# \*\*\* PUBLIC DISCLOSURE COPY \*\*\*

# Form 990

**Return of Organization Exempt From Income Tax** 

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations) Do not enter social security numbers on this form as it may be made public.



		f the Treasu nue Service			Go to www.irs.go	v/Form990 for ins	tructions ar	nd the latest	information.	-	Inspec	
				ar year, or tax ye				d ending				
B	Check if applicable		ame o	f organization					D Employer	identifica	tion number	
	Address SPINA BIFIDA ASSOCIATION OF AMERICA											
	Name Doing business as 58-1342181										1	
	initial return	N	umber	and street (or P.0	D. box if mail is not (	delivered to street add	ress)	Room/suite	E Telephone			
	Final return/			WILSON H				800	(202	) 944	-3285	
	termin ated					d ZIP or foreign po:	stal code		G Gross receipts	\$	2,526	<u>,480.</u>
Amended ARLINGTON, VA 22209 H(a) is this a group return												
	Applic tion					RA STRUWE			for subo	rdinates?	Yes	X No
_	pendir	<u> </u>		AS C ABO	/E				H(b) Are all subc			No
	I Tax-exempt status: X 501(c)(3) 501(c)( )											
				SBAA.ORG	<u> </u>			<u> </u>	H(c) Group e			
ĸ	Form of			X Corporation	Trust	Association (	)ther 🕨	L Year	of formation: 1	973 M	State of legal do	micile: WL
P	Part I	Sumr								1 001	T DINT	
4	1	Briefty d	lescrit	e the organizatio	n's mission or mo	st significant activit	ies: THE	MISSIO	N OF THI	SPII	NA BIFIL	JA
ctivities & Covernance		ASSO	CIA			A BETTER A						
Č	2	Check t				continued its operat					ts.	12
	5 3			-	-	y (Part VI, line 1a)						12
C.	24					overning body (Par					·	15
9	5					year 2021 (Part V,						575
1	6					) 						0.
2						column (C), line 12						0.
_	b	Net unre	elated	business taxable	income from Forr	n 990-T, Part I, line	11		6.2		0	
	1								<u>Prior Year</u> 1,460,0		<u>Current Y</u> 2,139	
9	8			•	VIII, line 1h)		37,4			<u>,230.</u> ,185.		
0	9	•		ce revenue (Part								,425.
Daviantia	<u>}</u> 10									928.		<u>,425.</u>
	11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)							1,521,		2,283	
_									12,			<u>, 458.</u>
									14;	0.	J	. <u>.</u>
			•		•				1,294,	-	1,223	
	8 15	Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)								0.	1,445	<u>,004.</u> 0.
ģ	21					169.	2.11.			0.		
-	ž b			• • •	rt IX, column (D), l		743,	810	809	,616.		
	- 1 17				n (A), lines 11a-11		2,051,		2,036			
						t IX, column (A), line			-529,			,818.
_	 ø	Revenue	e Iess	expenses. Subtra	CT ING 18 TOTT III	e 12			ginning of Curre		End of Y	
ts o		<b>T</b> . <b>i</b>		Dent V. 6 10)				00	1,403,		1,442	
SSe	ब 20 स			Part X, line 16)					493,			,534.
Net Assets or	121 1 m			(Part X, line 26)		m line 20			910,		1,206	
	<u>न 22</u> Part II	Sign	atun	Block	ubtract time 21 no	<u></u>						
					examined this retur	n, including accompa	nvina schedul	es and stateme	ents, and to the b	est of my k	nowledge and b	alief, it is
						icer) is based on all in						
	o, con oc			a thun							022	
Sig		Si Si	gnatur	e of officer				8	Date	1		8 8
	919 11 - 11 - 11 - 11 - 11 - 11 - 11 - 1	Í S	ARA	STRUWE .	PRESIDEN	r and ceo						
				print name and title								
_		Print/Tv	ne pre	parer's name		Preparer's signatu	ire /	7	Date	Check	PTIN	
Pai	id			. FOX			(ll	1	0/21/22	self-employed	P01365	820
	Iorage	Firm's n	ame	MARCUM	LLP			70	Firm's	EIN ▶ 1	1-19863	23
Us	e Only	Firm's a	ddress	<b>1899 L</b>	STREET, 1	NW, SUITE	850			11		
	WASHINGTON, DC 20036 Phone no. (202) 227-4000											
Ma	ay the IF	RS discu	iss thi	the second se		ove? See instruction	ons				X Yes	No
_	132001 12-09-21 LHA For Paperwork Reduction Act Notice, see the separate instructions. Form 990 (2021)											
		EE S	CHE	DULE O FO	OR ORGANIZ	LATION MIS	SION S	TATEMEN	T CONTI	NUATI	ON	
				***		ICALLY FI					COPY	
							•11	/			JUTI	

	990 (2021) SPINA BIFIDA ASSOCIATION OF AMERICA 58-1342181 Page 2
Par	t III       Statement of Program Service Accomplishments         Check if Schedule O contains a response or note to any line in this Part III       X
1	Briefly describe the organization's mission:
•	TO PROVIDE INFORMATION ABOUT THE BIRTH DEFECT OF SPINA BIFIDA AND ITS
	RELATED CONDITIONS AND SUPPORT TO INDIVIDUALS LIVING WITH IT THROUGH
	EDUCATION, ADVOCACY, RESEARCH, AND SERVICE; TO FACILITATE RESEARCH
	INTO THE CAUSES, EFFECTS, AND TREATMENT OF SPINA BIFIDA; AND TO
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.
	(Code:) (Expenses \$768,772. including grants of \$3,458. ) (Revenue \$115,185.
	RESEARCH AND CLINICAL CARE - THE SPINA BIFIDA ASSOCIATION (THE
	ASSOCIATION) DEVELOPED THE SPINA BIFIDA COLLABORATIVE CARE NETWORK
	(SBCCN) TO IMPROVE THE HEALTH CARE OF PEOPLE WITH SPINA BIFIDA,
	ENABLING THEM TO HAVE BETTER CARE. THE SBCCN, WHEN COMPLETED, WILL
	BUILD A SYSTEM THAT MONITORS, TRACKS, AND EVALUATES CARE PROVIDED IN
	SPINA BIFIDA CLINICS AND OTHER HEALTH CARE SETTINGS. THE SBCCN IS MADE
	UP OF PEOPLE OF DIFFERENT BACKGROUNDS AND EXPERIENCES: SPINA BIFIDA
	ASSOCIATION (SBA) STAFF, CHAPTER LEADERS, DOCTORS, NURSES, PSYCHOLOGISTS, THE CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC),
	PSYCHOLOGISTS, THE CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC), PARENTS OF CHILDREN WITH SPINA BIFIDA, AND ADULTS WITH SPINA BIFIDA.
	THE ASSOCIATION WORKED IN CONJUNCTION WITH THE NATIONAL CENTER ON BIRTH
	DEFECTS AND DEVELOPMENTAL DISABILITIES TO CONTINUE RESEARCH THROUGH THE
4b	
40	(Code:) (Expenses \$375,452. including grants of \$) (Revenue \$) (Reven
	CAREGIVERS AND PERSONS LIVING WITH SPINA BIFIDA WITH TOOLS AND
	RESOURCES AT CRITICAL POINTS IN DEVELOPMENT AND TRANSITION. EDUCATION
	AND INFORMATIONAL RESOURCES WERE PROVIDED TO OVER 325,000 PEOPLE WITH
	SPINA BIFIDA, PARENTS, AND CAREGIVERS AS WE CONTINUED TO EXPAND OUR
	REACH IN 2020 AS A RESULT OF INCORPORATING SOCIAL MEDIA.
4c	(Code:) (Expenses \$ 251, 327. including grants of \$ 0. ) (Revenue \$ 0.
	MEMBER SERVICES/CHAPTER DEVELOPMENT - THE ASSOCIATION PROMOTES THE
	GROWTH AND DEVELOPMENT OF ITS 16 CHAPTERS THROUGH TECHNICAL ASSISTANCE
	IN CAPACITY BUILDING, COMMUNICATIONS, PROGRAMMATIC RESOURCES AND
	GRANTS.
4.1	Other program services (Describe on Schedule O.)
4d	(Expenses \$ 193,759. including grants of \$ 0.) (Revenue \$ 0.)
4a 4e	Total program service expenses ► 1,589,310.
4e	Form 990 (202
4e	Total program service expenses       1,589,310.         Form 990 (202*)         2       2

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Part IV Checklist of Required Schedules

			Yes	No
1	Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)?			
	If "Yes," complete Schedule A	1	X	
2	Is the organization required to complete Schedule B, Schedule of Contributors? See instructions	2	Х	
3	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for			
	public office? If "Yes," complete Schedule C, Part I	3		<u> </u>
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? If "Yes," complete Schedule C, Part II	4	Х	
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 Rev. Proc. 98-19? If "Yes," complete Schedule C, Part III	5		X
6	Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to			v
_	provide advice on the distribution or investment of amounts in such funds or accounts? If "Yes," complete Schedule D, Part I	6		<u> </u>
7	Did the organization receive or hold a conservation easement, including easements to preserve open space,	_		v
•	the environment, historic land areas, or historic structures? If "Yes," complete Schedule D, Part II	7		<u> </u>
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete			х
~	Schedule D, Part III	8		
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?			х
10	If "Yes," complete Schedule D, Part IV	9		
10	Did the organization, directly or through a related organization, hold assets in donor-restricted endowments	10	х	
11	or in quasi endowments? <i>If "Yes," complete Schedule D, Part V</i> If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VII, IX, or X,		- 11	
	as applicable.			
~	Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes." complete Schedule D.			
a		11a	х	
h	Part VI Did the organization report an amount for investments - other securities in Part X, line 12, that is 5% or more of its total			
<sup>D</sup>	assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VII	11b		х
c	Did the organization report an amount for investments - program related in Part X, line 13, that is 5% or more of its total			
•	assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VIII	11c		х
d	Did the organization report an amount for other assets in Part X, line 15, that is 5% or more of its total assets reported in			
	Part X, line 16? If "Yes," complete Schedule D, Part IX	11d		х
е	Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X	11e	Х	
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	Х	
12a	Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete			
	Schedule D, Parts XI and XII	12a	Х	
b	Was the organization included in consolidated, independent audited financial statements for the tax year?			
	If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional	12b		Х
13	Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E	13		Х
14a	Did the organization maintain an office, employees, or agents outside of the United States?	14a		Х
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		X
15	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any			
	foreign organization? If "Yes," complete Schedule F, Parts II and IV	15		X
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		X
17	Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX,			
	column (A), lines 6 and 11e? If "Yes," complete Schedule G, Part I. See instructions	17		_X_
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		<u> </u>
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		X
	Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H	20a		X
	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			v
	domestic government on Part IX, column (A), line 1? If "Yes." complete Schedule I. Parts I and II	21	990	X (2021)
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			Yes	No
22	Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on			
	Part IX, column (A), line 2? If "Yes," complete Schedule I, Parts I and III	22	X	
23	Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5, about compensation of the organization's current			
	and former officers, directors, trustees, key employees, and highest compensated employees? If "Yes," complete			
	Schedule J	23	Х	
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		X
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? If "Yes," complete Schedule L, Part I	25a		X
b	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and			
	that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? If "Yes." complete			
	Schedule L. Part I	25b		X
26	Did the organization report any amount on Part X, line 5 or 22, for receivables from or payables to any current			
	or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35%			
	controlled entity or family member of any of these persons? If "Yes," complete Schedule L, Part II	26		x
27	Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee,			
	creator or founder, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled			
	entity (including an employee thereof) or family member of any of these persons? If "Yes," complete Schedule L, Part III	27		x
28	Was the organization a party to a business transaction with one of the following parties (see the 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		x
h	A family member of any individual described in line 28a? If "Yes," complete Schedule L, Part IV	28b		x
	A 35% controlled entity of one or more individuals and/or organizations described in line 28a or 28b? If	200		<u> </u>
U	"Yes," complete Schedule L, Part IV	28c		x
29	Did the organization receive more than \$25,000 in non-cash contributions? If "Yes," complete Schedule M	29		x
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation	23		<u> </u>
30	contributions? If "Yes," complete Schedule M	30		x
31	Did the organization liquidate, terminate, or dissolve and cease operations? If "Yes," complete Schedule N, Part I	31		X
32	Did the organization requidate, terminate, or dissolve and cease operations? <i>If "yes," complete Schedule N, Part I</i>	31		
32		32		x
22	Schedule N, Part II Did the organization own 100% of an entity disregarded as separate from the organization under Regulations	32		
33		20		x
24	sections 301.7701-2 and 301.7701-3? If "Yes," complete Schedule R, Part 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			x
05 -	Part V, line 1	34		X
	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	<u>35a</u>		
a	If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity	0.51		
~~	within the meaning of section 512(b)(13)? If "Yes," complete Schedule R, Part V, line 2	35b		<u> </u>
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization?			x
07	If "Yes," complete Schedule R, Part V, line 2	36		
37	Did the organization conduct more than 5% of its activities through an entity that is not a related organization	0-		v
00	and that is treated as a partnership for federal income tax purposes? <i>If</i> "Yes," <i>complete Schedule R, Part VI</i>	37		X X
38	Did the organization complete Schedule O and provide explanations on Schedule O for Part VI, lines 11b and 19?		v	
Par	Note: All Form 990 filers are required to complete Schedule O           t V         Statements Regarding Other IRS Filings and Tax Compliance	38	Х	I
rai				
	Check if Schedule O contains a response or note to any line in this Part V			
			Yes	No
	Enter the number reported in box 3 of Form 1096. Enter -0- if not applicable <b>1a 38</b>	-		
	Enter the number of Forms W-2G included on line 1a. Enter -0- if not applicable <b>1b</b>			
с	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming		37	
	(gambling) winnings to prize winners?	1c	X	<u> </u>
132004	. 12-09-21 <b>Δ</b>	Form	990	(2021)
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.021)			ASSOCIATION			
Statements	Regarding	Other IRS	Filings and Tax Co	ompl	iance	(continued)

					Yes	No		
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements,		1-					
	filed for the calendar year ending with or within the year covered by this return	2a	15	2b	х			
b	<b>b</b> If at least one is reported on line 2a, did the organization file all required federal employment tax returns?							
39	<ul> <li>Note: If the sum of lines 1a and 2a is greater than 250, you may be required to <i>e-file</i>. See instructions.</li> <li>3a Did the organization have unrelated business gross income of \$1,000 or more during the year?</li> </ul>							
	If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation on Schedule			3a 3b		X		
	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 a		-	4a		x		
b	If "Yes," enter the name of the foreign country							
	See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Ad	ccoun	ts (FBAR).					
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?			5a		X		
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transact			5b		X		
С	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?			<u>5c</u>				
6a	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the	-				x		
L	any contributions that were not tax deductible as charitable contributions?			<u>6a</u>				
a	If "Yes," did the organization include with every solicitation an express statement that such contribution were not tax deductible?			6b				
7	Organizations that may receive deductible contributions under section 170(c).			0.0				
'a	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and ser	vices c	rovided to the pavor?	7a		x		
b				7b				
с	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it wa							
	to file Form 8282?			7c		X		
d	If "Yes," indicate the number of Forms 8282 filed during the year	7d						
е	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit co	ontrac	t?	7e		X X		
f	f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?							
g								
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization			7h				
8	8 Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?							
9	Sponsoring organizations maintaining donor advised funds.			8				
	a Did the sponsoring organization make any taxable distributions under section 4966?							
b								
10	Section 501(c)(7) organizations. Enter:							
а	Initiation fees and capital contributions included on Part VIII, line 12	10a						
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities	10b		-				
11	Section 501(c)(12) organizations. Enter:	ı	1					
	Gross income from members or shareholders	11a		-				
b	Gross income from other sources. (Do not net amounts due or paid to other sources against							
10-	amounts due or received from them.)	1041	2	10-				
	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form If "Yes," enter the amount of tax-exempt interest received or accrued during the year	1041 12b	r 	12a				
13	Section 501(c)(29) qualified nonprofit health insurance issuers.	120		1				
	Is the organization licensed to issue qualified health plans in more than one state?			13a				
	Note: See the instructions for additional information the organization must report on Schedule O.							
b	Enter the amount of reserves the organization is required to maintain by the states in which the							
	organization is licensed to issue qualified health plans	13b						
	Enter the amount of reserves on hand	13c						
				14a		X		
	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation on Schedul			14b				
15	Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuner			4-		v		
	excess parachute payment(s) during the year?			15		X		
16	If "Yes," see the instructions and file Form 4720, Schedule N.	incor	ne?	16		x		
16	Is the organization an educational institution subject to the section 4968 excise tax on net investment If "Yes," complete Form 4720, Schedule O.	IIICOF		10				
17	Section 501(c)(21) organizations. Did the trust, any disqualified person, or mine operator engage in	anv						
	activities that would result in the imposition of an excise tax under section 4951, 4952 or 4953?	-		17				
_	If "Yes," complete Form 6069.							
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Form 990 (2021)

Part V

Form 990	(2021)
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### SPINA BIFIDA ASSOCIATION OF AMERICA

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

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

		1 1		Yes	N	
<b>1</b> a	Enter the number of voting members of the governing body at the end of the tax year	1a	12			
	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.					
b	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					
	officer, director, trustee, or key employee?		2			
3	Did the organization delegate control over management duties customarily performed by or under the	-				
					X X X	
4	Did the organization make any significant changes to its governing documents since the prior Form 9					
5	Did the organization become aware during the year of a significant diversion of the organization's ass					
6	Did the organization have members or stockholders?		6	X		
7a	Did the organization have members, stockholders, or other persons who had the power to elect or ap		-	x		
<b>h</b>	more members of the governing body? Are any governance decisions of the organization reserved to (or subject to approval by) members, si		7		+	
D				x		
~	persons other than the governing body?		7			
	Did the organization contemporaneously document the meetings held or written actions undertaken during the year	,		v		
	The governing body?				+	
b	Each committee with authority to act on behalf of the governing body?		8		+	
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be real				x	
	organization's mailing address? If "Yes," provide the names and addresses on Schedule O		g			
	tion B. Policies (This Section B requests information about policies not required by the Internal Re	evenue Code.)			<b>T</b>	
~				Yes a X	N	
	Did the organization have local chapters, branches, or affiliates?		10	<u>a                                    </u>	-	
b	If "Yes," did the organization have written policies and procedures governing the activities of such ch					
	and branches to ensure their operations are consistent with the organization's exempt purposes?				-	
	Has the organization provided a complete copy of this Form 990 to all members of its governing body	y before filing the for	m? <b>11</b>	a X		
	Describe on Schedule O the process, if any, used by the organization to review this Form 990.					
	Did the organization have a written conflict of interest policy? If "No," go to line 13					
С	Did the organization regularly and consistently monitor and enforce compliance with the policy? If "	,		v		
_	on Schedule O how this was done				-	
3	Did the organization have a written whistleblower policy?				-	
4	Did the organization have a written document retention and destruction policy?		1			
5	Did the process for determining compensation of the following persons include a review and approva	I by independent				
	persons, comparability data, and contemporaneous substantiation of the deliberation and decision?			v		
	The organization's CEO, Executive Director, or top management official		15			
b	Other officers or key employees of the organization		15	b	X	
	If "Yes" to line 15a or 15b, describe the process on Schedule O. See instructions.					
6a	Did the organization invest in, contribute assets to, or participate in a joint venture or similar arranger	nent with a				
-	taxable entity during the year?		16	a	X	
b	If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluat					
	in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organ	lization's				
00	exempt status with respect to such arrangements?		16	b		
	tion C. Disclosure	A TI VO VV	MD M	<u>мт</u>	1/7	
	List the states with which a copy of this Form 990 is required to be filed $\blacktriangleright$ AL, AR, CA, FL, G					
8	Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, and	nd 990-1 (section 50	1(c)(3)s on	y) availa	able	
	for public inspection. Indicate how you made these available. Check all that apply.					
_		n on Schedule O)				
9	Describe on Schedule O whether (and if so, how) the organization made its governing documents, co	onflict of interest poli	cy, and fina	ancial		
	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 boo CLENDAE DROUM $(202)$ $0.44$ 2295	oks and records				
	$\frac{\text{GLENRAE BROWN} - (202) 944 - 3285}{1600 \text{ NTLGON DOWNEYARD $300 \text{ ADD TNOTION VALUE $22200}}$					
	1600 WILSON BOULEVARD, 800, ARLINGTON, VA 22209				<b>)</b> (202	
	12-09-21 SEE SCHEDULE O FOR FULL LIST OF STATES					

Form 990 (2)	021) SPINA BIFIDA ASSOCIATION OF AMERICA SOmpensation of Officers, Directors, Trustees, Key Employees, Highest Compens	<u>58-1342181</u> ated	Page 1
	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 Complet	te this table for all persons required to be listed. Report compensation for the calendar year ending with or wi	thin the organization's	s tax year.

• List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.

• List all of the organization's current key employees, if any. See the instructions for definition of "key employee."

• List the organization's five current highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (box 5 of Form W-2, Form 1099-MISC, and/or box 1 of Form 1099-NEC) of more than \$100,000 from the organization and any related organizations.

• List all of the organization's **former** officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.

• List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations.

See the instructions for the order in which to list the persons above.

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

(A)	(B)	(C)						(D)	(E)	(F)
Name and title	Average	Position (do not check more than one			ne	Reportable	Estimated			
	hours per	box	ox, unles		ess person is both an nd a director/trustee)			compensation	compensation	amount of
	week		cer an	a a a	recto	or/trus	tee)	from	from related	other
	(list any	ndividual trustee or director						the	organizations	compensation
	hours for related	e or d	tee			sated		organization (W-2/1099-MISC/	(W-2/1099-MISC/ 1099-NEC)	from the organization
	organizations	rustee	l trus		ee	npen		1099-NEC)	1099-NEC)	and related
	below	dual t	nstitutional trustee	-	ƙey employee	st cor	1	1000 1120)		organizations
	line)	Indivi	In stit t	Officer	Key ei	Highest compensated employee	Former			
(1) SARA STRUWE	37.50									
PRESIDENT AND CEO		1		Х				140,400.	Ο.	28,505.
(2) GLENRAE BROWN	37.50									
CHIEF FINANCE OFFICER				Х				110,250.	0.	26,030.
(3) SHELIAH ROY	37.50									
CHIEF OPERATING OFFICER				Х				100,000.	0.	8,558.
(4) MICHAEL HARTY, JR.	5.00									
CHAIR		Х		Х				0.	0.	0.
(5) NICOLE GOWER	2.00									
IMMEDIATE PAST CHAIR - UNTIL 12/21		Х		Х				0.	0.	0.
(6) MARIA BOURNIAS, ESQ, CPA	2.00									
CHAIR-ELECT		Х		Х				0.	0.	0.
(7) ANSHUL VARMA	2.00									
TREASURER/SECRETARY		Х		Х				0.	0.	0.
(8) BRAD DICIANNO	2.00									
BOARD MEMBER		Х						0.	0.	0.
(9) NANCY GORE	2.00									
BOARD MEMBER		Х						0.	0.	0.
(10) WILSON NEYLAND	2.00									
BOARD MEMBER - UNTIL 12/21		Х						0.	0.	0.
(11) CHASE PHILLIPS	2.00									
BOARD MEMBER		Х						0.	0.	0.
(12) KATHRYN SMITH	2.00									
BOARD MEMBER		Х						0.	0.	0.
(13) MARIE THOMING	2.00									
BOARD MEMBER		Х						0.	0.	0.
(14) MCKAY TOLBOE	2.00									
BOARD MEMBER - UNTIL 12/21		Х						0.	0.	0.
(15) JOHN WIENER, MD	2.00									
BOARD MEMBER		Х						0.	0.	0.
										000

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Form 990 (2021)

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2021.04030 SPINA BIFIDA ASSOC

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Form 990 (2021) SPINA BI	FIDA ASS	OC	ΊA	ΤI	ON	0	F	AMERICA	58-13	4218	1 г	Page <b>8</b>
Part VII Section A. Officers, Directors, Trus	tees, Key Emp	oloye	ees,	and	l Hig	ghes	t C	ompensated Employee	s (continued)			
(A)	(B)			(0				(D)	(E)		(F)	
Name and title	Average			Posi	ition			Reportable	Reportable		Estimat	ed
	hours per					than o s both		compensation	compensation		amount	of
	week					r/trust		from	from related		other	
	(list any	ctor						the	organizations	co	ompens	
	hours for	direc				Ð		organization	(W-2/1099-MIS		from th	
	related	ee or	stee			nsate		(W-2/1099-MISC/	1099-NEC)		organiza	tion
	organizations	trust	al tru		yee	a m pe		1099-NEC)	,		and rela	
	below	dual	ution	5	nplo	est cc oyee	er	,		0	rganizat	ions
	line)	ndividual trustee or director	nstitutional trustee	Officer	Key employee	Highest compensated employee	Former				0	
		_	_		×	1 0	<u> </u>					
						$\left  \right $						
										_		
1b Subtotal						1		350,650.			63,0	
c Total from continuation sheets to Part VI	I, Section A					]		0.		0.		0.
d Total (add lines 1b and 1c)								350,650.		0.	63,0	93.
2 Total number of individuals (including but n							n re		000 of reportable			
compensation from the organization		000		u uo		,						3
											Yes	No
											103	
<b>3</b> Did the organization list any <b>former</b> officer,			•	•	-		Ŭ					
line 1a? If "Yes," complete Schedule J for s										3	;	X
4 For any individual listed on line 1a, is the su	im of reportabl	е со	mpe	nsat	tion	and	oth	ner compensation from the	ne organization			
and related organizations greater than \$150	0,000? If "Yes.	" со	mple	ete S	Sche	dule	J f	or such individual		4	X	
5 Did any person listed on line 1a receive or a												
rendered to the organization? If "Yes." corr	-				-			-		5		x
Section B. Independent Contractors	ipiele Schedule	<u>,                                    </u>	or su	<u>CH Ļ</u>	Jers	011 .				J	·	
· · · · · · · · · · · · · · · · · · ·												
1 Complete this table for your five highest co										ensation	from	
the organization. Report compensation for	the calendar ye	ear e	ndin	g wi	ith c	or wit	<u>hin</u>	the organization's tax y	ear.			
(A)								(B)			(C)	
Name and business	address	NC	ONE					Description of s	ervices	Com	pensatio	on
							+					
O Total number of independent contractors /					hh e -			abova) who meaning the	we then			
2 Total number of independent contractors (i		י ווח	mea	101	-		ea	above) who received mo				
\$100,000 of compensation from the organi	zation 🕨				C	,					000	
										For	m <b>990</b>	(2021)

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		2021) SPINA BIFIDA ASS	OCIATION	OF AMER	RICA	58-1342	181 Page <b>9</b>
Pa	rt VI	Statement of Revenue					
		Check if Schedule O contains a response or not	e to any line in th		(D)	(0)	
			Т	(A) otal revenue	<b>(B)</b> Related or exempt	<b>(C)</b> Unrelated	(D) Revenue excluded
						business revenue	from tax under
<u> </u>							sections 512 - 514
tts Its	1 a	Federated campaigns 1a 49	,586.				
irar	b	Membership dues 1b					
¶o No	c	Fundraising events 1c					
ar lit	c	Related organizations 1d					
s, o	e	Government grants (contributions) 1e 924	.,024.				
io Si o	f	All other contributions, gifts, grants, and					
but		similar amounts not included above   If   1,165	5,626.				
d dr	ç	Noncash contributions included in lines 1a-1f	5,897.				
Contributions, Gifts, Grants and Other Similar Amounts	h	Total. Add lines 1a-1f	🕨 2,1	.39,236.			
		Busir	ness Code				
e	2 a	CONFERENCE & MEETINGS 54	1800 1	15,185.	115,185.		
, vic	b			-	-		
Ser	c						
am Sve	c						
Program Service Revenue	e						
Pro	f	All other program service revenue					
	c	Total. Add lines 2a-2f	▶ 1	15,185.			
	3	Investment income (including dividends, interest, and		,			
	•	other similar amounts)		7,879.			7,879.
	4	Income from investment of tax-exempt bond proceed		,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,			.,
	5	Royalties					
	Ŭ	(i) Real (ii) F	Personal				
	6 a						
	08	Less: rental expenses 6b					
		Rental income or (loss) 6c					
		Net rental income or (loss)         Gross amount from sales of         (i) Securities	i) Other				
	1 8						
6		Less: cost or other basis and sales expenses					
evenue							
				12,546.			12,546.
Other R		Net gain or (loss)	🕨	12,540.			12,540.
the	8 a	Gross income from fundraising events (not					
0		including \$ of					
		contributions reported on line 1c). See					
		Part IV, line 18					
	b						
	C	Net income or (loss) from fundraising events	····· <b>&gt;</b>				
	9 a	Gross income from gaming activities. See					
		Part IV, line 19 9a					
		Less: direct expenses 9b					
		Net income or (loss) from gaming activities	🕨 📘				
	10 a	Gross sales of inventory, less returns					
		and allowances 10a					
	b	Less: cost of goods sold 10b					
	c	Net income or (loss) from sales of inventory					
s			ness Code				
e sou	11 a	MISCELLANEOUS INCOME 90	0099	8,850.			8,850.
scellaneo Revenue	b						
eve	c						
Miscellaneous Revenue	c	All other revenue					
<		Total. Add lines 11a-11d		8,850.			
	12	Total revenue. See instructions	▶ 2,2	283,696.	115,185.	0.	29,275.
132009	9 12-09	-21					Form <b>990</b> (2021)

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<sup>9</sup> 2021.04030 SPINA BIFIDA ASSOC**COPY**<sup>193407\_1</sup>

Form 990 (2021) SPINA BIFIDA . Part IX Statement of Functional Expenses SPINA BIFIDA ASSOCIATION OF AMERICA

X

Section 501(c)(3) and 501(c)(4) organizations must complete all columns. All other organizations must complete column (A).								
Check if Schedule O contains a response or note to any line in this Part IX								
Do not include amounts reported on lines 6h (A) (B) (C)								

	not include amounts reported on lines 6b,	(A) Total expenses	(B) Program service	<b>(C)</b> Management and	(D) Fundraising
	8b, 9b, and 10b of Part VIII.		expenses	general expenses	expenses
1	Grants and other assistance to domestic organizations	200.	200.		
•	and domestic governments. See Part IV, line 21	200.	200.		
2	Grants and other assistance to domestic	3,258.	3,258.		
2	individuals. See Part IV, line 22	5,230.	J,2J0.		
3	Grants and other assistance to foreign				
	organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16				
4	Benefits paid to or for members				
5	Compensation of current officers, directors,				
5	trustees, and key employees	413,743.	365,556.	34,314.	13,873.
6	Compensation not included above to disqualified	1107/101		01/0110	
v	persons (as defined under section 4958(f)(1)) and				
	persons described in section 4958(c)(3)(B)				
7	Other salaries and wages	606,756.	493,130.	34,252.	79,374.
8	Pension plan accruals and contributions (include				- / -
-	section 401(k) and 403(b) employer contributions)				
9	Other employee benefits	118,921.	97,215.	6,184.	15,522.
10	Payroll taxes	84,384.	70,793.	5,536.	8,055.
11	Fees for services (nonemployees):	-	-		-
а	Management				
	Legal				
	Accounting	39,093.	28,388.	4,672.	6,033.
	Lobbying	159,288.	125,838.	11,150.	6,033. 22,300.
	Professional fundraising services. See Part IV, line 17				
f	Investment management fees	3,857.		3,857.	
g	Other. (If line 11g amount exceeds 10% of line 25,				
	column (A), amount, list line 11g expenses on Sch 0.)	230,733.	161,430.	861.	<u>68,442.</u> 1,330.
12	Advertising and promotion	2,325.	609.	386.	1,330.
13	Office expenses	184,831.	96,728.	23,019.	65,084.
14	Information technology	25,850.	19,338.	761.	5,751.
15	Royalties				
16	Occupancy	80,078.	66,435.	8,739.	4,904.
17	Travel	10,102.	10,102.		
18	Payments of travel or entertainment expenses				
	for any federal, state, or local public officials		00 011	2 01 7	
19	Conferences, conventions, and meetings	26,085.	22,811.	3,217.	57.
20	Interest				
21	Payments to affiliates	29,234.	22 274	2 0 0 2	2 070
22	Depreciation, depletion, and amortization	29,234.	22,374.	2,982.	3,878.
23	Insurance				
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 0.) MISCELLANEOUS	5,396.	1,265.	928.	3,203.
a b		4,967.	1,203.	3,598.	90.
с С	TAXES	3,931.	1,555.	2,004.	372.
d	STAFF DEVELOPMENT	2,304.	603.	383.	1,318.
	All other expenses	1,542.	403.	256.	883.
25	Total functional expenses. Add lines 1 through 24e	2,036,878.	1,589,310.	147,099.	300,469.
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)				
13201	0 12-09-21				Form <b>990</b> (2021)
		10			. ,

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### SPINA BIFIDA ASSOCIATION OF AMERICA Check if Schedule O contains a response or note to any line in this Part X (A)

Part X Balance Sheet

				(A) Beginning of year		( <b>D</b> ) End of year
1	Cash - non-interest-bearing			236,118.	1	381,363.
2	Savings and temporary cash investments			441,369.		293,728.
3	Pledges and grants receivable, net	81,811.	3	153,998.		
4	Accounts receivable, net			,	4	
5	Loans and other receivables from any current or				· ·	
	trustee, key employee, creator or founder, subst					
	controlled entity or family member of any of the				5	
6	Loans and other receivables from other disqualit				-	
	under section 4958(f)(1)), and persons described				6	
7	Notes and loans receivable, net				7	
8	Inventories for sale or use			5,139.	8	5,139.
9				43,501.	9	<u>5,139.</u> 70,414.
	Land, buildings, and equipment: cost or other					
	basis. Complete Part VI of Schedule D	10a	257,460.			
b	Less: accumulated depreciation	10b	<u>257,460.</u> 222,620.	62,368.	10c	34,840. 502,392.
11	Investments - publicly traded securities			532,673.	11	502,392.
12	Investments - other securities. See Part IV, line 1				12	
13	Investments - program-related. See Part IV, line				13	
14	Intangible assets				14	
15	Other assets. See Part IV, line 11			662.		662.
16	Total assets. Add lines 1 through 15 (must equa			1,403,641.	16	1,442,536.
17	Accounts payable and accrued expenses			70,149.	17	57,155.
18	Grants payable				18	
19	Deferred revenue			15,744.	19	8,532.
20	<b>–</b>				20	
21	Escrow or custodial account liability. Complete I	Part IV o	Schedule D		21	
22	Loans and other payables to any current or form	ner office	r, director,			
	trustee, key employee, creator or founder, subst	antial co	ntributor, or 35%			
	controlled entity or family member of any of thes	se persor	ns		22	
23	Secured mortgages and notes payable to unrela	ted third	parties		23	
24	Unsecured notes and loans payable to unrelated	d third pa	urties	229,100.	24	0.
25	Other liabilities (including federal income tax, pa	yables to	related third			
	parties, and other liabilities not included on lines	s <b>1</b> 7-24).	Complete Part X			
	of Schedule D			178,553.		<u>170,847.</u> 236,534.
26	Total liabilities. Add lines 17 through 25			493,546.	26	236,534.
	Organizations that follow FASB ASC 958, che	ck here				
	and complete lines 27, 28, 32, and 33.			625 040		064 500
27			······ -	635,249.		964,522.
28	Net assets with donor restrictions			274,846.	28	241,480.
	Organizations that do not follow FASB ASC 958, check here 🕨 🛄					
	and complete lines 29 through 33.					
29	Capital stock or trust principal, or current funds		29			
30	Paid-in or capital surplus, or land, building, or ec				30	
31	Retained earnings, endowment, accumulated in			010 005	31	1 206 002
32	Total net assets or fund balances			<u>910,095.</u> 1,403,641.		<u>1,206,002.</u> 1,442,536.
33	Total liabilities and net assets/fund balances			1,403,041.	33	Form <b>990</b> (2021)

(B)

Form **990** (2021)

Form 990 (2021)

Assets

Liabilities

Net Assets or Fund Balances

	990 (2021) SPINA BIFIDA ASSOCIATION OF AMERICA	58-134	12181	Pa	<sub>ge</sub> 12
Pa	rt XI Reconciliation of Net Assets				
	Check if Schedule O contains a response or note to any line in this Part XI				
1	Total revenue (must equal Part VIII, column (A), line 12)	1	2,283		
2	Total expenses (must equal Part IX, column (A), line 25)	2	2,030		
3	Revenue less expenses. Subtract line 2 from line 1	3			18.
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4			95.
5	Net unrealized gains (losses) on investments	5	49	9,0	89.
6	Donated services and use of facilities	6			
7	Investment expenses	7			
8	Prior period adjustments	8			
9	Other changes in net assets or fund balances (explain on Schedule O)	9			0.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32,		4		~ ~
	column (B))	10	1,200	5,0	02.
Pa	rt XII Financial Statements and Reporting				
	Check if Schedule O contains a response or note to any line in this Part XII				X
				Yes	No
1	Accounting method used to prepare the Form 990: Cash X Accrual Other				
	If the organization changed its method of accounting from a prior year or checked "Other," explain on Schedule	Ο.			
2a	Were the organization's financial statements compiled or reviewed by an independent accountant?		. <b>2</b> a		X
	If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed	on a			
	separate basis, consolidated basis, or both:				
	Separate basis Consolidated basis Both consolidated and separate basis				
b	Were the organization's financial statements audited by an independent accountant?		. 2b	Х	
	If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate	e basis,			
	consolidated basis, or both:				
	X 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			37	
	review, or compilation of its financial statements and selection of an independent accountant?		. <b>2</b> c	Х	
	If the organization changed either its oversight process or selection process during the tax year, explain on Sch				
3a	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Sin	•			37
	Act and OMB Circular A-133?		3a		X
b	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the requi				
	or audits, explain why on Schedule O and describe any steps taken to undergo such audits			000	(2021)
			E a rma		$(n \cap \cap 1)$

Form **990** (2021)

SCH	EDL	JLE	Α

Department of the Treasury Internal Revenue Service

(Form 990)

Total

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

Complete if the organization is a section 501(c)(3) organization or a section

4947(a)(1) nonexempt charitable trust. Attach to Form 990 or Form 990-EZ.

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

OMB No. 1545-0047
2021
Open to Public Inspection

Name of the organization	
--------------------------	--

Employer	ident	ificat	ion	num
5	8 – 1	342	218	<b>1</b>

Nar	ame of the organization Employer identification number								
		SPIN	A BIFIDA A	SSOCIATION O	F AMEF	RICA		5	8-1342181
Pa	nrt I	Reason for Public C	Charity Status.	(All organizations must o	omplete th	nis part.) S	ee instruction	S.	
The	organ	ization is not a private found:							
1	<b>Š</b>	A church, convention of chu	,	•		,	I)(A)(i).		
2	$\square$	A school described in secti					- <del>//</del> - //-		
3	$\square$	A hospital or a cooperative				(b)(1)(A)(ii	ii).		
4	$\square$	A medical research organiza					-	(iii) Enter	the hospital's name
7		city, and state:		njunotion with a noopital	accombed	000000			the hoopital e hame,
5		•	or the benefit of a co	llege or university owned	l or operate	ed by a do	vernmental u	nit describe	ed in
Ű		An organization operated for the benefit of a college or university owned or operated by a governmental unit described in <b>section 170(b)(1)(A)(iv).</b> (Complete Part II.)							
6		A federal, state, or local gov		oontal unit described in	soction 17	70(h)(1)(A)	64		
	X	An organization that normal	-					o gonoral i	public described in
'	- 23	-	•	Initial part of its support if	on a gove	minentai		ie general j	
0		section 170(b)(1)(A)(vi). (Co		(1)(A)(ui) (Complete Der	• 11 \				
8		A community trust describe							
9		An agricultural research org				-		-	-
		or university or a non-land-g	rant college of agric	ulture (see instructions).	Enter the r	name, city	, and state of	the college	eor
40		university:		H					
10		An organization that normal							
		activities related to its exem		-					-
		income and unrelated busin		(less section 511 tax) fro	m busines	ses acqui	red by the org	janization a	atter June 30, 1975.
		See section 509(a)(2). (Cor	-	the stand of the s			0(-)(4)		
11		An organization organized a	•						
12		An organization organized a	-	-	-			•	
		more publicly supported org	-						Sheck the box on
		lines 12a through 12d that o						-	
а		<b>Type I.</b> A supporting orga	-	-	• • •	-			
		the supported organizatio			majority o	of the direc	tors or truste	es of the su	upporting
		organization. You must c	-						
b		<b>Type II.</b> A supporting orga	-				-		-
		control or management of			ame perso	ns that co	ntrol or manag	ge the supp	ported
		organization(s). You mus	t complete Part IV,	Sections A and C.					
c		Type III functionally integ	grated. A supportin	g organization operated	in connect	ion with, a	and functional	ly integrate	ed with,
	_	its supported organizatior	n(s) (see instructions	). You must complete I	Part IV, Se	ctions A,	D, and E.		
c		Type III non-functionally	integrated. A supp	porting organization oper	ated in cor	nnection w	vith its suppor	ted organiz	zation(s)
		that is not functionally inte	egrated. The organiz	ation generally must sat	isfy a distr	ibution rec	quirement and	an attentiv	veness
	_	requirement (see instructi	•						
e		Check this box if the orga					Туре I, Туре	II, Type III	
		functionally integrated, or	Type III non-function	nally integrated supporti	ng organiz	ation.			
f		er the number of supported o	•						
<u>c</u>		vide the following information			(iv) is the orac	inization listed			
	(	i) Name of supported	(ii) EIN	(iii) Type of organization (described on lines 1-10	in your governi		(v) Amount of	-	(vi) Amount of other
		organization		above (see instructions))	Yes	No	support (see ir	istructions)	support (see instructions)

Schedule A (Form 990) 2021



# Schedule A (Form 990) 2021 SPINA BIFIDA ASSOCIATION OF AMERICA 58-13 Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)

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

Sec	Section A. Public Support									
Cale	ndar year (or fiscal year beginning in) 🕨	<b>(a)</b> 2017	<b>(b)</b> 2018	<b>(c)</b> 2019	(d) 2020	<b>(e)</b> 2021	<b>(f)</b> Total			
1	Gifts, grants, contributions, and									
	membership fees received. (Do not									
	include any "unusual grants.")	1539962.	2905554.	1718305.	1460028.	2139236.	9763085.			
2	Tax revenues levied for the organ-									
	ization'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	1539962.	2905554.	1718305.	1460028.	2139236.	9763085.			
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)						1098202.			
	Public support. Subtract line 5 from line 4.						8664883.			
Sec	tion B. Total Support									
Cale	ndar year (or fiscal year beginning in) 🕨	(a) 2017	<b>(b)</b> 2018	<b>(c)</b> 2019	(d) 2020	(e) 2021	<b>(f)</b> Total			
7	Amounts from line 4	1539962.	2905554.	1718305.	1460028.	2139236.	9763085.			
8	Gross income from interest,									
	dividends, payments received on									
	securities loans, rents, royalties,									
	and income from similar sources	4,612.	4,043.	21,806.	14,227.	7,879.	52,567.			
9	Net income from unrelated business									
	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.)			5.	25.	8,850.	8,880.			
11	Total support. Add lines 7 through 10						9824532.			
12	Gross receipts from related activities,	etc. (see instructio	ons)			12	621,065.			
13	First 5 years. If the Form 990 is for th	ne organization's fir	rst, second, third, t	fourth, or fifth tax y	ear as a section 5	01(c)(3)				
	organization, check this box and stop									
Sec	ction C. Computation of Publi	c Support Per	centage							
14	Public support percentage for 2021 (I	ine 6, column (f), d	ivided by line 11, c	olumn (f))		14	88.20 %			
15	Public support percentage from 2020	Schedule A, Part	II, line 14			15	<u>87.91 %</u>			
	33 1/3% support test - 2021. If the o					ore, check this boy	k and			
	stop here. The organization qualifies	as a publicly suppo	orted organization				► X			
b	33 1/3% support test - 2020. If the o	organization did no	t check a box on I	ine 13 or 16a, and	line 15 is 33 1/3%	or more, check thi	s box			
	and stop here. The organization qual									
17a	10% -facts-and-circumstances test									
	and if the organization meets the fact									
	meets the facts-and-circumstances te			-						
b	10% -facts-and-circumstances test	-			-					
	more, and if the organization meets th	-								
	organization meets the facts-and-circu									
18	Private foundation. If the organization		-							
							(Form 990) 2021			

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Schedule A					ASSOCIATION			58-13
Part III	Support	Schedule fo	r Organiz	ations Des	cribed in Section &	509(a	a)(2)	

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

Sec	Stion A. Public Support						
Cale	ndar year (or fiscal year beginning in) 🕨	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total
1	Gifts, grants, contributions, and						
	membership fees received. (Do not						
	include any "unusual grants.")						
2	Gross receipts from admissions, merchandise sold or services per- formed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3	Gross receipts from activities that						
	are not an unrelated trade or bus- iness under section 513						
4	Tax revenues levied for the organ-						
	ization'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						
	Amounts included on lines 1, 2, and 3 received from disgualified 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.)						
Sec	ction B. Total Support						
Cale	ndar year (or fiscal year beginning in) 🕨	(a) 2017	<b>(b)</b> 2018	<b>(c)</b> 2019	(d) 2020	(e) 2021	(f) Total
9	Amounts from line 6						
10a	Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources						
b	Unrelated business taxable income (less section 511 taxes) from businesses						
	acquired after June 30, 1975						
с	Add lines 10a and 10b						
	Net income from unrelated business activities not included on 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.)						
	Total support. (Add lines 9, 10c, 11, and 12.)						
14	First 5 years. If the Form 990 is for the	ne organization's fi	rst, second, third, t	fourth, or fifth tax	year as a section 5	01(c)(3) organi	zation,
Sec	check this box and stop here						
15	Public support percentage for 2021 (	ine 8, column (f), d	livided by line 13, o	column (f))		15	%
	Public support percentage from 2020	1	1			16	%
17				ne 13, column (f))		17	%
18	Investment income percentage from					18	%
	33 1/3% support tests - 2021. If the						
	more than 33 1/3%, check this box a						
b	33 1/3% support tests - 2020. If the	-	•		•••••		%, and
-	line 18 is not more than 33 1/3%, che	-					
20	<b>Private foundation.</b> If the organization						
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			15				. ,

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Yes No

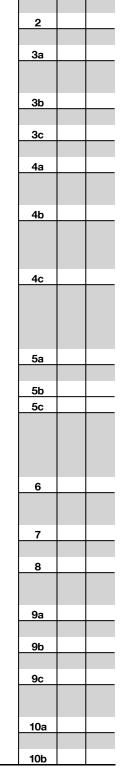
### Part IV Supporting Organizations

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

### Section A. All Supporting Organizations

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

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Schedule A (Form 990) 2021

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### Schedule A (Form 990) 2021 SPINA BIFIDA ASSOCIATION OF AMERICA 58-

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Par	t IV	Supporting Organizations (continued)				
				Yes	No	
11	Has t	he organization accepted a gift or contribution from any of the following persons?				
а	A per	son who directly or indirectly controls, either alone or together with persons described on lines 11b and				
	11c b	pelow, the governing body of a supported organization?	11a			
b A family member of a person described on line 11a above? 11b						
с	A 35%	% controlled entity of a person described on line 11a or 11b above? If "Yes" to line 11a, 11b, or 11c, provide				
	detail	in Part VI.	11c			
Sec	tion E	B. Type I Supporting Organizations				
				Yes	No	
1	more direct effect organ	ne governing body, members of the governing body, officers acting in their official capacity, or membership of one or supported organizations have the power to regularly appoint or elect at least a majority of the organization's officers, tors, or trustees at all times during the tax year? <i>If "No," describe in</i> <b>Part VI</b> <i>how the supported organization(s)</i> tively operated, supervised, or controlled the organization's activities. If the organization had more than one supported nization, describe how the powers to appoint and/or remove officers, directors, or trustees were allocated among the orted organizations and what conditions or restrictions, if any, applied to such powers during the tax year.	1			
2		ne 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. Section C. Type II Supporting Organizations

			Yes	No
1	Were a majority of the organization's directors or trustees during the tax year also a majority of the directors			
	or trustees of each of the organization's supported organization(s)? 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 examination(a)	1	I	

### Section D. All Type III Supporting Organizations

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

### Section E. Type III Functionally Integrated Supporting Organizations

1 Check the box next to the method that the organization used to satis	isfy the Integral Part Test duri	ing the year (see instructions).
--	----------------------------------	----------------------------------

- a The organization satisfied the Activities Test. Complete line 2 below.
- **b** The organization is the parent of each of its supported organizations. *Complete* **line 3** *below.*

с	The organization supported a governmental entity.	Describe in Part VI how you supported a governmental entity (see instructions).
	 ······································	Describe in a second you supported a governmental entity (see instructions).

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- 2 Activities Test. Answer lines 2a and 2b below.
- **a** Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? 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.
- b Did the activities described on line 2a, above, constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.
- 3 Parent of Supported Organizations. Answer lines 3a and 3b below.

**a** Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? *If* "Yes" or "*No*" *provide details in* **Part VI.** 

**b** Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? *If "Yes," describe in* **Part VI** *the role played by the organization in this regard.* 

 Yes
 No

 2a

 2a

 2b

 3a

 3b

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Sche	dule A (Form 990) 2021 SPINA BIFIDA ASSOCIATIO			58-1342181 Page 6
Pa	rt V Type III Non-Functionally Integrated 509(a)(3) Supporting	g Orga	nizations	
1	Check here if the organization satisfied the Integral Part Test as a qualifying	g trust on	n Nov. 20, 1970 ( <i>explain</i>	in Part VI). See instructions.
	All other Type III non-functionally integrated supporting organizations must	complete	e Sections A through E.	
Sect	ion 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		
Sect	ion 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		
е	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 0.015 of line 3 (for greater amount,			
	see instructions).	4		
5	Net value of non-exempt-use assets (subtract line 4 from line 3)	5		
6	Multiply line 5 by 0.035.	6		
7	Recoveries of prior-year distributions	7		
8	Minimum Asset Amount (add line 7 to line 6)	8		
Sect	ion C - Distributable Amount			Current Year
1	Adjusted net income for prior year (from Section A, line 8, column A)	1		
2	Enter 0.85 of line 1.	2		
3	Minimum asset amount for prior year (from Section B, line 8, column A)	3		
4	Enter greater of line 2 or line 3.	4		
5	Income tax imposed in prior year	5		
6	Distributable Amount. Subtract line 5 from line 4, unless subject to			
	emergency temporary reduction (see instructions).	6		
7	Check here if the current year is the organization's first as a non-functional	y integra	ted Type III supporting o	rganization (see

Schedule A (Form 990) 2021

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instructions).

SPINA BIFIDA ASS	OCIATION OF	AMERICA
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Par	t V Type III Non-Functionally Integrated 509(	a)(3) Supporting Orga	nizations (continu	ued)	
Secti	on D - Distributions				Current Year
1	Amounts paid to supported organizations to accomplish exer	mpt purposes		1	
2	Amounts paid to perform activity that directly furthers exemp				
	organizations, in excess of income from activity	2			
3	Administrative expenses paid to accomplish exempt purpose	s of supported organizations	S	3	
4	Amounts paid to acquire exempt-use assets			4	
5	Qualified set-aside amounts (prior IRS approval required - pro	ovide details in <b>Part VI</b> )		5	
6	Other distributions ( <i>describe in Part VI</i> ). See instructions.			6	
7	Total annual distributions. Add lines 1 through 6.			7	
8	Distributions to attentive supported organizations to which the	ne organization is responsive			
	(provide details in <b>Part VI</b> ). See instructions.	C I		8	
9	Distributable amount for 2021 from Section C, line 6			9	
10	Line 8 amount divided by line 9 amount			10	
		(i)	(ii)		(iii)
Secti	on E - Distribution Allocations (see instructions)	Excess Distributions	Underdistribution Pre-2021	าร	Distributable Amount for 2021
_1	Distributable amount for 2021 from Section C, line 6				
2	Underdistributions, if any, for years prior to 2021 (reason-				
	able cause required - explain in Part VI). See instructions.				
3	Excess distributions carryover, if any, to 2021				
a	From 2016				
b	From 2017				
C	From 2018				
d	From 2019				
е	From 2020				
f	Total of lines 3a through 3e				
g	Applied to underdistributions of prior years				
h	Applied to 2021 distributable amount				
i	Carryover from 2016 not applied (see instructions)				
j	Remainder. Subtract lines 3g, 3h, and 3i from line 3f.				
4	Distributions for 2021 from Section D,				
	line 7: \$				
а	Applied to underdistributions of prior years				
b	Applied to 2021 distributable amount				
с	Remainder. Subtract lines 4a and 4b from line 4.				
5	Remaining underdistributions for years prior to 2021, if				
	any. Subtract lines 3g and 4a from line 2. For result greater				
	than zero, explain in Part VI. See instructions.				
6	Remaining underdistributions for 2021. Subtract lines 3h				
	and 4b from line 1. For result greater than zero, explain in				
	Part VI. See instructions.				
7	Excess distributions carryover to 2022. Add lines 3j				
-	and 4c.				
8	Breakdown of line 7:				
	Excess from 2017				
	Excess from 2018				
	Excess from 2019				
	Excess from 2020				
	Excess from 2020				

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	e A (Form 9						SSOCIA'				58-1342181	Page <b>8</b>
Part V	Part IV line 1; Section	, Section Part IV, S	A, lines 1, 3 Section D, lin 5, 6, and 8	2, 3b, 3c, 4 nes 2 and 3	1b, 4c, 5a, 3; Part IV, \$	6, 9a, 9 Section	b, 9c, 11a, 1 E, lines 1c, 2	1b, and <sup>-</sup> 2a, 2b, 3a	11c; Part IV a, and 3b; P	, Section B, lines art V, line 1; Par	or 17b; Part III, line 12; s 1 and 2; Part IV, Sectior t V, Section B, line 1e; Pa ional information.	ı C, ırt V,
SCHEI				LINE	10. E	XPL	ANATION	FOR	OTHER	INCOME:		
	ELLAEN		,	-								
	AMOUN		5.									
	AMOUN		25.									
	AMOUN		8,8	50								
2021	AMOON	<u>1. y</u>	0,0	50.								
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	5 1508	72.10	3407				20 2021.0	4030	SPTNA	BTFTDA 2	ASSOCIATION	

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# Schedule of Contributors

Attach to Form 990 or Form 990-PF. to www.irs.gov/Form990 for the latest information. OMB No. 1545-0047

# 2021

Employer identification number

58-1342181

Filers of:	Section:
Form 990 or 990-EZ	X 501(c)( 3 ) (enter number) organization
	4947(a)(1) nonexempt charitable trust <b>not</b> treated as a private foundation
	527 political organization
Form 990-PF	501(c)(3) exempt private foundation
	4947(a)(1) nonexempt charitable trust treated as a private foundation
	501(c)(3) taxable private foundation

SPINA BIFIDA ASSOCIATION OF AMERICA

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

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

### General Rule

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

### Special Rules

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

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

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

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

LHA For Paperwork Reduction Act Notice, see the instructions for Form 990, 990-EZ, or 990-PF.

Schedule B (Form 990) (2021)

COPY

### Schedule B (Form 990)

Department of the Treasury

Internal Revenue Service

Name of the organization

Organization type (check one):

		\$694,924.	PersonXPayroll
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
2 		\$270,275.	PersonXPayrollNoncash(Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
<u> </u>		\$229,100.	Person X Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		\$	Person Payroll Noncash Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		\$	Person Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
123452 11-11-21		\$	Person Payroll Noncash (Complete Part II for noncash contributions.)

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

(b)

Name, address, and ZIP + 4

(a)

No.

Employer identification number

(d)

Type of contribution

58-1342181

(c)

**Total contributions** 

452 11-11-2

10511026 150872 193407

from Part I	Description of noncash property given	(See instructions.)	Date received
		\$	
(a) No.	(b)	(c)	(d)
from	Description of noncash property given	<b>FMV (or estimate)</b> (See instructions.)	Date received
Part I			
		\$	
(a)		(c)	
No. from	(b) Description of noncash property given	FMV (or estimate)	(d) Date received
Part I		(See instructions.)	
		\$	
(a)		(c)	
No. from	(b) Description of noncash property given	FMV (or estimate)	(d) Date received
Part I	Description of noncash property given	(See instructions.)	Date received
		\$	
(a)			
No.	(b)	(c) FMV (or estimate)	(d)
from Part I	Description of noncash property given	(See instructions.)	Date received
		\$	
(a)			
No.	(b)	(c) FMV (or estimate)	(d)
from Part I	Description of noncash property given	(See instructions.)	Date received
<u> </u>		\$	
123453 11-11-21			Schedule B (Form 990) (2021)

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### SPINA BIFIDA ASSOCIATION OF AMERICA

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

(b)

Schedule B (Form 990) (2021) Name of organization

(a)

No.

Page 3

Employer identification number

(d)

58-1342181

(c)

FMV (or estimate)

Schedule B (Form 990) (20

10511026 150872 193407

Schedule E	3 (Form 990) (2021)		Page 4		
Name of or	rganization		Employer identification number		
SPINA Part III	from any one contributor. Complete columns (a)	ns to organizations described in sect	58-1342181 ion 501(c)(7), (8), or (10) that total more than \$1,000 for the year For organizations		
	completing Part III, enter the total of exclusively religious, cl Use duplicate copies of Part III if additional s	naritable, etc., contributions of <b>\$1,000 or les</b>	ss for the year. (Enter this info. once.) ► \$		
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held		
			_		
-		(e) Transfer of gift			
-	Transferee's name, address, an	d ZIP + 4	Relationship of transferor to transferee		
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held		
-		(e) Transfer of gift			
-	Transferee's name, address, and ZIP + 4		Relationship of transferor to transferee		
(a) No.					
`from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held		
	Transferee's name, address, an	(e) Transfer of gift	of gift Relationship of transferor to transferee		
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held		
-		(e) Transfer of gift			
-	Transferee's name, address, an	d ZIP + 4	Relationship of transferor to transferee		
100454	~				
123454 11-11-	-2 1	25	Schedule B (Form 990) (2021)		

### 10511026 150872 193407

25 2021.04030 SPINA BIFIDA ASSOC**COPY**<sup>193407\_1</sup>

SCHEDULE C	CHEDULE C Political Campaign and Lobbying Activities						
(Form 990)	2021						
	-	anizations Exempt From Income if the organization is described		.,	. Open to Public		
Department of the Treasury Internal Revenue Service	of the Treasury						
If the organization answ	wered "Yes," on	Form 990, Part IV, line 3, or For	m 990-EZ, Part V, line	e 46 (Political Campaign A	ctivities), then		
<ul> <li>Section 501(c)(3) org</li> </ul>	anizations: Com	plete Parts I-A and B. Do not com	plete Part I-C.				
<ul> <li>Section 501(c) (other</li> </ul>	r than section 50	01(c)(3)) organizations: Complete F	Parts I-A and C below. [	Do not complete Part I-B.			
<ul> <li>Section 527 organiza</li> </ul>	ations: Complete	e Part I-A only.					
		Form 990, Part IV, line 4, or For					
		nave filed Form 5768 (election und		•	•		
	•	nave NOT filed Form 5768 (electio		•	•		
Tax) (See separate inst		I Form 990, Part IV, line 5 (Proxy	Tax) (See separate in	Istructions) or Form 990-E	Z, Part V, line 35C (Proxy		
		ions: Complete Part III.					
Name of organization	/ (/ 0	•		Emplo	over identification number		
		IFIDA ASSOCIATION			58-1342181		
Part I-A Comple	ete if the org	anization is exempt unde	r section 501(c) o	r is a section 527 org	anization.		
1 Provide a description	on of the organiz	ation's direct and indirect political	campaign activities in	Part IV.			
2 Political campaign	activity expendit	ures		▶\$			
<b>3</b> Volunteer hours for	political campai	gn activities					
Part I-B Comple	ata if the ora	anization is exempt unde	r section $501(c)/3$	1			
-	-						
		incurred by the organization unde incurred by organization manager		► \$			
		n 4955 tax, did it file Form 4720 fo					
<b>b</b> If "Yes," describe ir							
Part I-C Comple	ete if the org	anization is exempt unde	r section 501(c), e	except section 501(c)	(3).		
1 Enter the amount d	irectly expended	by the filing organization for sect	ion 527 exempt function	on activities > \$			
2 Enter the amount o	f the filing organ	ization's funds contributed to othe	er organizations for sec	tion 527			
exempt function ac	tivities			►\$			
	-	. Add lines 1 and 2. Enter here an					
		1120-POL for this year?					
		nployer identification number (EIN) tion listed, enter the amount paid					
	-	omptly and directly delivered to a					
	•	additional space is needed, provid		· · ·	oog. ogaloa lana ol a		
(a) Name	ġ.	(b) Address	(c) EIN	(d) Amount paid from	(e) Amount of political		
()	-		(0) =	filing organization's	contributions received and		
				funds. If none, enter -0	promptly and directly delivered to a separate		
					political organization.		
					If none, enter -0		
For Paperwork Reduct	ion Act Notice,	see the Instructions for Form 99	0 or 990-EZ.	S	chedule C (Form 990) 2021		

LHA

132041 11-03-21

		DA ASSOCIATIO			342181 Page 2			
Part II-A Complete if the org	anization is ex	empt under section	501(c)(3) and file	d Form 5768 (ele	ction under			
section 501(h)).		ffiliate dama and face dation						
A Check      if the filing organization expenses, and share	-	ffiliated group (and list in	Part IV each affiliated	group member's name	e, address, EIN,			
	,	and "limited control" pro	visions apply					
	ts on Lobbying Exp			<b>(a)</b> Filing organization's	(b) Affiliated group totals			
	(The term "expenditures" means amounts paid or incurred.)							
1a Total lobbying expenditures to influ	1a Total lobbying expenditures to influence public opinion (grassroots lobbying)							
<b>b</b> Total lobbying expenditures to influ	• •			<u>5,775.</u> 153,513.				
c Total lobbying expenditures (add lin	nes 1a and 1b)			159,288.				
d Other exempt purpose expenditure	s			1,873,733.				
e Total exempt purpose expenditures		2,033,021.						
f Lobbying nontaxable amount. Ente		251,651.						
If the amount on line 1e, column (a) of	r (b) is: The I	obbying nontaxable amo	ount is:					
Not over \$500,000								
Over \$500,000 but not over \$1,000	<i>.</i>	000 plus 15% of the exce						
Over \$1,000,000 but not over \$1,50		000 plus 10% of the exce 000 plus 5% of the exces						
Over \$1,500,000 but not over \$17,								
Over \$17,000,000	\$1,0C	0,000.						
g Grassroots nontaxable amount (en	tor 250/ of line 1f			62,913.				
h Subtract line 1g from line 1a. If zero				02,519.				
i Subtract line 1f from line 1c. If zero	, , , ,			0.				
j If there is an amount other than zer								
reporting section 4911 tax for this					Yes No			
<b>T</b>	4-Year A	veraging Period Under	Section 501(h)					
(Some organizations the		501(h) election do not h arate instructions for lin		f the five columns be	low.			
	Lobbying Exp	enditures During 4-Yea	r Averaging Period					
Calendar year (or fiscal year beginning in)	<b>(a)</b> 2018	<b>(b)</b> 2019	<b>(c)</b> 2020	<b>(d)</b> 2021	<b>(e)</b> Total			
2a Lobbying nontaxable amount	241,876	. 261,515.	252,712.	251,651.	1,007,754.			
<ul> <li>b Lobbying ceiling amount (150% of line 2a, column(e))</li> </ul>					1,511,631.			
· · · · · · · · · · · · · · · · ·								
<b>c</b> Total lobbying expenditures	168,659	. 206,315.	141,188.	159,288.	675,450.			
<b>d</b> Grassroots nontaxable amount	60,469	. 65,379.	63,178.	62,913.	251,939.			
e Grassroots ceiling amount				•				
(150% of line 2d, column (e))					377,909.			
			<b>C</b> 000		00.775			
f Grassroots lobbying expenditures	6,000	. 6,000.	6,000.	5,775.	23,775. Ile C (Form 990) 2021			
				Schedu	ue C (Form 990) 2021			

### SPINA BIFIDA ASSOCIATION OF AMERICA

# Part II-B Complete if the organization is exempt under section 501(c)(3) and has NOT filed Form 5768 (election under section 501(h)).

For e	ach "Yes" response on lines 1a through 1i below, provide in Part IV a detailed description	(a	)	(t	<b>)</b>
	e lobbying activity.	Yes	No	Amo	ount
1	During the year, did the filing organization attempt to influence foreign, national, state, or local legislation, including any attempt to influence public opinion on a legislative matter or referendum, through the use of: Volunteers?				
h					
	Paid staff or management (include compensation in expenses reported on lines 1c through 1i)? Media advertisements?				
d	Mailings to members, legislators, or the public?				
	Publications, or published or broadcast statements?				
	Grants to other organizations for lobbying purposes?				
g					
•	Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means?				
i	Other activities?				
j	Total. Add lines 1c through 1i				
	Did the activities in line 1 cause the organization to be not described in section 501(c)(3)?				
b	If "Yes," enter the amount of any tax incurred under section 4912				
с	If "Yes," enter the amount of any tax incurred by organization managers under section 4912				
d	If the filing organization incurred a section 4912 tax, did it file Form 4720 for this year?		_		
Par	t III-A Complete if the organization is exempt under section 501(c)(4), section	n 501(c)(5	), or sec	tion	
	501(c)(6).				
				Yes	No
1	Were substantially all (90% or more) dues received nondeductible by members?				
2	Did the organization make only in-house lobbying expenditures of \$2,000 or less?				
3	Did the organization agree to carry over lobbying and political campaign activity expenditures from the			1°	
Par	t III-B Complete if the organization is exempt under section 501(c)(4), section 501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered ' answered "Yes."				3, is
1	Dues, assessments and similar amounts from members		1		
2	Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of politic	al			
	expenses for which the section 527(f) tax was paid).				
а	Current year		. 2a		
b	Carryover from last year		2b		
с	Total		2c		
3	Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues				
4	If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the exce	ess			
	does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and po	olitical			
	expenditure next year?				
_5	Taxable amount of lobbying and political expenditures. See instructions				
Par	t IV Supplemental Information				
Provi	de the descriptions required for Part I-A, line 1; Part I-B, line 4; Part I-C, line 5; Part II-A (affiliated group	list); Part II-A	A, lines 1 a	nd 2 (See	

instructions); and Part II-B, line 1. Also, complete this part for any additional information.

Schedule C (Form 990) 2021

132043 11-03-21

Department of the Treasury

### **Supplemental Financial Statements**

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

OMB No. 1545-0047 Ĺ **Open to Public** Inspection

Internal Revenue Service Name of the organization Go to www.irs.gov/Form990 for instructions and the latest information.

Employer identification number 58-1342181

	SPINA BIFIDA ASSOC	IATION OF AMERICA		58-1342181
Par	t I Organizations Maintaining Donor Advise	d Funds or Other Similar Fund	s or Acc	counts. Complete if the
	organization answered "Yes" on Form 990, Part IV, lir	ie 6.		·
		(a) Donor advised funds	(b	) Funds and other accounts
1	Total number at end of year			
2	Aggregate value of contributions to (during year)			
3	Aggregate value of grants from (during year)			
4	Aggregate value at end of year			
5	Did the organization inform all donors and donor advisors in	writing that the assets held in donor adv	rised funds	3
	are the organization's property, subject to the organization's	0		
6	Did the organization inform all grantees, donors, and donor a			
	for charitable purposes and not for the benefit of the donor of			
				ĭ n n
Par				
1	Purpose(s) of conservation easements held by the organizati	on (check all that apply).		
	Preservation of land for public use (for example, recrea		of a histor	ically important land area
	Protection of natural habitat			ed historic structure
	Preservation of open space			
2	Complete lines 2a through 2d if the organization held a quali	fied conservation contribution in the forr	n of a con	servation easement on the last
_	day of the tax year.		Ì	Held at the End of the Tax Year
а	Total number of conservation easements		F	2a
b			L	2b
c	Number of conservation easements on a certified historic str		F	2c
d	Number of conservation easements included in (c) acquired			
	listed in the National Register			2d
3	Number of conservation easements modified, transferred, re			
-	vear ►			
4	Number of states where property subject to conservation ea	sement is located		
5	Does the organization have a written policy regarding the pe		_ f	
-	violations, and enforcement of the conservation easements i			Yes No
6	Staff and volunteer hours devoted to monitoring, inspecting,			
-	•	······································		
7	Amount of expenses incurred in monitoring, inspecting, hand	lling of violations, and enforcing conserv	vation ease	ements during the year
-	► \$	······g - · · · · · · · · · · · · · · ·		
8	Does each conservation easement reported on line 2(d) abov	e satisfy the requirements of section 17	0(h)(4)(B)(i)	
-				
9	In Part XIII, describe how the organization reports conservati			
•	balance sheet, and include, if applicable, the text of the foot	-		
	organization's accounting for conservation easements.			
Par	t III Organizations Maintaining Collections of	f Art, Historical Treasures, or C	Other Si	nilar Assets.
	Complete if the organization answered "Yes" on Form	990, Part IV, line 8.		
1a	If the organization elected, as permitted under FASB ASC 95	8. not to report in its revenue statement	and balar	nce sheet works
	of art, historical treasures, or other similar assets held for pul	•		
	service, provide in Part XIII the text of the footnote to its final			
b	If the organization elected, as permitted under FASB ASC 95			sheet works of
	art, historical treasures, or other similar assets held for public			
	provide the following amounts relating to these items:			
	(i) Revenue included on Form 990, Part VIII, line 1			▶ \$
				► \$
2	If the organization received or held works of art, historical tre			
-	the following amounts required to be reported under FASB A			
а	Revenue included on Form 990, Part VIII, line 1	-		▶ \$
	Assets included in Form 990, Part X			► \$
	For Paperwork Reduction Act Notice, see the Instruction			Schedule D (Form 990) 2021
	10-28-21			
.5200		29		

4	9						
		~	~	~	~	~	

		IFIDA ASSOC						58-13		
Par	t III Organizations Maintaining C								(contin	ued)
3	Using the organization's acquisition, accession	on, and other records	s, check any o	f the f	ollowing that	make si	ignificant ι	use of its		
	collection items (check all that apply):									
а	Public exhibition	d	Loan c	or excl	hange progra	am				
b	Scholarly research	е	Other_							
с	Preservation for future generations									
4	Provide a description of the organization's co	ellections and explain	how they furt	her th	e organizatio	n's exen	npt purpo	se in Part	XIII.	
5	During the year, did the organization solicit o	r receive donations o	f art, historica	l treas	ures, or othe	er similar	assets			
	to be sold to raise funds rather than to be ma								Yes	No
Par	t IV Escrow and Custodial Arrang	gements. Comple	te if the organ	izatio	n answered "	'Yes" on	Form 990	), Part IV, I	ine 9, or	
	reported an amount on Form 990, Par	t X, line 21.								
1a	Is the organization an agent, trustee, custodi	an or other intermedi	ary for contrib	utions	or other ass	sets not i	included			
	on Form 990, Part X?								Yes	No No
b	If "Yes," explain the arrangement in Part XIII	and complete the foll	owing table:							
									Amount	
с	Beginning balance						. 1c			
	Additions during the year									
	Distributions during the year									
f	Ending balance									
2a	Did the organization include an amount on Fe								Yes	No
b	If "Yes," explain the arrangement in Part XIII.									
Par	t V Endowment Funds. Complete i	f the organization and	swered "Yes"	on Fo	rm 990, Part	IV, line 1	10.			
		(a) Current year	(b) Prior ye	ar	(c) Two year	rs back	(d) Three y	/ears back	(e) Four	years back
1a	Beginning of year balance	67,903.	64,	564.	62	2,552.		62,563.		61,087.
b	Contributions									
	Net investment earnings, gains, and losses	3,232.	З,	339.	2	2,012.		-11.		1,476.
d	Grants or scholarships									
	Other expenditures for facilities									
	and programs									
f	Administrative expenses									
g	End of year balance	71,135.	67,	903.	64	1,564.		62,552.		62,563.
2	Provide the estimated percentage of the curr	ent year end balance	(line 1g, colu	mn (a)	) held as:					
а	Board designated or quasi-endowment	84.3460	_%							
	Permanent endowment  .0000	%								
с	Term endowment  15.6530	%								
	The percentages on lines 2a, 2b, and 2c sho	uld equal 100%.								
3a	Are there endowment funds not in the posse	ssion of the organizat	tion that are h	eld an	d administer	ed for th	e organiza	ation	_	
	by:									Yes No
	(i) Unrelated organizations								3a(i)	X
	(ii) Related organizations								3a(ii)	X
b	If "Yes" on line 3a(ii), are the related organiza	tions listed as require	ed on Schedul	e R?					3b	
4	Describe in Part XIII the intended uses of the	organization's endow	vment funds.							
Par	t VI Land, Buildings, and Equipm	ent.								
	Complete if the organization answered	d "Yes" on Form 990	, Part IV, line 1	1a. S	ee Form 990	, Part X,	line 10.			
	Description of property	(a) Cost or ot	her (b)	Cost	or other	<b>(c)</b> A	ccumulate	ed	(d) Bool	k value
		basis (investm	nent) I	oasis (	(other)	de	preciation			
1a	Land									
	Buildings									
	Leasehold improvements				2,484.		117,2	99.	15	5,185.
	Equipment				3,931.		28,8			5,112.
	Other				1,045.		76,5	02.		1,543.
	. Add lines 1a through 1e. (Column (d) must e		K. column (B)			. <u></u>				1,840.
								Schedule	D (Form	990) 2021

Schedule	e D (Form 990) 2021	SPINA BI	FID	A ASSOCIATION	OF	AMERICA	58-1342181	Page 3
Part V								
	Complete if the org	anization answered	l "Yes" o	on Form 990, Part IV, line	11b. S	See Form 990, Part X, line 12	2.	
(a) Des	cription of security or cate	GOTY (including name of s	ecurity)	(b) Book value	(	c) Method of valuation: Cost	t or end-of-year market va	lue
(1) Finar	ncial derivatives							
(2) Clos	ely held equity interests							
(3) Othe								
(A)								
(B)								
(C)								
(D)								
(E)								
(F)								
(G)								
(H)								
Total. (Co	I. (b) must equal Form 990	), Part X, col. (B) line	12.) 🕨					
Part V	III Investments -	Program Relat	ed.					
	Complete if the org	anization answered	l "Yes" o	on Form 990, Part IV, line	11c. S	See Form 990, Part X, line 13	3.	
	(a) Description of	investment		(b) Book value	(	c) Method of valuation: Cost	t or end-of-year market va	lue
(1)								
(2)								
(3)								
(4)								
(5)								
(6)								
(7)								
(8)								
(9)								
	l. (b) must equal Form 990	), Part X, col. (B) line	13.) 🕨					
Part I	Other Assets.							
	Complete if the org	anization answered	l "Yes" o	on Form 990, Part IV, line	11d. S	See Form 990, Part X, line 15	5.	
			(a) I	Description			(b) Book val	ue
(1)								
(2)								
(3)								
(4)								
(5)								
(6)								
(7)								
(8)								
(9)								
	olumn (b) must equal Fo	orm 990, Part X, col	. (B) line	15.)			🕨	
Part X								
				on Form 990, Part IV, line	11e o	r 11f. See Form 990, Part X,		
1.	<b>(a)</b> D	escription of liability	/				(b) Book val	ue
	ederal income taxes							
	DEFERRED REN	T AND LEAS	SEHOI	D				
(3)	INCENTIVES						170,	847.
(4)								
(5)								
(6)								
(7)								
(8)								
(9)								
Total. (C	olumn (b) must equal Fo	orm 990, Part X, col	. (B) line	25.)			🕨 170,	847.
	., .		. ,	,		rganization's financial staten	nents that reports the	

organization's liability for uncertain tax positions under FASB ASC 740. Check here if the text of the footnote has been provided in Part XIII

Schedule D (Form 990) 2021

X

132053 10-28-21

	dule D (Form 990) 2021 SPINA BIFIDA ASSOCIATION O		-		1342181 Page 4
Pa	t XI Reconciliation of Revenue per Audited Financial Stateme		levenue per Re	turn.	
	Complete if the organization answered "Yes" on Form 990, Part IV, line 12a	a.			
1	Total revenue, gains, and other support per audited financial statements			1	2,334,783.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:				
а	Net unrealized gains (losses) on investments		49,089.		
b	Donated services and use of facilities	<b>2</b> b	5,855.		
С	Recoveries of prior year grants	. 2c			
d	Other (Describe in Part XIII.)	2d			
е	Add lines 2a through 2d			2e	54,944.
3	Subtract line 2e from line 1			3	2,279,839.
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:				
а	Investment expenses not included on Form 990, Part VIII, line 7b	4a	3,857.		
b	Other (Describe in Part XIII.)	. 4b			
-	Add lines <b>4a</b> and <b>4b</b>			4c	3,857.
С	Add lines 4a and 4b				
5	Total revenue. Add lines <b>3</b> and <b>4c.</b> ( <i>This must equal Form 990. Part I. line 12.</i> )			5	3,857. 2,283,696.
5					<u>2,283,696.</u> n.
5	Total revenue. Add lines 3 and 4c. ( <i>This must equal Form 990, Part I, line 12.</i> ) <b>t XII</b> Reconciliation of Expenses per Audited Financial Statem Complete if the organization answered "Yes" on Form 990, Part IV, line 12a	ents With	Expenses per F		า.
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)	ents With	Expenses per F		2,283,696. n. 2,038,876.
5 Pa	Total revenue. Add lines 3 and 4c. ( <i>This must equal Form 990, Part I, line 12.</i> ) <b>t XII</b> Reconciliation of Expenses per Audited Financial Statem Complete if the organization answered "Yes" on Form 990, Part IV, line 12a	ents With	Expenses per F	Returi	า.
5 Pa 1	Total revenue. Add lines 3 and 4c. ( <i>This must equal Form 990, Part I, line 12,</i> ) <b>t XII</b> Reconciliation of Expenses per Audited Financial Statem Complete if the organization answered "Yes" on Form 990, Part IV, line 12a Total expenses and losses per audited financial statements	ents With	Expenses per F	Returi	า.
5 Pa 1 2	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)         rt XII         Reconciliation of Expenses per Audited Financial Statem         Complete if the organization answered "Yes" on Form 990, Part IV, line 12a         Total expenses and losses per audited financial statements         Amounts included on line 1 but not on Form 990, Part IX, line 25:	ents With a.	Expenses per F	Returi	า.
5 Pa 1 2	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)         Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)         Reconciliation of Expenses per Audited Financial Statem         Complete if the organization answered "Yes" on Form 990, Part IV, line 12a         Total expenses and losses per audited financial statements         Amounts included on line 1 but not on Form 990, Part IX, line 25:         Donated services and use of facilities         Prior year adjustments	2a 2b	Expenses per F	Returi	า.
5 Pa 1 2 a b	Total revenue. Add lines 3 and 4c. (This must equal Form 990. Part I, line 12.) <b>t XII</b> Reconciliation of Expenses per Audited Financial Statem         Complete if the organization answered "Yes" on Form 990, Part IV, line 12a         Total expenses and losses per audited financial statements         Amounts included on line 1 but not on Form 990, Part IX, line 25:         Donated services and use of facilities         Prior year adjustments	2a 2b 2c	Expenses per F	Returi	n. 2,038,876.
5 Pa 1 2 a b c d	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)         Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)         Reconciliation of Expenses per Audited Financial Statem         Complete if the organization answered "Yes" on Form 990, Part IV, line 12a         Total expenses and losses per audited financial statements         Amounts included on line 1 but not on Form 990, Part IX, line 25:         Donated services and use of facilities         Prior year adjustments       Other losses	2a 2b 2c 2d	Expenses per F	Returi	n. 2,038,876.
5 Pa 1 2 a b c d	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)         Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)         Reconciliation of Expenses per Audited Financial Statem         Complete if the organization answered "Yes" on Form 990, Part IV, line 12a         Total expenses and losses per audited financial statements         Amounts included on line 1 but not on Form 990, Part IX, line 25:         Donated services and use of facilities         Prior year adjustments         Other losses         Other (Describe in Part XIII.)         Add lines 2a through 2d	2a 2b 2c 2d	Expenses per F	1	า.
5 Pa 1 2 a b c d e	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)         Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)         Reconciliation of Expenses per Audited Financial Statem         Complete if the organization answered "Yes" on Form 990, Part IV, line 12a         Total expenses and losses per audited financial statements         Amounts included on line 1 but not on Form 990, Part IX, line 25:         Donated services and use of facilities         Prior year adjustments       Other losses         Other (Describe in Part XIII.)       Other (Describe in Part XIII.)	2a 2b 2c 2d	Expenses per F	1 2e	n. 2,038,876.
5 Pa 1 2 a b c d e 3	Total revenue. Add lines 3 and 4c. (This must equal Form 990. Part I. line 12.) <b>t XII</b> Reconciliation of Expenses per Audited Financial Statem         Complete if the organization answered "Yes" on Form 990, Part IV, line 12a         Total expenses and losses per audited financial statements         Amounts included on line 1 but not on Form 990, Part IX, line 25:         Donated services and use of facilities         Prior year adjustments       Other losses         Other (Describe in Part XIII.)       Add lines 2a through 2d         Subtract line 2e from line 1       1	2a 2b 2c 2d	Expenses per F	1 2e	n. 2,038,876.
5 Pa 1 2 a b c d e 3 4	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.) <b>Reconciliation of Expenses per Audited Financial Statem</b> Complete if the organization answered "Yes" on Form 990, Part IV, line 12a         Total expenses and losses per audited financial statements         Amounts included on line 1 but not on Form 990, Part IX, line 25:         Donated services and use of facilities         Prior year adjustments         Other losses         Other (Describe in Part XIII.)         Add lines 2a through 2d         Subtract line 2e from line 1         Amounts included on Form 990, Part IX, line 25, but not on line 1:	2a 2b 2c 2d 2d	Expenses per F	1 2e	n. 2,038,876. 5,855. 2,033,021.
5 Pa 1 2 a b c d e 3 4	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.) <b>Reconciliation of Expenses per Audited Financial Statem</b> Complete if the organization answered "Yes" on Form 990, Part IV, line 12a         Total expenses and losses per audited financial statements         Amounts included on line 1 but not on Form 990, Part IX, line 25:         Donated services and use of facilities         Prior year adjustments         Other losses         Other (Describe in Part XIII.)         Add lines 2a through 2d         Subtract line 2e from line 1         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	2a 2b 2c 2d 2d 4a 4b	Expenses per F	1 2e	n. <u>2,038,876.</u> <u>5,855.</u> <u>2,033,021.</u> <u>3,857.</u>
5 Pa 1 2 a b c d e 3 4 a b c 5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)         Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)         Reconciliation of Expenses per Audited Financial Statem         Complete if the organization answered "Yes" on Form 990, Part IV, line 12a         Total expenses and losses per audited financial statements         Amounts included on line 1 but not on Form 990, Part IX, line 25:         Donated services and use of facilities         Prior year adjustments         Other losses         Other (Describe in Part XIII.)         Add lines 2a through 2d         Subtract line 2e from line 1         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         Other (Describe in Part XIII.)	2a 2b 2c 2d 2d 4a 4b	Expenses per F	1 2e 3	n. 2,038,876. 5,855. 2,033,021.

Provide the descriptions required for Part II, lines 3, 5, and 9; Part III, lines 1a and 4; Part IV, lines 1b and 2b; Part V, line 4; Part X, line 2; Part XI, lines 2d and 4b; and Part XII, lines 2d and 4b. Also complete this part to provide any additional information.

### PART V, LINE 4:

THE ENDOWMENT FUNDS ARE USED TO FUND SCHOLARSHIPS FOR PEOPLE WITH SPINA

BIFIDA, FUND GRANTS TO PROMOTE THE PREVENTION AND CURE OF SPINA BIFIDA,

AND TO IMPROVE THE LIVES OF THOSE LIVING WITH SPINA BIFIDA.

PART X, LINE 2:

THE ASSOCIATION EVALUATED ITS UNCERTAINTY IN INCOME TAXES FOR THE YEAR

ENDED DECEMBER 31, 2021, AND DETERMINED THAT THERE WERE NO MATTERS THAT

WOULD REQUIRE RECOGNITION IN THE FINANCIAL STATEMENTS OR THAT MAY HAVE ANY

32

EFFECT ON ITS TAX-EXEMPT STATUS.

132054 10-28-21

Schedule D (Form 990) 2021	SPINA BIFIDA	ASSOCIATION OF	AMERICA	58-1342181 Page 5
Schedule D (Form 990) 2021 Part XIII Supplemental Info	rmation (continued)			
				Schedule D (Form 990) 2021
132055 10-28-21				

33 2021.04030 SPINA BIFIDA ASSOC**COPY**<sup>193407\_1</sup>

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SCHEDULE I (Form 990) Department of the Treasury Internal Revenue Service		Go	irants and Oth vernments, an ete if the organization Go to www.ir	nd Individua n answered "Yes" Attach to For	l <b>s in the Uni</b> on Form 990, Pa	ted States rt IV, line 21 or 22.		OMB No. 1545-0047
Name of the organization	ation		<b>,</b>					Employer identification number
			IATION OF A	MERICA				58-1342181
	Information on Grants a							
-	nization maintain records t		-			-		
	o award the grants or assis rt IV the organization's pro		oring the use of grant :					
	and Other Assistance to I					anization answered "Y	es" on Form 990. Par	t IV. line 21, for any
	t that received more than \$							,
• •	address of organization overnment	<b>(b)</b> EIN	<b>(c)</b> IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of noncash assistance	<b>(f)</b> Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
2 Enter total nur	nber of section 501(c)(3) a	nd government org	anizations listed in the	e line 1 table				
	nber of other organizations							
LHA For Paperwo	rk Reduction Act Notice,	see the Instruction	ons for Form 990.					Schedule I (Form 990) 2021

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



Part III

	recipients	Cash gran	Cash assistance	
MERGENCY ASSISTANCE AWARDS	3	1,340.	0.	
OTH ASSISTANCE	25	1,250.	٥.	
ESEARCH AWARDS	61	610.	0.	
LINICAL CARE PARTNER AWARDS	4	369.	0.	
B-YOU AWARDS	30	300.	0.	

(c) Amount of

cash grant

(d) Amount of non-

cash assistance

(e) Method of valuation

(book, FMV, appraisal, other)

PART I, LINE 2:

THE ASSOCIATION PERFORMS A FINANCIAL AND PROGRAM REVIEW FOR EACH GRANT

DISBURSEMENT TO ENSURE THAT SUCH GRANTS ARE USED FOR PROPER PURPOSES AND

ARE NOT OTHERWISE DIVERTED FROM THE INTENDED USE.

#### SPINA BIFIDA ASSOCIATION OF AMERICA Schedule I (Form 990) 2021

Part III can be duplicated if additional space is needed.

(a) Type of grant or assistance

Grants and Other Assistance to Domestic Individuals. Complete if the organization answered "Yes" on Form 990, Part IV, line 22.

(b) Number of

recipients

58-1342181

(f) Description of noncash assistance

Page 2

Schedule I (Form 990) SPINA BIFID	A ASSOCIATION	N OF AMERIC	CA		58-1342181 Pag
Part III Continuation of Grants and Other Assistance to	Domestic Individuals (	Schedule I (Form 99	90), Part III.)		1
(a) Type of grant or assistance	<b>(b)</b> Number of recipients	( <b>c)</b> Amount of cash grant	(d) Amount of non- cash assistance	<b>(e)</b> Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance
DUCATION OUTREACH - PARTICIPATION	29.	290.	0.		
DVOCACY AWARDS	2.	123.	0.		
					Schedule I (Form 9

Schedule I (Form 990)

SC	HEDULE J	Compensation Information	I	OMB No. 1	545-004	47
(Fo	rm 990)	For certain Officers, Directors, Trustees, Key Employees, and Highest	-	00	<b>n</b> 4	
•	-	Compensated Employees		20	<b>८</b>	
-		<ul> <li>Complete if the organization answered "Yes" on Form 990, Part IV, line 23.</li> <li>Attach to Form 990.</li> </ul>		Open to	Publ	ic
	tment of the Treasury al Revenue Service	Go to www.irs.gov/Form990 for instructions and the latest information.		Inspe	ction	
Nam	e of the organizatio		Employer	identificatio	on nui	mber
		SPINA BIFIDA ASSOCIATION OF AMERICA	58-2	134218	1	
Pa	rt I Question	s Regarding Compensation				
					Yes	No
1a	Check the appropr	iate box(es) if the organization provided any of the following to or for a person listed on Form	990,			
	Part VII, Section A	line 1a. Complete Part III to provide any relevant information regarding these items.				
	First-class or	charter travel Housing allowance or residence for perso	nal use			
	Travel for con	npanions	sidence			
	Tax indemnifi	cation and gross-up payments Health or social club dues or initiation fee	s			
	Discretionary	spending account Personal services (such as maid, chauffer	ır, chef)			
b	If any of the boxes	on line 1a are checked, did the organization follow a written policy regarding payment or				
	reimbursement or	provision of all of the expenses described above? If "No," complete Part III to explain		1b		
2	Did the organizatio	n require substantiation prior to reimbursing or allowing expenses incurred by all directors,				
	trustees, and office	ers, including the CEO/Executive Director, regarding the items checked on line 1a?		2		
3	Indicate which, if a	ny, of the following the organization used to establish the compensation of the organization's	i			
	CEO/Executive Dir	ector. Check all that apply. Do not check any boxes for methods used by a related organizati	on to			
	establish compens	ation of the CEO/Executive Director, but explain in Part III.				
	Compensatio	n committee Written employment contract				
	Independent	compensation consultant X Compensation survey or study				
	Form 990 of c	ther organizations X Approval by the board or compensation c	ommittee			
4	During the year, di	d any person listed on Form 990, Part VII, Section A, line 1a, with respect to the filing				
	organization or a re	elated organization:				
а	Receive a severand	e payment or change-of-control payment?		<u>4a</u>		X
b	Participate in or re	ceive payment from a supplemental nonqualified retirement plan?		4b		X
С		ceive payment from an equity-based compensation arrangement?		4c		X
	If "Yes" to any of li	nes 4a-c, list the persons and provide the applicable amounts for each item in Part III.				
		c)(3), 501(c)(4), and 501(c)(29) organizations must complete lines 5-9.				
5		on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensatio	'n			
	contingent on the					37
						X
b		zation?		<u>5b</u>		X
_		or 5b, describe in Part III.				
6	-	on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation	'n			
	contingent on the	-				v
						X
b		zation?		<u>6b</u>		X
-		or 6b, describe in Part III.				
7		on Form 990, Part VII, Section A, line 1a, did the organization provide any nonfixed payments		_		v
~		nes 5 and 6? If "Yes," describe in Part III		7		X
8		reported on Form 990, Part VII, paid or accrued pursuant to a contract that was subject to the				v
~				8		X
9		lid the organization also follow the rebuttable presumption procedure described in		-		
		n 53.4958-6(c)?				
LHA	For Paperwork F	eduction Act Notice, see the Instructions for Form 990.	Schee	dule J (Forn	n 990)	2021

132111 11-02-21

### Part II Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees. Use duplicate copies if additional space is needed.

For each individual whose compensation must be reported on Schedule J, report compensation from the organization on row (i) and from related organizations, described in the instructions, on row (ii). Do not list any individuals that aren't listed on Form 990, Part VII.

Note: The sum of columns (B)(i)-(iii) for each listed individual must equal the total amount of Form 990, Part VII, Section A, line 1a, applicable column (D) and (E) amounts for that individual.

<b>(A)</b> Name and Title		(B) Breakdown of W	/-2 and/or 1099-MIS compensation	C and/or 1099-NEC	(C) Retirement and other deferred	(D) Nontaxable benefits	(E) Total of columns (B)(i)-(D)	in column (B)
		(i) Base compensation	(ii) Bonus & incentive compensation	(iii) Other reportable compensation	compensation			reported as deferred on prior Form 990
(1) SARA STRUWE	(i)	140,400.	0.	0.	0.	28,505.	168,905.	0.
PRESIDENT AND CEO	(ii)	0.	0.	0.	0.	0.	0.	0.
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i) (ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							

Schedule J (Form 990) 2021

Part III Supplemental Information

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

Schedule J (Form 990) 2021



SCHEDULE O (Form 990)

Department of the Treasury

Name of the organization

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 Form 990-EZ.

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

Employer identification number 58-1342181

OMB No. 1545-0047

SPINA BIFIDA ASSOCIATION OF AMERICA

### FORM 990, PART I, LINE 1, DESCRIPTION OF ORGANIZATION MISSION:

IMPACTED BY SPINA BIFIDA

FORM 990, PART III, LINE 1, DESCRIPTION OF ORGANIZATION MISSION:

EDUCATE AND TRAIN THE PROFESSIONALS INVOLVED IN THE TREATMENT OF SPINA

BIFIDA.

FORM 990, PART III, LINE 4A, PROGRAM SERVICE ACCOMPLISHMENTS:

NATIONAL SPINA BIFIDA PATIENT REGISTRY (NSBPR). THE SPINA BIFIDA

COLLABORATIVE CARE NETWORK PRODUCED GUIDELINES FOR THE CARE OF PEOPLE

LIVING WITH SPINA BIFIDA WHICH INCLUDED RESEARCH FROM THE NSBPR.

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

GOVERNMENT RELATIONS

EXPENSES \$ 159,288. INCLUDING GRANTS OF \$ 0. REVENUE \$ 0.

INFORMATION AND REFERRAL

EXPENSES \$ 34,471. INCLUDING GRANTS OF \$ 0. REVENUE \$ 0.

FORM 990, PART VI, SECTION A, LINE 6:

EACH CHAPTER OF THE ASSOCIATION WHICH MEETS THE AFFILIATION STANDARDS OF

THE ASSOCIATION AND IS IN GOOD STANDING AT THE TIME OF EACH RELEVANT

MEETING IS REFERRED TO AS A MEMBER.

FORM 990, PART VI, SECTION A, LINE 7A:

DELEGATES ARE APPOINTED BY EACH CHAPTER. THESE DELEGATES APPROVE THE NEW

LHAFor Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ.Schedule O (Form 990) 202113221111-11-21

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Schedule O (Form 990) 2021 Page 2					
Name of the organization SPINA BIFIDA ASSOCIATION OF AMERICA	Employer identification number 58-1342181				
MEMBERS OF THE BOARD OF DIRECTORS AND THE SLATE OF OFFICER	S OF THE BOARD.				

FORM 990, PART VI, SECTION A, LINE 7B:

ANY CHANGES IN THE ASSOCIATION'S BYLAWS AND ARTICLES OF INCORPORATION ARE

REQUIRED TO BE APPROVED BY A MAJORITY OF THE CHAPTER DELEGATES PRESENT AT THE ANNUAL BOARD MEETING.

FORM 990, PART VI, SECTION B, LINE 11B:

THE DRAFT VERSION OF THE FEDERAL FORM 990 IS REVIEWED BY THE PRESIDENT AND CEO AS WELL AS THE CHIEF FINANCIAL OFFICER. IT IS THEN IS GIVEN TO THE AUDIT COMMITTEE FOR REVIEW, DISCUSSION AND APPROVAL. A COPY OF THE DRAFT FEDERAL FORM 990 IS PROVIDED TO THE ENTIRE BOARD OF DIRECTORS PRIOR TO FILING WITH THE INTERNAL REVENUE SERVICE.

FORM 990, PART VI, SECTION B, LINE 12C:

ANNUAL WRITTEN CONFIRMATION IS REQUIRED FROM ALL BOARD MEMBERS WHO IDENTIFY ANY POTENTIAL CONFLICTS OF INTEREST. THE CONFIRMATION FORM STATES THAT BOARD MEMBERS FOR WHOM THERE IS A CONFLICT ON A GIVEN ISSUE WILL NOT BE INVOLVED IN ANY DISCUSSIONS NOR VOTES ON AREAS OF CONFLICT. THE ANNUAL CONFLICT OF INTEREST (COI) STATEMENTS ARE REVIEWED BY THE BOARD CHAIR AND THE CEO AND, IF ANY COI ITEMS ARE IDENTIFIED, THEY WILL BE BROUGHT TO THE BOARD FOR REVIEW. IN ADDITION, BOARD MEMBERS ARE EXPECTED TO IDENTIFY ANY POTENTIAL CONFLICTS THAT MAY ARISE THROUGHOUT THE YEAR AND AFTER THE COI STATEMENTS ARE SIGNED.

FORM 990, PART VI, SECTION B, LINE 15A:

THERE IS A FORMAL REVIEW OF THE CHIEF EXECUTIVE OFFICER'S (CEO)

COMPENSATION BY THE BOARD OF DIRECTORS. A FORMAL REVIEW IS MADE BY THE CEO 132212 11-11-21 Schedule O (Form 990) 2021 41

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Schedule O (Form 990) 2021	Page 2
Name of the organization SPINA BIFIDA ASSOCIATION OF AMERICA	Employer identification number 58-1342181
FOR ALL OTHER EMPLOYEES. THE BOARD OF DIRECTORS EMPLOYS A	COMBINATION OF
PERFORMANCE EVALUATION AND REVIEW OF BOTH LOCAL AND NATIO	NAL COMPENSATION
SURVEYS TO ESTABLISH THE COMPENSATION OF THE CEO. SIMILAR	LY, THE CEO
EMPLOYS PERFORMANCE REVIEWS AND DOCUMENTATION ON REGIONAL	COMPENSATION
STUDIES TO REVIEW ALL STAFF INCLUDING THE CONTROLLER. ALL	STAFF PERFORMANCE
REVIEWS AND COMPENSATION CHANGES ARE PRESENTED TO THE CEO	PRIOR TO
FINALIZING FOR WRITTEN APPROVAL. THE COMPENSATION STUDY L	AST TOOK PLACE
DURING DECEMBER 2019.	
FORM 990, PART VI, LINE 17, LIST OF STATES RECEIVING COPY	OF FORM 990:
AL, AR, CA, FL, GA, IL, KS, KY, MD, MA, MI, MN, MS, NH, NJ, NM, NY, NC, OK,	OR, PA, RI, SC, TN, UT
VA,WI,WV	
FORM 990, PART VI, SECTION C, LINE 19:	
THE ASSOCIATION MAKES ITS GOVERNING DOCUMENTS, CONFLICT O	F INTEREST POLICY,
AND FINANCIAL STATEMENTS AVAILABLE TO THE PUBLIC ON THEIR	WEBSITE.
FORM 990, PART IX, LINE 11G, OTHER FEES:	
CONSULTING SERVICES:	
PROGRAM SERVICE EXPENSES	161,430.
MANAGEMENT AND GENERAL EXPENSES	861.
FUNDRAISING EXPENSES	68,442.
TOTAL EXPENSES	230,733.
TOTAL OTHER FEES ON FORM 990, PART IX, LINE 11G, COL A	230,733.
FORM 990, PART I, LINE 5 & PART V, LINE 2A	
THE ASSOCIATION HAS CONTRACTED WITH A PROFESSIONAL EMPLOY	ER

ORGANIZATION, ADP TOTALSOURCE, TO SERVE AS THE EMPLOYER OF RECORD FOR

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Schedule O (Form 990) 2021

10461026 150872 193407

132212 11-11-21

Name of the organization SPINA BIFIDA	ASSOCIATION OF	AMERICA	Employer identification number 58-1342181
THE ASSOCIATION'S EMPLOYEES			
FOR TAX FILINGS RELATED TO	EMPLOYEES. ADP	TOTALSOURCE I	SSUED 15 W-2
FORMS IN 2021 FOR ASSOCIATI	ON EMPLOYEES.		
132212 11-11-21			Schedule O (Form 990) 202