trust interests Securities - Miscellaneous 12 Qualified conservation contribution - Historic structures 14 Qualified conservation contribution - Other 15 Real estate - Residential Real estate - Commercial 16 Real estate - Other 17 18 Collectibles 19 2,500. 464,342. Χ FMV 20 Drugs and medical supplies 21 Taxidermy Historical artifacts 22 Scientific specimens 23 Archeological artifacts 24 Other ▶( LEGAL SERVICES X 31,263. 25 26 Other ►( 27 Other ►( 28 Other ►(

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

Number of Forms 8283 received by the organization during the tax year for contributions for

which the organization completed Form 8283, Part V, Donee Acknowledgement . . . . . . . . . .

29

DYSTROPHIC EPIDERMOLYSIS BULLOSA

Schedule M (Form 990) (2020) Page **2** 

Part II Suppler

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

11-2519726

Schedule M (Form 990) (2020)

JSA

RESEARCH ASSOCIATION OF AMERICA

# **SCHEDULE 0** (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 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.

DYSTROPHIC EPIDERMOLYSIS BULLOSA

11-2519726

**Employer identification number** 

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 AGENCIIES 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 UPOPN WRITTEN REQUEST TO THE EXECUTIVE DIRECTOR.

PART XI LINE 9

VALUE OF DONATED MEDICAL SUPPLIES, LEGAL SERVICES AND DONATED INVENTORY

Schedule O (Form 990 or 990-EZ) 2020 Page 2

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

ATTACHMENT 1

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

DEBRA IS DEDICATED TO FINDING A CURE FOR EBIDERMOLYSIS BULLOSA " EB" WHICH EFFECTS 1 OUT OF EVERY 50,000 LIVE BIRTHS IN THE UNITED STATES TODAY. EB IS A GENETICALLY BASED DISEASE CHARACTERIZED BY CHRONIC, PAINFULL BLISTERING. THE SKIN AND MUCOUS MEMBRANES ARE SO FRAGILE THAT THE SLIGHTEST TOUCH CAN CAUSE SEVERE BLISTERING INSIDE AND OUTSIDE THE BODY. PRESENT AT BIRTH, EB EFFECTS MEN AND WOMEN OF ALL RACES AND ETHNIC GROUPS, AND SOMETIMES, WHEN THERE IS NO FAMILY HISTORY. IT OCCURS AS THE RESULT OF A SPONTANEOUS GENTIC MUTATION. TODAY, THERE IS NO CURE OR TREATMENT FOR EB, EXCEPT DAILY WOUND CARE AND BANDAGING.GENETIC RESEARCH IS MAKING PROGRESS TOWARDS TREATMENTS AND A CURE.

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

DESCRIPTION

GRANTS

EXPENSES

REVENUE

131,160.

TOTALS 131,160.

ATTACHMENT 3

FORM 990, PART X - PREPAID EXPENSES AND DEFERRED CHARGES

DESCRIPTION ENDING
BOOK VALUE

PREPAID EXPENSES 58,958.

TOTALS 58,958.

Schedule O (Form 990 or 990-EZ) 2020 Page 2 DYSTROPHIC EPIDERMOLYSIS BULLOSA Employer identification number Name of the organization RESEARCH ASSOCIATION OF AMERICA 11-2519726 ATTACHMENT 4 FORM 990, PART X - INVESTMENTS - PUBLICLY TRADED SECURITIES COST ENDING DESCRIPTION BOOK VALUE OR FMV MUTUAL FUNDS 833,049. FMV TOTALS 833,049.

Form 4562

# **Depreciation and Amortization**

(Including Information on Listed Property)

Attach to your tax return.

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

20**20** 

OMB No. 1545-0172

Attachment Sequence No. 179

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

DYSTROPHIC EPIDERMOLYSIS BULLOSA

Identifying number 11-2519726

Business or activity to which this form relates GENERAL DEPRECIATION **Election To Expense Certain Property Under Section 179** Part I 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 2019 Form 4562 10 10 Business income limitation. Enter the smaller of business income (not less than zero) or line 5. See instructions 11 11 Section 179 expense deduction. Add lines 9 and 10, but don't enter more than line 11 Carryover of disallowed deduction to 2021. 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 15 2,968 Other depreciation (including ACRS) 16 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 2020 Tax Year Using the General Depreciation System (b) Month and year (c) Basis for depreciation (d) Recovery (e) Convention (g) Depreciation deduction (a) Classification of property (business/investment use (f) Method 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 yrs. 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 2020 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 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

2,968

11-2519726 Form 4562 (2020) Listed Property (Include automobiles, certain other vehicles, Part V certain aircraft, and property used entertainment, recreation, or amusement.) **Note:** For any vehicle for which you are using the standard mileage rate or deducting lease expense, complete **only** 24a, 24b, columns (a) through (c) of Section A, all of Section B, and Section C if applicable. Section A - Depreciation and Other Information (Caution: See the instructions for limits for passenger automobiles.) 24a Do you have evidence to support the business/investment use claimed? Yes No 24b If "Yes," is the evidence written? Yes No (e) (b) (i) Business Basis for depreciation Type of property (list Date placed Recovery Method/ Depreciation Flected section 179 investment use (business/investment vehicles first) Convention deduction cost in service percentage Special depreciation allowance for qualified listed property placed in service during the tax year and used more than 50% in a qualified business use. See instructions 26 Property used more than 50% in a qualified business use: % 27 Property used 50% or less in a qualified business use: S/I -S/L -% S/L -Add amounts in column (h), lines 25 through 27. Enter here and on line 21, page 1. Add amounts in column (i), line 26. Enter here and on line 7, page 1 Section B - Information on Use of Vehicles Complete this section for vehicles used by a sole proprietor, partner, or other "more than 5% owner," or related person. If you provided vehicles to your employees, first answer the questions in Section C to see if you meet an exception to completing this section for those vehicles. (c) (f) Vehicle 1 Vehicle 2 Vehicle 3 Vehicle 4 Vehicle 5 Vehicle 6 Total business/investment miles driven during the year (don't include commuting miles) Total commuting miles driven during the year. other personal (noncommuting) 33 Total miles driven during the year. Add lines 30 through 32 34 Was the vehicle available for personal Yes No Yes No Yes No Yes No Yes No Yes No use during off-duty hours? 35 Was the vehicle used primarily by a more than 5% owner or related person? Is another vehicle available for personal Section C - Questions for Employers Who Provide Vehicles for Use by Their Employees Answer these questions to determine if you meet an exception to completing Section B for vehicles used by employees who aren't more than 5% owners or related persons. See instructions. Yes No 37 Do you maintain a written policy statement that prohibits all personal use of vehicles, including commuting, by your employees? 38 Do you maintain a written policy statement that prohibits personal use of vehicles, except commuting, by your employees? See the instructions for vehicles used by corporate officers, directors, or 1% or more owners 39 Do you treat all use of vehicles by employees as personal use? 40 Do you provide more than five vehicles to your employees, obtain information from your employees about the use of the vehicles, and retain the information received? 41 Do you meet the requirements concerning qualified automobile demonstration use? See instructions Note: If your answer to 37, 38, 39, 40, or 41 is "Yes," don't complete Section B for the covered vehicles. Part VI Amortization (e) (b) (c) (d) Amortization (a) Date amortization Description of costs Amortizable amount Code section Amortization for this year period or begins percentage Amortization of costs that begins during your 2020 tax year (see instructions):

43 Amortization of costs that began before your 2020 tax year

Total. Add amounts in column (f). See the instructions for where to report

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

<sup>\*</sup>Assets Retired

JSA 0X9024 1.000