PDF copy of the signed form to signatureforms@form990.org or fax it to 866-699-3916 Exempt Organization Declaration and Signature for Electronic Filing

Form **8453-E0**

2019

OMB No. 1545-0047

		Treasury	ı	or use	with Fo	rms 9	990, 990-EZ	, 990-P	F, 1120-POL	, and 8868	3		اک ا	913
Name of	the same of the last of the la	organizatio	on								Emp	loyer iden	ntification r	umber
SIEGEL	RARE	NEURO	IMMUNE ASSO	CIATIO	N							9	1-178046	7
Part	1	Type of	Return and	Returr	Inform	natio	n (Whole D	ollars	Only)					
check t	he bo	x on line 2b, 3b,	e type of retu 1a, 2a, 3a, 4 4b, or 5b, whi Do not comp	a, or 5a chever	below is applic	and the	ne amount o blank (do no	n that I	line of the reti	um being f	filed w	rith this	form was	s blank, ther
2a Fo 3a Fo 4a Fo	orm 99 orm 11 orm 99	120-POL 90-PF ch	here ► heck here ► check here ► heck here ► hk here ►	□ b	Total Total Tax b	reven tax (F ased	oue, if any (Fo form 1120-Po on investme	orm 990 OL, line ent inco	0, Part VIII, co 0-EZ, line 9) 22) ome (Form 99	 0-PF, Part	 V1, lir	 ne 5) .	2b 3b	906,729
Part I		Declara	tion of Offic	er										
6	without organial orga	drawal (d nization's st contac I also a mation ne	e U.S. Treasurirect debit) er sederal taxes the U.S. Treatthorize the firecessary to ans	itry to the owed or issury Financial in the swering th	he finan n this ret nancial A nstitution uiries an	cial in turn, a gent a ns invo	estitution accord the finance at 1-888-353- blved in the police issues relative	ount indicated in institution in ins	dicated in the ution to debit to later than 2 ting of the electhe payment.	tax prepa the entry to ousiness da tronic payn	ration this a ays pri nent c	softwar account. or to the of taxes t	re for pay To revok e paymen to receive	e a payment t (settlement confidentia
	990-l	uted the PF (as sp	nis return is be electronic dis ecifically ident	closure ified in F	consent Part I abo	conta ove) to	ined within the selected	his retu state a	rm allowing di gency(ies).	sclosure by	tne i	IKS OT T	nis Form	990/990-62
organiza true, cor return. I to the IF	ation's rect, a conse	2019 ele and comp ant to allo I to recei	rjury, I declare ectronic return elete. I further of the my intermed ve from the IR return or refun	and acc declare t diate ser S (a) an	company that the a vice pro acknow	ring so amoun vider, rledge	chedules and it in Part I about transmitter, of ment of recei	statem ove is the or electr	nents, and, to the amount sho ne amount sho ronic return ori	the best of wn on the gainator (ER	copy (of the org send the	ganization e organiza	n's electronic ation's return
Sign Here) 2	ignature o	of officer	al	lek	4	Date	1/13	124 <u>1</u>	inda Maleci tle	ky, Tre	easurer		-
Part II] D	eclarat	ion of Elect	ronic F	Return	Origi	nator (ERC) and	Paid Prepa	rer (see ir	nstruc	ctions)		
my know on the re informati IRS e-file	vledge. eturn. ion to l e Provi	. If I am of The organized widers for	riewed the about the about the about the about the about the accompanying parer declarations.	, I am no er will ha ed have f rns. If I a	ot respor ave sign followed am also dules ar	ed this all oth the Pa	for reviewing s form before ner requireme aid Preparer, tements, and	the retter I subrents in Punder under to the	mit the return. Pub. 4163, Mod penalties of pe best of my kn	I will give dernized e- erjury I decl nowledge a	the o File (Mare the	fficer a d leF) Infor	copy of a rmation for e examine	all forms and or Authorized ed the above
ERO's	ERO's						Date		Check if also paid preparer	Check if self- employed		O's SSN o	or PTIN	
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Firm's address ▶

Phone no.

Form **990**

Return of Organization Exempt From Income Tax

OMB No. 1545-0047

2019

Open to Public Inspection

Department of the Treasury Internal Revenue Service

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

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

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

A	For the	2019 calend	dar year, or tax year beginning	01/01 , 2019 ,	and endir	ng 12/	<u>3</u> 1	, 20 19		
В	Check if	applicable:	C Name of organization SIEGEL	RARE NEUROIMMUNE ASSOCIA	ATION		D Emple	oyer identification number		
	Address	change	Doing business as					91-1780467		
	Name ch	nange	Number and street (or P.O. box if	f mail is not delivered to street address))	Room/suite	E Teleph	none number		
	Initial ret	urn	1787 Sutter Parkway					855-380-3330		
	Final retu	urn/terminated	City or town, state or province, c	ountry, and ZIP or foreign postal code	•					
	Amende	d return	Powell, OH, 43065				G Gross	receipts \$ 915,426		
	Applicat	ion pending	F Name and address of principal off	ficer: Sanford Siegel		H(a) Is this a g	roup return fo	or subordinates? Yes Vo		
			1787 Sutter Parkway, Powell,	OH 43065		H(b) Are all	subordinat	es included? Tyes No		
ı	Tax-exe	mpt status:	✓ 501(c)(3)) ◀ (insert no.) 4947(a)(1) c	or 527	If "No," attac	ch a list. (s	ee instructions)		
J	Website	: ► www.w	earesrna.org			H(c) Group	exemption	number ►		
K	Form of o	organization: 🗸	Corporation Trust Associa	ation ☐ Other ► L	Year of form	ation: 1996	M State	of legal domicile: WA		
Р	art I	Summa	ry				•			
	1	Briefly des	cribe the organization's miss	ion or most significant activitie	es: TO SU	JPPORT AND A	DVOCAT	E FOR		
é		-	_	GNOSED WITH RARE NEUROIMI						
Activities & Governance			d on Schedule O, Statement 1)							
Jern (2	Check this	box ▶ ☐ if the organization	discontinued its operations or	disposed	d of more than	25% of	its net assets.		
30	3		_	erning body (Part VI, line 1a).	-		3	15		
જ	4		_	rs of the governing body (Part			4	12		
ies	5		-	n calendar year 2019 (Part V, li			5	5		
Ę.	6			necessary)	-		6	100		
Aci	7a			Part VIII, column (C), line 12			7a	0		
	b			from Form 990-T, line 39 .			7b	0		
		•		·		Prior Ye	ar	Current Year		
a)	8	Contributio	794,861	879,153						
Revenue	9		ervice revenue (Part VIII, line	•			0	0		
eve	10	_		a), lines 3, 4, and 7d)			-2,597	27,576		
æ	11		-	es 5, 6d, 8c, 9c, 10c, and 11e)			0	0		
	12			nust equal Part VIII, column (A),			792,264	906,729		
	13	•		X, column (A), lines 1–3)			152,772	192,231		
	14			K, column (A), line 4)			0	0		
w	15			benefits (Part IX, column (A), line			279,445			
Expenses	16a			column (A), line 11e)	-		0	0		
pen	b		raising expenses (Part IX, col							
Ä	17		enses (Part IX, column (A), lin	es 11a–11d 11f–24e)			284,933	436,371		
	18			equal Part IX, column (A), line			717,150	966,213		
	19	•	•	8 from line 12	•		75,114	-59,484		
- Se		11010110010	200 Oxponioco: Gubardor into 1			Beginning of Cur		End of Year		
Net Assets or Fund Balances	20	Total asset	ts (Part X, line 16)				699,946	675,082		
Ass	21		(D L)(II 00)				120,185	154,805		
Net Set	22		or fund balances. Subtract I				579,761	520,277		
	art II		re Block		<u> </u>	1	377,701	320,211		
				return, including accompanying schedu	ıles and stat	tements and to th	e hest of r	ny knowledge and helief it is		
				officer) is based on all information of v				, miemeage and sener, mie		
Sig	an	Signatu	ure of officer			Dat	е			
He		Linds	a Malecky Treasurer							
	-		a Malecky, Treasurer or print name and title							
	.: al	1,	e preparer's name	Preparer's signature	1	Date	Check	if PTIN		
Pa							self-emp	<u> </u>		
	epare	Firms's man		l .		Fi		-		
Us	e Onl	Firm's nan					's EIN ►			
Ma	v the IF	Firm's add		shown above? (see instruction	s)	Pnor	ne no.	Yes No		

Part	
_	Check if Schedule O contains a response or note to any line in this Part III
1	Briefly describe the organization's mission:
	TO SUPPORT AND ADVOCATE FOR INDIVIDUALS AND THEIR FAMILIES DIAGNOSED WITH RARE NEUROIMMUNE DISORDERS OF THE CENTRAL NERVOUS SYSTEM; TO PROMOTE AWARENESS AND TO EMPOWER PATIENTS, FAMILIES,
	CLINICIANS AND SCIENTISTS THROUGH EDUCATION PROGRAMS AND PUBLICATIONS AND TO ADVANCE THE
	(Continued on Schedule O, Statement 2)
2	Did the organization undertake any significant program services during the year which were not listed on the
_	prior Form 990 or 990-EZ?
	If "Yes," describe these new services on Schedule O.
3	Did the organization cease conducting, or make significant changes in how it conducts, any program
	services?
	If "Yes," describe these changes on Schedule O.
4	Describe the organization's program service accomplishments for each of its three largest program services, as measured by
	expenses. Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others,
	the total expenses, and revenue, if any, for each program service reported.
	(O
4a	(Code:) (Expenses \$ 485,236 including grants of \$ 0) (Revenue \$ 62,527)
	The SRNA publishes a newsletter 3 times a year and an annual report that is distributed to its membership. The newsletters
	contain articles written by physicians that focus on rare neuroimmunologic disorders as well as the most effective treatments for
	symptom management. Regular updates that relate information about new treatments and research are also included. The SRNA maintains an extensive website with educational materials that include specific symptom and condition information for rare
	neuroimmunologic diseases; podcasts with physicians, blogs written by medical professionals as well as SRNA members; and
	archives of all past newsletters. The website also facilitates support contracts between patients and their families through support
	groups and social media contacts. In addition, the SRNA has held a symposium to bring together individuals diagnosed with rare
	neuroimmune disorders and the clinicians and researchers that focus on these disorders. This event is the only one of its kind. Our
	goal is to continue providing this valuable resource to our community for many years to come.
	-Y
4b	(Code:) (Expenses \$ 67,319 including grants of \$ 0) (Revenue \$ 42,610)
	The SRNA partners with the Center for Courageous Kids (CCK) in Scottsville, KY to hold an annual summer camp for children
	(ages 5 - 17) and their families who have been impacted by these rare neuroimmunologic disorders. The entire week of camp is
	offered to these children and their families free of charge and allows these children to experience the joys of camp and connect
	with others who experience the same symptoms and conditions.
4c	(Code:) (Expenses \$ 260,437 including grants of \$ 192,231) (Revenue \$ 44,980)
	The SRNA provides research grants to medical institutions for work on understanding of treatments for these neuroimmunologic
	disorders. Two James T. Lubin Fellows were active in 2019. This fellowship supports the post-residency training of a clinician at
	an academic medical facility, who is committed to a career in academic medicine with a specialization in rare neuroimmunologic
	diseases and research. The SRNA is also providing support to participating medical centers by assisting in the recruitment of
	pediatric patients to take part in the CAPTURE (Collaborative Assessment of Pediatric Transverse Myelitis: Understand, Reveal,
	Educate) study funded by PCORI. The study is designed to assess the current state of Pediatric TM (including AFM or Acute
	Flaccid Myelitis) in terms of diagnosis, treatment and outcomes. The SRNA is also supporting the first study to investigate the
	Safety of the Transplantation of Human Glial Restricted Progenitor Cells in Transverse Myelitis.
4d	Other program services (Describe on Schedule O.)
	(Expenses \$ 0 including grants of \$ 0) (Revenue \$ 0)
10	Total program service expenses • 100 and 100 a

Part	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,"			
2	complete Schedule A	2	V	
3	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? <i>If "Yes," complete Schedule C, Part I </i>	3		,
4	Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? <i>If "Yes," complete Schedule C, Part II</i>	4		,
5	Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? If "Yes," complete Schedule C, Part III	5		,
6	Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? If "Yes," complete Schedule D, Part I	6		~
7	Did the organization receive or hold a conservation easement, including easements to preserve open space,			
8	the environment, historic land areas, or historic structures? <i>If "Yes," complete Schedule D, Part II</i> Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If "Yes," complete Schedule D, Part III </i>	8		\(\tau \)
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? <i>If</i> "Yes," complete Schedule D, Part IV	9		<i>v</i>
10	Did the organization, directly or through a related organization, hold assets in donor-restricted endowments or in quasi endowments? <i>If "Yes," complete Schedule D, Part V </i>	10		~
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," complete Schedule D, Part VI	11a	~	
b	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		,
С	Did the organization report an amount for investments—program related in Part X, line 13, that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VIII	11c		~
d	Did the organization report an amount for other assets in Part X, line 15, that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part IX	11d		,
е	Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X	11e		~
f	Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? If "Yes," complete Schedule D, Part X	11f		~
12a	Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI and XII	12a	~	
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		~
13	Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E	13		~
14a	Did the organization maintain an office, employees, or agents outside of the United States?	14a		~
b	Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? If "Yes," complete Schedule F, Parts I and IV	14b		,
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? <i>If "Yes," complete Schedule F, Parts II and IV</i>	15		_
16	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? If "Yes," complete Schedule F, Parts III and IV.	16		~
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? <i>If "Yes," complete Schedule G, Part I</i> (see instructions)	17		~
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	~	
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		,
20a	Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H	20a		~
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	~	

Part	Checklist of Required Schedules (continued)			
			Yes	No
22	Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? If "Yes," complete Schedule I, Parts I and III	22		,
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		,
24a	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		V
b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		
С	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?	24c		
d	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d		
25a	Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i>	25a		~
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		_
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? <i>If "Yes," complete Schedule L, Part II</i>	26		~
27	Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity (including an employee thereof) or family member of any of these persons? If "Yes," complete Schedule L, Part III	27		V
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? <i>If</i> "Yes," complete Schedule L, Part IV	28a		-
b	A family member of any individual described in line 28a? If "Yes," complete Schedule L, Part IV	28b		~
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		~
29	Did the organization receive more than \$25,000 in non-cash contributions? If "Yes," complete Schedule M	29	~	
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? If "Yes," complete Schedule M	30		~
31	Did the organization liquidate, terminate, or dissolve and cease operations? If "Yes," complete Schedule N, Part I	31		~
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If "Yes," complete Schedule N, Part II	32		~
33	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If</i> "Yes," <i>complete Schedule R, Part I</i>	33		~
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		~
35a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a		~
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? <i>If "Yes," complete Schedule R, Part V, line 2 </i>	36		~
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? <i>If "Yes," complete Schedule R, Part VI</i>	37		~
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? Note: All Form 990 filers are required to complete Schedule O.	38	~	
Part				_
	Check if Schedule O contains a response or note to any line in this Part V		Yes	No
1a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable 1a 0			
b	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	~	

Part '	Statements Regarding Other IRS Filings and Tax Compliance (continued)				
				Yes	No
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax				
		2a 5			
b	If at least one is reported on line 2a, did the organization file all required federal employment tax	k returns? .	2b	~	
	Note: If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instru-				
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?		3a		~
	If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation on Sch	nedule O .	3b		
	At any time during the calendar year, did the organization have an interest in, or a signature or other				
	a financial account in a foreign country (such as a bank account, securities account, or other financial		4a		1
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 Ac	counts (FBAR).			
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax ye		5a		~
	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter t		5b		~
	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?		5c		
	Does the organization have annual gross receipts that are normally greater than \$100,000				
	organization solicit any contributions that were not tax deductible as charitable contributions? .		6a	~	
b	If "Yes," did the organization include with every solicitation an express statement that such co	ontributions or			
	gifts were not tax deductible?		6b	~	
7	Organizations that may receive deductible contributions under section 170(c).				
а	Did the organization receive a payment in excess of \$75 made partly as a contribution and page 200.	artly for goods			
	and services provided to the payor?		7a		
	If "Yes," did the organization notify the donor of the value of the goods or services provided? .		7b		
С	Did the organization sell, exchange, or otherwise dispose of tangible personal property for	which it was			
	required to file Form 8282?		7с		
		7d			
	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal bell		7e		
	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit		7f		
_	If the organization received a contribution of qualified intellectual property, did the organization file Form 88	•	7g		
	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file		7h		
	Sponsoring organizations maintaining donor advised funds. Did a donor advised fund mai	ntained by the	_		
	sponsoring organization have excess business holdings at any time during the year?		8		
	Sponsoring organizations maintaining donor advised funds.				
	Did the sponsoring organization make any taxable distributions under section 4966?		9a		
	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person	n?	9b		
10	Section 501(c)(7) organizations. Enter:	- 1			
	· · · · · · · · · · · · · · · · · · ·	0a			
	1 / / /	0b			
11	Section 501(c)(12) organizations. Enter:	. 1			
		1a			
b	Gross income from other sources (Do not net amounts due or paid to other sources				
	9	1b			
	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of	1	12a		
	· · · · · · · · · · · · · · · · · · ·	2b			
13	Section 501(c)(29) qualified nonprofit health insurance issuers.				
а	Is the organization licensed to issue qualified health plans in more than one state?		13a		
_	Note: See the instructions for additional information the organization must report on Schedule (J.			
	Enter the amount of reserves the organization is required to maintain by the states in which				
		3b			
		3c	4.4		
	Did the organization receive any payments for indoor tanning services during the tax year?		14a		~
	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation on So		14b		
15	Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in re				_
	excess parachute payment(s) during the year?		15		~
	If "Yes," see instructions and file Form 4720, Schedule N.	mant i=====0	40		
16	Is the organization an educational institution subject to the section 4968 excise tax on net invest If "Yes," complete Form 4720, Schedule O.	ment income?	16		-
	n res, complete form 4720, sometitile O.				

Governance, Management, and Disclosure For each "Yes" response to lines 2 through 7b below, and for a

response to line 8a, 8b, or 10b below, describe the circumstances, processes, or changes on Schedule O. See instructions. Section A. Governing Body and Management No 1a Enter the number of voting members of the governing body at the end of the tax year . . . 1a 15 If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain on Schedule O. Enter the number of voting members included on line 1a, above, who are independent . 1b 12 2 Did any officer, director, trustee, or key employee have a family relationship or a business relationship with 2 ~ Did the organization delegate control over management duties customarily performed by or under the direct 3 3 supervision of officers, directors, trustees, or key employees to a management company or other person? . 4 4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed? 5 Did the organization become aware during the year of a significant diversion of the organization's assets? . 5 6 6 Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body? 7a Are any governance decisions of the organization reserved to (or subject to approval by) members, 7b R Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following: 8a 8b ~ Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses on Schedule O 9 Section B. Policies (This Section B requests information about policies not required by the Internal Revenue Code.) No 10a **b** 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 Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? 11a **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? *If "No," go to line 13* 12a 12b ~ Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," 12c 13 Did the organization have a written whistleblower policy? 13 14 14 Did the organization have a written document retention and destruction policy? Did the process for determining compensation of the following persons include a review and approval by 15 independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision? The organization's CEO, Executive Director, or top management official 15a 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 16a V 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 Section C. Disclosure List the states with which a copy of this Form 990 is required to be filed ▶ See Schedule O, Statement 3 17 Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, and 990-T (Section 501(c) 18 (3)s only) available for public inspection. Indicate how you made these available. Check all that apply. Own website ✓ Another's website ✓ Upon request Other (explain on Schedule O) Describe on Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, 19 and financial statements available to the public during the tax year. 20 State the name, address, and telephone number of the person who possesses the organization's books and records ▶ Linda Malecky, (215)499-9335

Part VI

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

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

Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees

1a Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year.

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
 - List all of the organization's current key employees, if any. See instructions for definition of "key employee."
- List the organization's five **current** highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations.
- List all of the organization's **former** officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations. See instructions for the order in which to list the persons above.

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

Check this box if fleither the organization ho		u o.g	<u> </u>		C)	ompo	71.00		Jineor, ameerer,	l tradition
(A)	(B)	١,,			ition			(D)	(E)	(F)
Name and title	Average		(do not check more than box, unless person is both					Reportable	Reportable	Estimated amount
	hours per week	office		nd a director/trustee)			tee)	compensation from the	compensation from related	of other compensation
	(list any	Individual trustee or director	Inst	Officer	Key employee	High	Former	organization	organizations	from the
	hours for related	vidu	Institutional trustee	cer	em	nest	ner	(W-2/1099-MISC)	(W-2/1099-MISC)	organization and related organizations
	organizations	al tr	onal		ploy	com				Tolatou organizationo
	below dotted line)	uste	trus		e	pen				
		Ф	tee			Highest compensated employee				
Sanford J Siegel	20.00									
President	0.00	~		~				0	0	0
Deborah Capen	20.00									
Secretary	0.00	~		~				0	0	0
Linda Malecky	20.00									
Treasurer, Vice President	0.00	~		~				0	0	0
Bruce L Downey	3.00									
Director	0.00	~						0	0	0
Benjamin M Greenberg MD	5.00									
Director	0.00	~						0	0	0
Douglas A Kerr MD PHD	3.00									
Director	0.00	~						0	0	0
Carlos A Pardo-Villamizar MD	5.00									
Director	0.00	~						0	0	0
Barbara Sattler	3.00									
Director	0.00	~						0	0	0
Jason Robbins	5.00									
Director	0.00	~						0	0	0
Anjali Forber-Pratt	5.00									
Director	0.00	~						0	0	0
Peter C Johnson	3.00									
Director	0.00	~						0	0	0
Dennis Wolfe	3.00									
Director	0.00	~						0	0	0
Lana Harder	5.00									
Director	0.00	~						0	0	0
James Timothy Lubin	20.00	1								
Executive Committee Member	0.00	~		~				0	0	0

Part	VII Section A. Officers, Directors, 7	Trustees,	Key I	Ξm	plo	yee	s, an	d F	lighest Compe	nsated Empl	oyees (continu	ıed)
					•	C)							
	(A)	(B)	(do n	ot ch		ition	e than o	one	(D)	(E)		(F)	
	Name and title	Average	٠,				is both		Reportable	Reportable	1	ated amo	unt
		hours per week		er and	_	irect	or/trus	—	compensation from the	compensation from related		of other opensation	n
		(list any	Indi or d	Inst	Officer	Key	High	Former	organization	organizations	fr	om the	
		hours for related	vidu	tri	cer	em	nest	ner	(W-2/1099-MISC)	(W-2/1099-MISC)	"	iization ar organizat	
		organizations	tor all tr	onal		Key employee	com				Tolatoa	or garnzar	10110
		below dotted line)	Individual trustee or director	Institutional trustee		ee	pen						
			0	tee			Highest compensated employee						
Dave	Fyans	3.00					<u> </u>						
Direct		0.00	~						0	(0
	-												
		 	1										
			1										
											-		
			1										
		 	1										
1b	Subtotal		٠			<u> </u>			0	()		0
С	Total from continuation sheets to Part	VII, Sectio	n A										
d									0	C)		0
2	Total number of individuals (including but	t not limited	d to th	ose	list	ted	above	e) w	ho received mor	e than \$100,00	0 of		
	reportable compensation from the organ	ization ►							0				
												Yes	No
3	Did the organization list any former of									•	d 3		~
_	employee on line 1a? If "Yes," complete												
4	For any individual listed on line 1a, is the organization and related organizations	sum of re	portai	oie (เรก	con	1pei ויס ו	nsatic f "Va	n a 。"	ind other compe	nsation from th	e h		
	individual	•						-	•		4		~
5	Did any person listed on line 1a receive of	or accrue co	ompe	nsat	tion	fro	m any	/ un	related organizat	tion or individua	al		
	for services rendered to the organization	? If "Yes," c	compl	ete	Sch	nedu	ule J 1	or s	such person .		5		~
Secti	on B. Independent Contractors												
1	Complete this table for your five high												
	compensation from the organization. Rep	ort compen	sation	n tor	r the	ca	lenda	r ye ⊺		within the orga			ear.
	(A) Name and business add	Iress							(B) Description of serv	vices	(C) Compens		
None									2000				
NOTIC													
2	Total number of independent contractor							th	nose listed abov	e) who			
	received more than \$100,000 of compens	ation from	the or	gan	izat	ion			0				

Part VIII Statement of Revenue

		Check if Schedule	Осо	ntains a re	spon	se or note to ar	ny line in this Pa	ırt VIII		\square
							(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512–514
ts	1a	Federated campaig	ns .		1a	0				
Contributions, Gifts, Grants and Other Similar Amounts	b	Membership dues			1b	0				
Ē,	С	Fundraising events			1c	224,822				
ifts ır A	d	Related organization	ns .		1d	0				
, G nila	е	Government grants	(cont	ributions)	1e	0				
ons Sir	f	All other contribution								
utio		and similar amounts no	ot incl	uded above	1f	654,331				
trib Ott	g	Noncash contribution								
on	_	lines 1a-1f			1g					
	h	Total. Add lines 1a-	-1f .		•		879,153			
ө	0-					Business Code				
vic	2a									
ser iue	b									
m S	C									
gram Ser Revenue	d									
Program Service Revenue	e f	All other program se	anvice	 . ravanua						
ъ.	g	Total. Add lines 2a-				•	0			
	3	Investment income								
		other similar amoun					23,823	0	0	23,823
	4	Income from investr				0	0	0	0	
	5				-		0	0	0	0
		•		(i) Real		(ii) Personal				
	6a	Gross rents	6a		0	0				
	b	Less: rental expenses	6b		0	0				
	С	Rental income or (loss)			0	0				
	d	Net rental income o	r (los	s)		<u> </u>	0	0	0	0
	7a	Gross amount from		(i) Securit	ies	(ii) Other				
		sales of assets		1	2,450	0				
		other than inventory	7a	•	2,400	Ů				
ne	b	Less: cost or other basis								
Revenue		and sales expenses .	7b		8,697	0				
Re		Gain or (loss)	7c		3,753	0		_		
er		Net gain or (loss)				<u></u>	3,753	0	0	3,753
Other	8a	Gross income from events (not including		ndraising						
		of contributions re		d on line						
		1c). See Part IV, line			8a					
	b	Less: direct expens			8b	0				
	C	Net income or (loss)					0		0	0
	9a	Gross income f			9 010		J			
	Ju	activities. See Part I			9a	0				
	b	Less: direct expens			9b	0				
		Net income or (loss)				es >	0	0	0	0
		Gross sales of ir	•							
		returns and allowan			10a	0				
	b	Less: cost of goods	sold		10b	0				
	С	Net income or (loss)			vento	ory ▶	0	0	0	0
SI						Business Code				
eor	11a									
an	b									
scellaneo Revenue	С									
Miscellaneous Revenue	d	All other revenue			-					
2	е	Total. Add lines 11a				<u> ▶</u>	0			
	12	Total revenue. See	instr	uctions .		<u> </u>	906,729	0	0	27,576

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).

0000	Charle if Cahadula O anataina a wasanana				
	Check if Schedule O contains a response				
	ot include amounts reported on lines 6b, 7b, o, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1	Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21 .	192,231	192,231		
2	Grants and other assistance to domestic individuals. See Part IV, line 22	0	0		
3	Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16	0	0		
4	Benefits paid to or for members	0	0		
5	Compensation of current officers, directors, trustees, and key employees	56,650	45,320	6,152	5,178
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	0	0	0
7	Other salaries and wages	234,081	230,017	2,207	1,857
8	Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	24,684	20,611	2,220	1,853
9	Other employee benefits	-2.017	-1,688	-182	-147
10	Payroll taxes	24,213	20,218	2,169	1,826
11	Fees for services (nonemployees):	21,210	20,210	2,137	1,020
а	Management	0	0	0	0
b	Legal	0	0	0	0
C	Accounting	0	0	0	0
d	Lobbying	0	0	0	0
	Professional fundraising services. See Part IV, line 17	0	U	U	
e f	Investment management fees	0	0	0	0
	Other. (If line 11g amount exceeds 10% of line 25, column	U	U	0	0
g	(A) amount, list line 11g expenses on Schedule O.) .	72,928	70,752	2,176	0
12	Advertising and promotion	0	0	0	0
13	Office expenses	1,005	0	1,005	0
14	Information technology	28,155	17,594	7,041	3,520
15	Royalties	0	0	0	0
16	Occupancy	0	0	0	0
17	Travel	14,269	11,674	1,449	1,146
18	Payments of travel or entertainment expenses for any federal, state, or local public officials				
19	Conferences, conventions, and meetings .	79,087	79,087	0	0
20	Interest	0	0	0	0
21	Payments to affiliates	0	0	0	0
22	Depreciation, depletion, and amortization .	2,561	0	2,561	0
23	Insurance	5,538	0	5,538	0
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.)				
а	Bank and Merchant Services	13,273	0	13,273	0
b	Publications and Postage	70,255	66,552	440	3,263
С	Member Support	98,806	18,668	0	80,138
d	Family Camp	41,898	41,898	0	0
е	All other expenses	8,596	58	8,538	0
25	Total functional expenses. Add lines 1 through 24e	966,213	812,992	54,587	98,634
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)	97,225	17,087	0	80,138
					Eorm 990 (2010)

Part X Balance Sheet

		Check if Schedule O contains a response or note to any line in this Par	tX		
			(A) Beginning of year		(B) End of year
	1	Cash—non-interest-bearing		1	0
	2	Savings and temporary cash investments	361,915	2	407,098
	3	Pledges and grants receivable, net	250,000	3	18,500
	4	Accounts receivable, net	0	4	0
	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	U		U
	U	under section 4958(f)(1)), and persons described in section 4958(c)(3)(B)	0	6	0
G	7	Notes and loans receivable, net	0	7	
Assets	8	Inventories for sale or use	0	8	0
Ass	9		0	9	0
•		· · · · · · · · · · · · · · · · · · ·	U	9	0
	10a	Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D 10a 27,962			
	b	Less: accumulated depreciation	7,727	10c	6,934
	11	Investments—publicly traded securities	80,304	11	242,550
	12	Investments—other securities. See Part IV, line 11	0	12	0
	13	Investments—program-related. See Part IV, line 11	0	13	0
	14	Intangible assets	0	14	0
	15	Other assets. See Part IV, line 11	0	15	0
	16	Total assets. Add lines 1 through 15 (must equal line 33)	699,946	16	675,082
	17	Accounts payable and accrued expenses	120,185	17	79,805
	18	Grants payable	0	18	0
	19	Deferred revenue	0	19	75,000
	20	Tax-exempt bond liabilities	0	20	0
	21	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%			
abi		controlled entity or family member of any of these persons	0	22	0
Ľ	23	Secured mortgages and notes payable to unrelated third parties	0	23	0
	24	Unsecured notes and loans payable to unrelated third parties	0	24	0
	25	Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17–24). Complete Part X			
		of Schedule D	0	25	0
	26	Total liabilities. Add lines 17 through 25	120,185	26	154,805
rces		Organizations that follow FASB ASC 958, check here ► ✓ and complete lines 27, 28, 32, and 33.			
alaı	27	Net assets without donor restrictions	579,761	27	520,277
B	28	Net assets with donor restrictions	0	28	0
Net Assets or Fund Balances		Organizations that do not follow FASB ASC 958, check here ▶ ☐ and complete lines 29 through 33.			
o	29	Capital stock or trust principal, or current funds		29	
ets	30	Paid-in or capital surplus, or land, building, or equipment fund		30	
SS	31	Retained earnings, endowment, accumulated income, or other funds		31	
¥ A	32	Total net assets or fund balances	579,761	32	520,277
ž	33	Total liabilities and net assets/fund balances	699,946	33	675,082
			,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,		Form 990 (2019)

Part	XI Reconciliation of Net Assets			•	
	Check if Schedule O contains a response or note to any line in this Part XI				
1	Total revenue (must equal Part VIII, column (A), line 12)			90	6,729
2	Total expenses (must equal Part IX, column (A), line 25)			96	6,213
3	Revenue less expenses. Subtract line 2 from line 1			-59	9,484
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A)) 4			579	9,761
5	Net unrealized gains (losses) on investments				0
6	Donated services and use of facilities				0
7	Investment expenses				0
8	Prior period adjustments				0
9	Other changes in net assets or fund balances (explain on Schedule O)				0
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line				
	32, column (B))			520	0,277
Part	XII Financial Statements and Reporting				
	Check if Schedule O contains a response or note to any line in this Part XII	<u></u>			
				Yes	No
1	Accounting method used to prepare the Form 990: Cash Accrual Other	_			
	If the organization changed its method of accounting from a prior year or checked "Other," explain Schedule O.	in			
2a	Were the organization's financial statements compiled or reviewed by an independent accountant?	. [2a		~
	If "Yes," check a box below to indicate whether the financial statements for the year were compiled				
	reviewed on a separate basis, consolidated basis, or both:				
	☐ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis				
b	Were the organization's financial statements audited by an independent accountant?	. 7	2b	~	
	If "Yes," check a box below to indicate whether the financial statements for the year were audited or	ı a 📗			
	separate basis, consolidated basis, or both:				
	☐ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis				
С	If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight	of			
	the audit, review, or compilation of its financial statements and selection of an independent accountant?		2c	~	
	If the organization changed either its oversight process or selection process during the tax year, explain Schedule O.	on			
За	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the	the			
	Single Audit Act and OMB Circular A-133?		3a		~
b	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the	the			
	required audit or audits, explain why on Schedule O and describe any steps taken to undergo such audits		3b		
				000	

Form **990** (2019)

SCHEDULE A (Form 990 or 990-EZ)

Department of the Treasury Internal Revenue Service

Public Charity Status and Public Support

OMB No. 1545-0047

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.

Open to Public Inspection

Employer identification number Name of the organization SIEGEL RARE NEUROIMMUNE ASSOCIATION 91-1780467 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.) A church, convention of churches, or association of churches described in section 170(b)(1)(A)(i). A school described in section 170(b)(1)(A)(ii). (Attach Schedule E (Form 990 or 990-EZ).) A hospital or a cooperative hospital service organization described in section 170(b)(1)(A)(iii). 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: An organization operated for the benefit of a college or university owned or operated by a governmental unit described in 5 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)(v). An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in section 170(b)(1)(A)(vi). (Complete Part II.) ☐ A community trust described in **section 170(b)(1)(A)(vi).** (Complete Part II.) 8 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). 12 An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2). See section 509(a)(3). Check the box in lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12d, Type I. A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving а the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization. You must complete Part IV, Sections A and B. b Type II. A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s). You must complete Part IV, Sections A and C. 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. Type III non-functionally integrated. A supporting organization operated in connection with its supported organization(s) d 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 I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization. Enter the number of supported organizations . . . Provide the following information about the supported organization(s). (iii) Type of organization (vi) Amount of (i) Name of supported organization (ii) EIN (iv) Is the organization (v) Amount of monetary (described on lines 1-10 listed in your governing support (see other support (see above (see instructions)) document? instructions) instructions) Yes No (A) (B) (C) (D) (E) **Total**

Part								
(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.)							
	on A. Public Support	() 0045	# > 0040	() 0047	(1) 00 (0	() 0040	(n =	
	dar year (or fiscal year beginning in)	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total	
1	Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")							
2	Tax revenues levied for the organization's benefit and either paid to or expended on its behalf							
3	The value of services or facilities furnished by a governmental unit to the organization without charge							
4	Total. Add lines 1 through 3							
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)							
6	Public support. Subtract line 5 from line 4							
	on B. Total Support				(0 00 10			
	dar year (or fiscal year beginning in)	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total	
7 8	Amounts from line 4							
9	similar sources							
J	activities, whether or not the business is regularly carried on							
10	Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)							
11 12	Total support. Add lines 7 through 10 Gross receipts from related activities, etc	`	,			12		
13	First five years. If the Form 990 is for the	•	n's first, secon	d, third, fourth	i, or fifth tax ye	ear as a sectio	n 501(c)(3)	
0 1:	organization, check this box and stop he		<u>.</u>	· · · · ·			▶ 📙	
	on C. Computation of Public Suppor			1 ookumn (f))		14	0/	
14 15	Public support percentage for 2019 (line 6) Public support percentage from 2018 Sci					15	<u>%</u>	
16a	33 ¹ / ₃ % support test—2019. If the organi							
	box and stop here. The organization qua							
b								
17a								
b	10%-facts-and-circumstances test—20 15 is 10% or more, and if the organization resupported organization	ation meets the neets the "fac	e "facts-and-c ts-and-circums	circumstances stances" test.	" test, check The organizati	this box and	stop here.	
18	Private foundation. If the organization di	d not check a	box on line 13,	, 16a, 16b, 17a	a, or 17b, chec	k this box and	see	

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

(Complete only if you checked the box on line 10 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

Secti	on A. Public Support			,		/	
Calen	dar year (or fiscal year beginning in) ▶	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
1	Gifts, grants, contributions, and membership fees						
	received. (Do not include any "unusual grants.")	609,806	520,011	680,610	794,861	879,153	3,484,441
2	Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the		·				
3	organization's tax-exempt purpose Gross receipts from activities that are not an	4,610	387	9,780	0	0	14,777
J	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	614,416	520,398	690,390	794,861	879,153	3,499,218
7a	Amounts included on lines 1, 2, and 3 received from disqualified persons .						
b	Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
С	Add lines 7a and 7b						
8	Public support. (Subtract line 7c from line 6.)						3,499,218
Secti	on B. Total Support						3,477,210
	dar year (or fiscal year beginning in) ▶	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
9	Amounts from line 6	614,416	520,398	690,390	794,861	879,153	3,499,218
10a	Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources.	-1,136	9,119	1,490	-2,598	6,991	13,866
b	Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975	·	·	·	·		
С	Add lines 10a and 10b	-1,136	9,119	1,490	-2,598	6,991	13,866
11	Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on	·	·	·	·	·	
12	Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
13	Total support. (Add lines 9, 10c, 11, and 12.)	613,280	529,517	691,880	792,263	886,144	3,513,084
14	First five years. If the Form 990 is for the organization, check this box and stop here	e organization	's first, secon		, or fifth tax ye	ear as a section	on 501(c)(3)
Secti	on C. Computation of Public Suppor			<u> </u>			
15	Public support percentage for 2019 (line 8			13 column (fl)		15	99.6 %
16	Public support percentage from 2018 Sch					16	99.43 %
	on D. Computation of Investment Inc			<u> </u>	<u></u>	10	77.43 /0
17	Investment income percentage for 2019 (I			v line 13 colu	mn (f))	17	0.4 %
18	Investment income percentage from 2018			•		18	0.57 %
19a	331/3% support tests—2019. If the organi						
. 54	17 is not more than 33 ¹ / ₃ %, check this box						
b	331/3% support tests—2018. If the organiz	_	_	-		_	_
~	line 18 is not more than 331/3%, check this b						
20	Private foundation. If the organization di	_	=	•			_

Part IV Supporting Organizations

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

Section A. All Supporting Organizations

Cu	on A. All Supporting Organizations			
			Yes	No
1	Are all of the organization's supported organizations listed by name in the organization's governing documents? If "No," describe in Part VI how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.	4		
_		1		
2	Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? If "Yes," explain in Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).	2		
3a	Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? If "Yes," answer	_		
Ju	(b) and (c) below.	3a		
L		Ja		
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.	3b		
_		JU		
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.	3с		
4a	Was any supported organization not organized in the United States ("foreign supported organization")? If "Yes," and if you checked 12a or 12b in Part I, answer (b) and (c) below.	4a		
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.	4b		
С	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.	4c		
5а	Did the organization add, substitute, or remove any supported organizations during the tax year? If "Yes," answer (b) and (c) below (if applicable). Also, provide detail in Part VI , including (i) the names and EIN numbers of the supported organizations added, substituted, or removed; (ii) the reasons for each such action; (iii) the authority under the organization's organizing document authority such action; and (iv) how the action			
	was accomplished (such as by amendment to the organizing document).	5a		
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?	5b		
С	Substitutions only. Was the substitution the result of an event beyond the organization's control?	5c		
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 .	6		
7		U		
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).	-		
_		7		
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).	8		
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 .	9a		
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.	9b		
С	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.	9c		
100		50		
10a	Was the organization subject to the excess business holdings rules of section 4943 because of section			
	4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated			
	supporting organizations)? If "Yes," answer 10b below.	10a		
b	Did the organization have any excess business holdings in the tax year? (Use Schedule C, Form 4720, to determine whether the organization had excess business holdings.)	10b		

Part	Supporting Organizations (continued)			
			Yes	No
11	Has the organization accepted a gift or contribution from any of the following persons?			
а	A person who directly or indirectly controls, either alone or together with persons described in (b) and (c) below, the governing body of a supported organization?	11a		
	A family member of a person described in (a) above?	11b		
	A 35% controlled entity of a person described in (a) or (b) above? If "Yes" to a, b, or c, provide detail in Part VI .	11c		
Secti	on B. Type I Supporting Organizations		\ <u>'</u>	
			Yes	No
1	Did the directors, trustees, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the tax year? If "No," describe in Part VI how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove directors or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.	1		
2	Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised, or controlled the supporting organization.	2		
Secti	on C. Type II Supporting Organizations			
			Yes	No
1	Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)? If "No," describe in Part VI how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s).	1		
Secti	on D. All Type III Supporting Organizations			
			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		
2	Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported			
-	organization(s) or (ii) serving on the governing body of a supported organization? If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).	2		
3	By reason of the relationship described in (2), did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year? If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.	3		
Secti	on E. Type III Functionally Integrated Supporting Organizations			
1 a b c	Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see in the organization satisfied the Activities Test. Complete line 2 below. 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 government entity (see in Part VI).			
2	Activities Test. Answer (a) and (b) below.		Yes	No
а	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 (a) constitute activities that, but for the organization's involvement, one or more	_u		
-	of the organization's supported organization(s) would have been engaged in? If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.	2b		
3	Parent of Supported Organizations. <i>Answer (a) and (b) below.</i>			
а	Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? <i>Provide details in Part VI.</i>	3a		
b	Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each	Ja		
	of its supported organizations? If "Yes," describe in Part VI the role played by the organization in this regard.	3b		

Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Org	gani	zations			
1 Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970 (explain in Part VI). See instructions. All other Type III non-functionally integrated supporting organizations must complete Sections A through E.					
Section A—Adjusted Net Income		(A) Prior Year	(B) Current Year (optional)		
1 Net short-term capital gain	1				
2 Recoveries of prior-year distributions	2				
3 Other gross income (see instructions)	3				
4 Add lines 1 through 3.	4				
5 Depreciation and depletion	5				
6 Portion of operating expenses paid or incurred for production or					
collection of gross income or for management, conservation, or					
maintenance of property held for production of income (see instructions)	6				
7 Other expenses (see instructions)	7				
8 Adjusted Net Income (subtract lines 5, 6, and 7 from line 4)	8				
Section B-Minimum Asset Amount		(A) Prior Year	(B) Current Year (optional)		
1 Aggregate fair market value of all non-exempt-use assets (see					
instructions for short tax year or assets held for part of year):					
a Average monthly value of securities	1a				
b Average monthly cash balances	1b				
c Fair market value of other non-exempt-use assets	1c				
d Total (add lines 1a, 1b, and 1c)	1d				
e Discount claimed for blockage or other factors (explain in detail in Part VI):					
2 Acquisition indebtedness applicable to non-exempt-use assets	2				
3 Subtract line 2 from line 1d.	3				
4 Cash deemed held for exempt use. Enter 1-1/2% of line 3 (for greater amount, see instructions).	4				
5 Net value of non-exempt-use assets (subtract line 4 from line 3)	5				
6 Multiply line 5 by .035.	6				
7 Recoveries of prior-year distributions	7				
8 Minimum Asset Amount (add line 7 to line 6)	8				
Section C-Distributable Amount			Current Year		
1 Adjusted net income for prior year (from Section A, line 8, Column A)	1				
2 Enter 85% of line 1.	2				
3 Minimum asset amount for prior year (from Section B, line 8, Column A)	3				
4 Enter greater of line 2 or line 3.	4				
5 Income tax imposed in prior year	5				
6 Distributable Amount. Subtract line 5 from line 4, unless subject to					
emergency temporary reduction (see instructions).	6				
7 Check here if the current year is the organization's first as a non-functionall instructions).	y int	egrated Type III supporti	ng organization (see		

Part	V Type III Non-Functionally Integrated 509(a)(3) Supporting Organi	zations (continued)	. 490 1
Sect	ion D-Distributions			Current Year
1	Amounts paid to supported organizations to accomplish e	exempt purposes		
2	Amounts paid to perform activity that directly furthers exe organizations, in excess of income from activity	rted		
3	Administrative expenses paid to accomplish exempt purp	nizations		
4	Amounts paid to acquire exempt-use assets			
5	Qualified set-aside amounts (prior IRS approval required)			
6	Other distributions (describe in Part VI). See instructions.			
7	Total annual distributions. Add lines 1 through 6.			
8	Distributions to attentive supported organizations to whic (provide details in Part VI). See instructions.	h the organization is res	ponsive	
9	Distributable amount for 2019 from Section C, line 6			
10	Line 8 amount divided by line 9 amount			
Sect	ion E—Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2019	(iii) Distributable Amount for 2019
1	Distributable amount for 2019 from Section C, line 6			
2	Underdistributions, if any, for years prior to 2019 (reasonable cause required—explain in Part VI). See instructions.			
3	Excess distributions carryover, if any, to 2019			
а	From 2014			
b	From 2015			
С	From 2016			
d	From 2017			
е	From 2018			
f	Total of lines 3a through e			
g	Applied to underdistributions of prior years			
h	Applied to 2019 distributable amount			
i	Carryover from 2014 not applied (see instructions)			
j	Remainder. Subtract lines 3g, 3h, and 3i from 3f.			
4	Distributions for 2019 from Section D, line 7:			
а	Applied to underdistributions of prior years			
b	Applied to 2019 distributable amount			
С	Remainder. Subtract lines 4a and 4b from 4.			
5	Remaining underdistributions for years prior to 2019, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, explain in Part VI. See instructions.			
6	Remaining underdistributions for 2019. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in Part VI. See instructions.			
7	Excess distributions carryover to 2020. Add lines 3j and 4c.			
8	Breakdown of line 7:			
а	Excess from 2015			
b	Excess from 2016			
С	Excess from 2017			
d	Excess from 2018			
е	Excess from 2019			

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 D (Form 990)

Supplemental Financial Statements

► Complete if the organization answered "Yes" on Form 990, Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b. ► Attach to Form 990.

OMB No. 1545-0047

Open to Public Inspection

Department of the Treasury Internal Revenue Service

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

Name C	i the organization		Employer identification number
SIEGE	L RARE NEUROIMMUNE ASSOCIATION		91-1780467
Par	Organizations Maintaining Donor Advi	sed Funds or Other Similar Fund	ls or Accounts.
	Complete if the organization answered "		
	Complete if the organization answered	(a) Donor advised funds	(b) Funds and other accounts
4	Total number at and of year	(a) Donor advised funds	(b) I dilas 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 a funds are the organization's property, subject to the		
6	Did the organization inform all grantees, donors, ar only for charitable purposes and not for the benefit conferring impermissible private benefit?	t of the donor or donor advisor, or fo	r any other purpose
Par	Conservation Easements.		
	Complete if the organization answered "	Yes" on Form 990. Part IV. line 7.	
1	Purpose(s) of conservation easements held by the conservation		
-	Preservation of land for public use (for example, recre	• • • • • • • • • • • • • • • • • • • •	f a historically important land area
	Protection of natural habitat		f a certified historic structure
	☐ Preservation of open space	_ 1 Tosorvation o	ra outinoa motorio diractaro
2	Complete lines 2a through 2d if the organization hel	d a qualified conservation contribution	in the form of a conservation
_	easement on the last day of the tax year.	d a qualified conservation contribution	Held at the End of the Tax Year
_			_
a			
b	Total acreage restricted by conservation easements		- - - - - - - - - -
C	Number of conservation easements on a certified hi	. ,	
d	Number of conservation easements included in (historic structure listed in the National Register $$.	c) acquired after 7/25/06, and not c	1 1
3	Number of conservation easements modified, trans	ferred, released, extinguished, or tern	ninated by the organization during the
4	tax year	vation accoment is leasted	
4	Number of states where property subject to consen		
5	Does the organization have a written policy reg violations, and enforcement of the conservation eas	ements it holds?	Yes 🗌 No
6	Staff and volunteer hours devoted to monitoring, inspec	ting, handling of violations, and enforcing	g conservation easements during the year
7	Amount of expenses incurred in monitoring, inspecting ▶\$	g, handling of violations, and enforcing of	conservation easements during the year
8	Does each conservation easement reported on line 2 and section 170(h)(4)(B)(ii)?		
9	In Part XIII, describe how the organization reports of balance sheet, and include, if applicable, the text of organization's accounting for conservation easemen	the footnote to the organization's fina	
Part	Organizations Maintaining Collections Complete if the organization answered "		Other Similar Assets.
1a	If the organization elected, as permitted under FAS	B ASC 958, not to report in its revenu	e statement and balance sheet works
	of art, historical treasures, or other similar assets service, provide in Part XIII the text of the footnote t	held for public exhibition, education	, or research in furtherance of public
b	If the organization elected, as permitted under FAS art, historical treasures, or other similar assets held provide the following amounts relating to these item	for public exhibition, education, or res	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, following amounts required to be reported under FA	historical treasures, or other similar	
а	Revenue included on Form 990, Part VIII, line 1	-	▶ \$

b Assets included in Form 990, Part X .

\$

	le D (Form 990) 2019				Page 2	
Part	Organizations Maintaining C	ollections of Art, His	storical Treasures	s, or Other Similar	Assets (continued)	
3	Using the organization's acquisition, accollection items (check all that apply):	cession, and other reco	rds, check any of th	ne following that make	significant use of its	
а	☐ Public exhibition		Loan or exchang			
b	☐ Scholarly research	е	Other			
С	☐ Preservation for future generations					
4	Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Par XIII.					
5	During the year, did the organization so assets to be sold to raise funds rather the					
Part	IV Escrow and Custodial Arrang	gements.				
	Complete if the organization a 990, Part X, line 21.	nswered "Yes" on Fo	rm 990, Part IV, lin	e 9, or reported an	amount on Form	
1a	Is the organization an agent, trustee, c included on Form 990, Part X?				not .	
b	If "Yes," explain the arrangement in Part	XIII and complete the fo	ollowing table:			
					Amount	
С	Beginning balance			1c		
d	Additions during the year			1d		
е	Distributions during the year			1e		
f	Ending balance			1f		
2a	Did the organization include an amount					
b	If "Yes," explain the arrangement in Part	XIII. Check here if the e	explanation has been	provided on Part XIII	<u> L</u>	
Par	t V Endowment Funds.					
	Complete if the organization a	nswered "Yes" on Fo	rm 990, Part IV, lin	e 10.		
		(a) Current year (b) Pr	ior year (c) Two yea	ars back (d) Three years b	ack (e) Four years back	
1a	Beginning of year balance					
b	Contributions					
С	Net investment earnings, gains, and losses					
d	Grants or scholarships					
е	Other expenditures for facilities and					
	programs					
f	Administrative expenses					
g	End of year balance					
2	Provide the estimated percentage of the	current year end baland	ce (line 1g, column (a	a)) held as:	·	
а	Board designated or quasi-endowment	▶ %				
b		_%				
С	Term endowment ▶ %	-				
	The percentages on lines 2a, 2b, and 2c	should equal 100%.				
3a	Are there endowment funds not in the porganization by:	· · · · · · · · · · · · · · · · · · ·	ization that are held	and administered for	the Yes No	
	(i) Unrelated organizations				. 3a(i)	
	.,					
b	If "Yes" on line 3a(ii), are the related orga					
4	Describe in Part XIII the intended uses o	·			. [53]	
Part						
	Complete if the organization a		rm 990, Part IV, lin	e 11a. See Form 99	0, Part X, line 10.	
	Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value	
1a	Land	0	0		0	
b	Buildings	0			0	
c	Leasehold improvements	0			0	

27,962

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

0

d Equipment

6,934

0

21,028

. ▶

0

0

Part VII	Investments – Other Securities.		· · · · · · · · · · · · · · · · · · ·
	Complete if the organization answered "Yes" on Form 990, Part I	V, line 11b. See F	orm 990, Part X, line 12.
	(a) Description of security or category (including name of security)	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1) Financial	derivatives		
	eld equity interests		
(3) Other			
(A)			
(B)			
(C)			
(D)			
(E)			
(F)			
(G) (H)			
	mn (b) must equal Form 990, Part X, col. (B) line 12.) . ▶		
Part VIII	Investments—Program Related.		
	Complete if the organization answered "Yes" on Form 990, Part I	V. line 11c. See Fo	orm 990. Part X. line 13.
	(a) Description of investment	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1)			
(2)			
(3)			
(4)			
(5)			
(6)			
(7)			
(8)			
(9)			
	mn (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 I	V, line 11d. See F	
	(a) Description		(b) Book value
(1)			
(2)			
(3)			
(4)			
(5)			
(6) (7)			
(8)			
(9)			
	mn (b) must equal Form 990, Part X, col. (B) line 15.)		>
	Complete if the organization answered "Yes" on Form 990, Part I line 25.	V, line 11e or 11f.	See Form 990, Part X,
1.	(a) Description of liability		(b) Book value
(1) Federal in	come taxes		
(2)			
(3)			
(4)			
(5)			
(6)			
(7)			
(8)			
(9)	mn (h) must squal Form 000. Part V and (D) line 05.)		
	mn (b) must equal Form 990, Part XI, col. (B) line 25.)	ization's financial stat	coments that reports the
	uncertain tax positions. In Part XIII, provide the text of the footnote to the organ s liability for uncertain tax positions under FASB ASC 740. Check here if the text		

Schedule D (Form 990) 2019 Page 4 Reconciliation of Revenue per Audited Financial Statements With Revenue per Return. Part XI Complete if the organization answered "Yes" on Form 990, Part IV, line 12a. Total revenue, gains, and other support per audited financial statements. 906,729 2 Amounts included on line 1 but not on Form 990. Part VIII. line 12: Net unrealized gains (losses) on investments 0 Donated services and use of facilities 0 h Recoveries of prior year grants 0 Other (Describe in Part XIII.) 0 Add lines 2a through 2d 2e 3 3 Subtract line **2e** from line **1** 906,729 Amounts included on Form 990. Part VIII. line 12, but not on line 1: Investment expenses not included on Form 990, Part VIII, line 7b 4a 0 4b 0 Add lines 4a and 4b 4c 0 Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.) 5 906,729 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. Total expenses and losses per audited financial statements 966,213 2 Amounts included on line 1 but not on Form 990, Part IX, line 25: Donated services and use of facilities 2a 0 Prior year adjustments 2b 0 Other losses 2c 0 Other (Describe in Part XIII.) 0 Add lines 2a through 2d . . 2e 0 3 3 Subtract line 2e from line 1 966,213 Amounts included on Form 990, Part IX, line 25, but not on line 1: Investment expenses not included on Form 990, Part VIII, line 7b 4a 0 Other (Describe in Part XIII.) 4b 0 Add lines **4a** and **4b** 4c Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.) 5 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

Provide the descriptions required for Part II, lines 3, 3, and 3, Part III, lines 1a and 4, Part IV, lines 1b and 2b, Part IV, line 4, Part IV, lines 2d and 4b, and Part XII, lines 2d and 4b. Also complete this part to provide any additional information.

SCHEDULE G (Form 990 or 990-EZ)

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

Department of the Treasury Internal Revenue Service Name of the organization

or if the	2019				
	Open to Public Inspection				
Employer identification number					

Ivanic	or the organization					Employer identific	outon number
SIEG	EL RARE NEUROIMMUNE ASSOCIA						1780467
Par	Fundraising Activities. Form 990-EZ filers are r				vered "Yes" on	Form 990, Part IV,	line 17.
1	Indicate whether the organization	on raised funds	through any	of the follo	owing activities. C	heck all that apply.	
а	☐ Mail solicitations		e		ion of non-govern		
b	Internet and email solicitatio	ns	f [ion of governmen	•	
C	☐ Phone solicitations		g		fundraising events	=	
d			9 -	_ орсски	idildidising event	,	
	☐ In-person solicitations						
2 a	2a Did the organization have a written or oral agreement with any individual (including officers, directors, trustees, or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services? Yes No						
b	If "Yes," list the 10 highest paid compensated at least \$5,000 by			draisers) pu	ursuant to agreen	nents under which th	e fundraiser is to be
	(i) Name and address of individual or entity (fundraiser)	(ii) Activity	custody c	ndraiser have or control of outions?	(iv) Gross receipts from activity	(v) Amount paid to (or retained by) fundraiser listed in col. (i)	(vi) Amount paid to (or retained by) organization
			Yes	No			
1							
2							
3							
4							
5							
6							
7							
8							
9							
10							
Total				•			
3	List all states in which the orga registration or licensing.	inization is regi	stered or lic	ensed to s	solicit contribution	s or has been notifi	ed it is exempt from
	·						

Fundraising Events. Complete if the organization answered "Yes" on Form 990, Part IV, line 18, or reported more than \$15,000 of fundraising event contributions and gross income on Form 990-EZ, lines 1 and 6b. List events with gross receipts greater than \$5,000.

			(a) Event #1	(b) Event #2	(c) Other events	(d) Total events
			TMA 25-Year Gala (event type)	IL Walk Run N Roll (event type)	5 (total number)	(add col. (a) through col. (c))
ne			, ,,	· · · · · · · · · · · · · · · · · · ·	, ,	
Revenue	1	Gross receipts	176,500	11,970	36,352	224,822
ш	2	Less: Contributions	0	11,970	36,352	48,322
	3	Gross income (line 1 minus line 2)	176,500	0	0	176,500
	4	Cash prizes	0	0	0	0
	5	Noncash prizes	0	0	0	0
nses	6	Rent/facility costs	32,220	0	0	32,220
Direct Expenses	7	Food and beverages	600	0	0	600
Direct	8	Entertainment	0	0	0	0
	9	Other direct expenses .	61,551	1,945	909	64,405
	10	Direct expense summary. Ad	ld lines 1 through 9 in a	olumn (d)		97,225
	11	Net income summary. Subtra	_	· ·		79,275
Pa	rt II		e organization answe			
		\$15,000 OH FOHH 990-E2	_, iiile oa.	(b) Pull tabs/instant		(d) Total gaming (add
enne			(a) Bingo	bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col. (a) through col. (c))
Revenue	1	Gross revenue				
es	2	Cash prizes				
Direct Expenses	3	Noncash prizes				
irect E	4	Rent/facility costs				
D	5	Other direct expenses .				
	6	Volunteer labor	☐ Yes %☐ No	☐ Yes %☐ No	☐ Yes %☐ No	
	7	Direct expense summary. Ad	ld lines 2 through 5 in c	olumn (d)		
	8	Net gaming income summary	y. Subtract line 7 from li	ne 1, column (d)		
•	-	-ntartha atata(a) in which the ar	anization conducts as	mina activitica.		
	a l	Enter the state(s) in which the or s the organization licensed to co f "No," explain:	onduct gaming activities	s in each of these states		🗌 Yes 🗌 No
10		Were any of the organization's g f "Yes," explain:	aming licenses revoked	•	-	

Jiledui	ie a (i oiii 330 di 330-L2) 2013		rage u
11	Does the organization conduct gaming activities with nonmembers?	☐ Yes	☐ No
12	Is the organization a grantor, beneficiary or trustee of a trust, or a member of a partnership or other entity		
	formed to administer charitable gaming?	☐ Yes	☐ No
13	Indicate the percentage of gaming activity conducted in:		
а	The organization's facility		<u>%</u>
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►		
15a	Does the organization have a contract with a third party from whom the organization receives gaming revenue?	☐ Yes	☐ No
b	If "Yes," enter the amount of gaming revenue received by the organization ▶ \$ and the amount of gaming revenue retained by the third party ▶ \$		
	Name ►		
	Address ▶		
16	Gaming manager information:		
	Name ►		
	Gaming manager compensation ► \$		
	Description of services provided ►		
	□ Director/officer □ Employee □ Independent contractor		
17 a b	Mandatory distributions: Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license?	☐ Yes	□No
Part			

SCHEDULE I (Form 990)

Grants and Other Assistance to Organizations, Governments, and Individuals in the United States

OMB No. 1545-0047

Open to Public Inspection

Employer identification number

Department of the Treasury Internal Revenue Service Name of the organization

Complete if the organization answered "Yes" on Form 990, Part IV, line 21 or 22.

▶ Attach to Form 990. ► Go to www.irs.gov/Form990 for the latest information.

SIEGEL RARE NEUROIMMUNE ASSOCIATION 91-1780467 **General Information on Grants and Assistance** Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? ✓ Yes Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States. Grants and Other Assistance to Domestic Organizations and Domestic Governments. Complete if the organization answered "Yes" on Form 990, Part II Part IV, line 21, for any recipient that received more than \$5,000. Part II can be duplicated if additional space is needed. (f) Method of valuation 1 (a) Name and address of organization (d) Amount of cash (b) EIN (c) IRC section (e) Amount of non-(g) Description of (h) Purpose of grant (book, FMV, appraisal, or government (if applicable) grant cash assistance noncash assistance or assistance other) (1) Sch I, Stmt 1 (9) (10)(11)(12)

Schedule I (Form 990) (2019) Grants and Other Assistance to Domestic Individuals. Complete if the organization answered "Yes" on Form 990, Part IV, line 22. Part III Part III can be duplicated if additional space is needed. (a) Type of grant or assistance (b) Number of (c) Amount of (d) Amount of (e) Method of valuation (book, (f) Description of noncash assistance recipients cash grant noncash assistance FMV, appraisal, other) 3 5 6 Supplemental Information. Provide the information required in Part I, line 2; Part III, column (b); and any other additional information. Schedule I, Part I, Line 2 - The Organization has a written Conflict of Interest policy covering both the Board of Directors and the Organization's Medical and Scientific Council. The Medical and Scientific Council reviews written progress reports regarding the research project which includes a final written report on the project as well as a financial accounting. Any person with a conflict recuses themselves from any vote to award grants.

Form: **Schedule I (2019)** EIN: **91-1780467**

Page: 1 Part II, Line 1

Descri	ption of Grants and Other	Assistance to Governments and	Organizations in the United States

		Recipient EIN	Amt. of cash grant	Amt. of non- cash asst.
Name and address	University of Alabama Birmingham UAB School of Public Health 1665 University Blvd Birmingham, AL 35294	63-6005396	83,731	0
IRC code section Method of valuation Desc. of Non-Cash Asst.				
Purpose of grant	Development of data base to support Phase I clinical trial in humans using human fetal derived glial restricted progenitor cells (Q Cells) in transverse myelitis.			
Name and address	Johns Hopkins Univ School of Medicine 900 N Wolfe St Meyer 6-181E Baltimore, MD 21287	52-0595110	8,500	0
IRC code section Method of valuation Desc. of Non-Cash Asst.	170			
Purpose of grant	Monies were provided to test DNA from SRNA community members with diagnosed transverse myelitis for a newly discovered genetic mutation			
Name and address	University of Texas Southwestern Medical Center 5323 Harry Hines Blvd Dallas, TX 75390	75-6002868	60,000	0
IRC code section Method of valuation Desc. of Non-Cash Asst.	170			
Purpose of grant	Fellowship award for salary, benefits and supplies for Fellow training in the clinical treatment of and research pertaining to rare neuroiummune disease	s		
Name and address	University of Utah 201 S Presidents Circle Room 416 Park Building Salt Lake City, UT 84112	87-6000525	40,000	0
IRC code section Method of valuation Desc. of Non-Cash Asst.				
Purpose of grant	Fellowship award for salary, benefits and supplies for Fellow training in the clinical treatment of and research pertaining to rare neuroiummune disease	s		

SCHEDULE M (Form 990)

Noncash Contributions

OMB No. 1545-0047

2019

Open to Public Inspection

Department of the Treasury Internal Revenue Service Name of the organization

1

2

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

(b)

Number of contributions or

items contributed

► Attach to Form 990.

(a)

Check if

applicable

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

SIEGEL RARE NEUROIMMUNE ASSOCIATION

Types of Property

Art—Works of art

Art—Historical treasures . . .

Employer identification number

91-1780467 (c) Noncash contribution (d) Method of determining amounts reported on Form 990, Part VIII, line 1g noncash contribution amounts

3	Art—Fractional interests							
4	Books and publications							
5	Clothing and household							
	goods							
6	Cars and other vehicles							
7	Boats and planes							
8	Intellectual property							
9	Securities-Publicly traded	~	3	134,170	FMV			
10	Securities-Closely held stock .							
11	Securities—Partnership, LLC, or trust interests							
12	Securities-Miscellaneous							
13	Qualified conservation contribution—Historic structures							
14	Qualified conservation contribution—Other							
15	Real estate - Residential							
16	Real estate—Commercial							
17	Real estate—Other							
18	Collectibles							
19	Food inventory							
20	Drugs and medical supplies							
21	Taxidermy							
22	Historical artifacts							
23	Scientific specimens							
24	Archeological artifacts							
25	Other ► ()							
26	Other ► () Other ► ()							
27	Other ► ()							
28	Other ► (
29	Number of Forms 8283 received	by the org	anization during the ta	x year for contributions for				
	which the organization completed	Form 8283	, Part IV, Donee Acknow	vledgement	29	0		
							Yes	No
30a	During the year, did the organizat 28, that it must hold for at least the	hree years f	rom the date of the initi	al contribution, and which is	n't require			
	to be used for exempt purposes f		• •			30a		~
b	If "Yes," describe the arrangement							
31	Does the organization have a contributions?	gift accep	tance policy that req	uires the review of any n	onstandar	d 31		٧
32a	Does the organization hire or use contributions?	•	_	ons to solicit, process, or s	ell noncasi	h 32a	~	
b	If "Yes," describe in Part II.							
33	If the organization didn't report an describe in Part II.	amount in o	column (c) for a type of p	property for which column (a)	is checked	d,		
or Pap	perwork Reduction Act Notice, see the Inst	ructions for Fe	orm 990.	Cat. No. 51227J	Schee	dule M (Fo	orm 990	0) 2019

Schedule M (Form 990) 2019 Supplemental Information. Provide the information required by Part I, lines 30b, 32b, and 33, and whether the organization is reporting in Part I, column (b), the number of contributions, the number of items received, or a combination of both. Also complete this part for any additional information. Schedule M, Part I, Line 32b - Securities are held in brokerage account until a sell order is placed through the brokerage

SCHEDULE O (Form 990 or 990-EZ)

Department of the Treasury

Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

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

► Attach to Form 990 or 990-EZ.

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

OMB No. 1545-0047

2019

Open to Public Inspection

Name of the organization	Employer identification number
SIEGEL RARE NEUROIMMUNE ASSOCIATION	91-1780467
Form 990, Part VI, Section B, Line 11b - 990 reviewed by officers and tied to independent audit	
Form 990, Part VI, Section B, Line 12c - Board review of conflict per policy	
Form 990, Part VI, Section B, Line 15 - Compensation for Executive Director. Numerous organizations of s	imilar size and program criteria
were contacted and interviewed regarding appropriate compensation for Executive Director. OANA was all	so consulted for similar
information. Compensation process for key employees is to do a market survey of similar organizations a	
	avortising for positions with similar
responsibilities	
Form 990, Part VI, Section C, Line 19 - The Governing Documents and Conflict of Interest Policy are not pu	ıblicly available. Financial
statements are posted on the SRNA website, are available by request, and are also available on Guidestar	•
Form 990, Part IX, Line 11g - Design, content and information technology consultant fees	

Schedule O, Statement 1

SIEGEL RARE NEUROIMMUNE ASSOCIATION

Form: **Form 990 (2019)** EIN: **91-1780467**

Page: 1 Part I, Line 1

Activity Or Mission Description

Description

NERVOUS SYSTEM; TO PROMOTE AWARENESS AND TO EMPOWER PATIENTS, FAMILIES, CLINICIANS AND SCIENTISTS THROUGH EDUCATION PROGRAMS AND PUBLICATIONS AND TO ADVANCE THE SCIENTIFIC UNDERSTANDING OF AND THERAPY DEVELOPMENT FOR THESE RARE DISORDERS BY SUPPORTING THE TRAINING OF CLINICIANS-SCIENTISTS DEDICATED TO THESE RARE DISORDERS AND BY SUPPORTING BASIC AND CLINICAL RESEARCH. OUR GOAL IS TO IMPROVE THE QUALITY OF LIFE OF INDIVIDUALS WITH RARE NEUROIMMUNE DISORDERS.

Schedule O, Statement 2

SIEGEL RARE NEUROIMMUNE ASSOCIATION

Form: **Form 990 (2019)** EIN: **91-1780467**

Page: 2 Part III, Line 1

Mission Description

Description

SCIENTIFIC UNDERSTANDING OF AND THERAPY DEVELOPMENT FOR THESE RARE DISORDERS BY SUPPORTING THE TRAINING OF CLINICIANS-SCIENTISTS DEDICATED TO THESE RARE DISORDERS AND BY SUPPORTING BASIC AND CLINICAL RESEARCH. OUR GOAL IS TO IMPROVE THE QUALITY OF LIFE OF INDIVIDUALS WITH RARE NEUROIMMUNE DISORDERS.

SIEGEL RARE NEUROIMMUNE ASSOCIATION

Form: **Form 990 (2019)** EIN: **91-1780467**

Page: 6 Part VI, Section C, Line 17

	States Where Copy Of Return Is Filed
States	
AK	
AL	
AR	
CA	
СО	
СТ	
DC	
FL	
GA	
HI	
IL	
KS	
KY	
MA	
MD	
ME	
MI	
MN	
MS	
NC	
ND	
NH	
NJ	
NM	
NV	
NY	
ОН	
ОК	
OR	
PA	
RI	
SC	
TN	
UT	
VA	
WA	
WI	

WV