** PUBLIC DISCLOSURE COPY **

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.

OMB No. 1545-0047 Open to Public Inspection

Department of the Treasury Internal Revenue Service

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

AF	or the	e 2022 calendar year, or tax year beginning and	enaing						
B c	heck if pplicabl	C Name of organization		D Employer identifie	cation number				
	Addre	SPINA BIFIDA ASSOCIATION OF AMERICA							
	Name chang	Doing business as		58-13421	81				
	Initial return	Number and street (or P.O. box if mail is not delivered to street address)	Room/suite	E Telephone number					
	Final return		800	(202) 94					
	termin ated			G Gross receipts \$	2,437,091.				
	Amen	ARLINGION, VA 22209		H(a) Is this a group return					
	Application	F Name and address of principal officer: SARA SIROWE		for subordinates	? Yes X No				
	pendir	SAME AS C ABOVE		H(b) Are all subordinates in	cluded? Yes No				
1 T	ax-ex	empt status: X 501(c)(3) 501(c) () (insert no.) 4947(a)(1)	or 527	If "No," attach a	list. See instructions				
	Vebsi			H(c) Group exemptio					
K F	orm of	organization: X Corporation Trust Association Other	L Year	of formation: $1973 _{ m N}$	1 State of legal domicile: WI				
Pa	rt I	Summary							
a)		Briefly describe the organization's mission or most significant activities: $\underline{ ext{THE}}$							
Activities & Governance		ASSOCIATION IS TO BUILD A BETTER AND BRIG	HTER E	TUTURE FOR A	LL THOSE				
rua	2	Check this box if the organization discontinued its operations or dispos	sed of more	than 25% of its net ass					
ove	3	Number of voting members of the governing body (Part VI, line 1a)		3	14				
<u>ت</u>		Number of independent voting members of the governing body (Part VI, line 1b)			14				
es 6		Total number of individuals employed in calendar year 2022 (Part V, line 2a)			16				
ξ	6	Total number of volunteers (estimate if necessary)		6	615				
Υcti	l			7a	0.				
_	b	Net unrelated business taxable income from Form 990-T, Part I, line 11	<u></u>		0.				
				Prior Year	Current Year				
Revenue	l	Contributions and grants (Part VIII, line 1h)		2,139,236.	2,092,167.				
	l	Program service revenue (Part VIII, line 2g)		115,185.	67,671.				
3e	ı	Investment income (Part VIII, column (A), lines 3, 4, and 7d)		20,425.	3,478.				
_	l	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)		8,850.	20,115.				
		Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)		2,283,696.	2,183,431.				
	l	Grants and similar amounts paid (Part IX, column (A), lines 1-3)		3,458.	37,427.				
	l	Benefits paid to or for members (Part IX, column (A), line 4)		0.	0.				
es		Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)		1,223,804.	1,352,048.				
Expenses		Professional fundraising fees (Part IX, column (A), line 11e)		0.	0.				
Ϋ́	l	Total fundraising expenses (Part IX, column (D), line 25)		000 616	016 220				
ш		Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)		809,616.	916,339.				
	l	Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)		2,036,878.	2,305,814.				
		Revenue less expenses. Subtract line 18 from line 12		246,818.	-122,383 .				
is or			Ве	ginning of Current Year	End of Year				
Net Assets or - -und Balances	20	Total assets (Part X, line 16)		1,442,536.	1,417,977.				
et A Ind	21	Total liabilities (Part X, line 26)		236,534.	403,752.				
_	rt II	Net assets or fund balances. Subtract line 21 from line 20		1,200,002.	1,014,223.				
		Ities of perjury, I declate that I have examined this return, including accompanying schedule:	and etatom	ante and to the heet of my	knowledge and helief it is				
		t, and complete. Declaration of preparer (other than officer) is based on all information of wh		-	knowledge and belief, it is				
ii uo,	COLLEC		iicii proparci	October	2 2023				
Sigr	1	Signature of officer		Date	2, 2020				
Her		SARA STRUWE, PRESIDENT AND CEO							
	•	Type or print name and title							
		Print/Type preparer's name Preparer's signature	[Date Check	PTIN				
Paid		AARON M. FOX AARON M. FOX	lo	9/29/23 if self-employ	P01365820				
	arer	Firm's name MARCUM LLP			1-1986323				
	Only	Firm's address 1899 L STREET, NW, SUITE 850							
	_	WASHINGTON, DC 20036		Phone no. (2	02) 227-4000				
May	the IF	RS discuss this return with the preparer shown above? See instructions			X Yes No				

4d Other program services (Describe on Schedule O.)

(Expenses \$ 223,636. including grants of \$

142.) (Revenue \$

4e Total program service expenses

1,970,707.

Form 990 (2022)

232002 12-13-22

Form 990 (2022) SPINA BIFIDA ASSOCIATION OF AMERICA 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	X	
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		X
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	X	
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		Х
6	Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to			
	provide advice on the distribution or investment of amounts in such funds or accounts? If "Yes," complete Schedule D, Part I	6		х
7	Did the organization receive or hold a conservation easement, including easements to preserve open space,			
-	the environment, historic land areas, or historic structures? If "Yes," complete Schedule D, Part II	7		х
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If</i> "Yes," <i>complete</i>	<u> </u>		
Ü	Schedule D, Part III	8		х
9	Did the organization report an amount in Part X, line 21, for escrow or custodial account liability, serve as a custodian for	۰		
9	amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services?			
		_		x
40	If "Yes," complete Schedule D, Part IV	9		
10	Did the organization, directly or through a related organization, hold assets in donor-restricted endowments	40	v	
	or in quasi endowments? If "Yes," complete Schedule D, Part V	10	X	
11	If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X,			
	as applicable.			
а	Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D,		7.7	
	Part VI	11a	_X_	
b	Did the organization report an amount for investments - other securities in Part X, line 12, that is 5% or more of its total			
	assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VII	11b		<u>X</u>
С	Did the organization report an amount for investments - program related in Part X, line 13, that is 5% or more of its total			
	assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VIII	11c		X
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		<u> X</u>
е	Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X	11e	X	
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	X	
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		X
13	Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E	13		X
14a	Did the organization maintain an office, employees, or agents outside of the United States?	14a		Х
b				
	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		Х
15	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any			
	foreign organization? If "Yes," complete Schedule F, Parts II and IV	15		х
16	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to			
. =	or for foreign individuals? If "Yes," complete Schedule F, Parts III and IV	16		х
17	Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX,			
••	column (A), lines 6 and 11e? If "Yes," complete Schedule G, Part I. See instructions	17		х
18	Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines	<u>''</u>		_ _ _
.5		18		х
19	1c and 8a? If "Yes," complete Schedule G, Part II	10		
19	,	10		х
20-	complete Schedule G, Part III	19		X
	Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H	20a		
	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	ا ہے ا		v
	domestic government on Part IX, column (A), line 1? If "Yes." complete Schedule I, Parts I and II	21		X

232003 12-13-22

	i (community)			
00	Did the constitution of the desired that the desired to the desire		Yes	No
22	Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on	00	х	
00	Part IX, column (A), line 2? If "Yes," complete Schedule I, Parts I and III	22		
23	Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5, about compensation of the organization's current			
	and former officers, directors, trustees, key employees, and highest compensated employees? If "Yes," complete		Х	
04-	Schedule J	23	Λ	
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	24a		x
h	Schedule K. If "No," go to line 25a	24a 24b		1
	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease	240		
C		24c		
٨	any tax-exempt bonds? Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d		
	Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit	24u		
2 5a	transaction with a disqualified person during the year? If "Yes," complete Schedule L, Part I	25a		x
h	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and	23a		1
b	that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? If "Yes." complete			
		25b		x
26	Schedule L, Part I Did the organization report any amount on Part X, line 5 or 22, for receivables from or payables to any current	200		
20	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		х
b	A family member of any individual described in line 28a? If "Yes," complete Schedule L, Part IV	28b		Х
	A 35% controlled entity of one or more individuals and/or organizations described in line 28a or 28b? <i>If</i>			
	"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		Х
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation			
-	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		Х
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If</i> "Yes," <i>complete</i>	<u> </u>		
-	Schedule N, Part II	32		Х
33	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations			
	sections 301.7701-2 and 301.7701-3? If "Yes," complete Schedule R, Part I	33		Х
34	Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Part II, III, or IV, and			
	Part V, line 1	34		Х
35a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a		Х
	If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity			
	within the meaning of section 512(b)(13)? If "Yes," complete Schedule R, Part V, line 2	35b		
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization?			
	If "Yes," complete Schedule R, Part V, line 2	36		X
37	Did the organization conduct more than 5% of its activities through an entity that is not a related organization			
	and that is treated as a partnership for federal income tax purposes? If "Yes," complete Schedule R, Part VI	37		X
38	Did the organization complete Schedule O and provide explanations on Schedule O for Part VI, lines 11b and 19?			
	Note: All Form 990 filers are required to complete Schedule O	38	Х	
Pai				
	Check if Schedule O contains a response or note to any line in this Part V			
			Yes	No
1a	Enter the number reported in box 3 of Form 1096. Enter -0- if not applicable			
b	Enter the number of Forms W-2G included on line 1a. Enter -0- if not applicable 1b 0			
С	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming			
	(gambling) winnings to prize winners?	10	x	

232004 12-13-22

Form 990 (2022) SPINA BIFIDA ASSOCIATION OF AMERICA
Part V Statements Regarding Other IRS Filings and Tax Compliance (continued)

				Yes	No				
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements,								
	filed for the calendar year ending with or within the year covered by this return	2a 16							
b	If at least one is reported on line 2a, did the organization file all required federal employment tax return	ns?	2b	X					
За	Did the organization have unrelated business gross income of \$1,000 or more during the year?		За		X				
b	If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation on Schedule	0	3b						
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other a	uthority over, a							
	financial account in a foreign country (such as a bank account, securities account, or other financial a	ccount)?	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 Advanced in the Financi	ccounts (FBAR).							
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?		5a		X				
	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction		5b		X				
	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?		5c						
6a	6a Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit								
	any contributions that were not tax deductible as charitable contributions?								
b	If "Yes," did the organization include with every solicitation an express statement that such contributi	ons or gifts	l						
_	were not tax deductible?		6b						
7	Organizations that may receive deductible contributions under section 170(c).		_		v				
	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and ser		7a		X				
			7b						
С	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was				х				
لم	to file Form 8282?	7d	7c						
	If "Yes," indicate the number of Forms 8282 filed during the year Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit or		7e		Х				
e f	f Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract? f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?								
g	If the organization received a contribution of qualified intellectual property, did the organization file Fo		7f 7g		X				
•	If the organization received a contribution of qualified intellectual property, and the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, airplanes, air		7 <u>9</u>						
8									
			8						
9	Sponsoring organizations maintaining donor advised funds.								
а	5								
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:								
а	Gross income from members or shareholders	11a							
b	Gross income from other sources. (Do not net amounts due or paid to other sources against								
	amounts due or received from them.)	11b							
	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form	1 1	12a						
	If "Yes," enter the amount of tax-exempt interest received or accrued during the year	12b	-						
13	Section 501(c)(29) qualified nonprofit health insurance issuers.								
а	Is the organization licensed to issue qualified health plans in more than one state?		13a						
	Note: See the instructions for additional information the organization must report on Schedule O.								
D	Enter the amount of reserves the organization is required to maintain by the states in which the	406							
	organization is licensed to issue qualified health plans	13b	-						
	Enter the amount of reserves on hand	13c	14a		Х				
	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation on Schedul Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuner		14b						
15	excess parachute payment(s) during the year?		15		х				
	If "Yes," see the instructions and file Form 4720, Schedule N.		13						
16	Is the organization an educational institution subject to the section 4968 excise tax on net investment	income?	16		Х				
	If "Yes," complete Form 4720, Schedule O.	. income?	10						
17	Section 501(c)(21) organizations. Did the trust, or any disqualified or other person engage in any ac	tivities							
••	that would result in the imposition of an excise tax under section 4951, 4952 or 4953?		17						
	If "Yes," complete Form 6069.								

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

	Check if Schedule O contains a response or note to any line in this Part VI						X				
Sec	tion A. Governing Body and Management										
						Yes	No				
1a	Enter the number of voting members of the governing body at the end of the tax year	1a	:	14							
	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	:	14							
2	Did any officer, director, trustee, or key employee have a family relationship or a business relationship	with a	any other								
	officer, director, trustee, or key employee?				2		_X_				
3	Did the organization delegate control over management duties customarily performed by or under the	direc	t supervision								
	of officers, directors, trustees, or key employees to a management company or other person?				3		_X_				
4	Did the organization make any significant changes to its governing documents since the prior Form 99	90 wa	s filed?		4		X				
5	5 Did the organization become aware during the year of a significant diversion of the organization's assets?										
6	Did the organization have members or stockholders?				6	Х					
7a	Did the organization have members, stockholders, or other persons who had the power to elect or ap	point	one or								
	more members of the governing body?				7a	Х					
b	Are any governance decisions of the organization reserved to (or subject to approval by) members, ste										
	persons other than the governing body?			[7b	Х					
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year	r by the	e following:								
а	The governing body?			.	8a	Х					
b	Each committee with authority to act on behalf of the governing body?				8b	Х					
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached	hed a	t the								
	organization's mailing address? If "Yes." provide the names and addresses on Schedule O				9		X				
Sec	tion B. Policies (This Section B requests information about policies not required by the Internal Re	/enue	Code.)								
				_		Yes	No				
10a	Did the organization have local chapters, branches, or affiliates?				10a	X					
b	If "Yes," did the organization have written policies and procedures governing the activities of such characteristics.	apters	, affiliates,								
	and branches to ensure their operations are consistent with the organization's exempt purposes? $$				10b	X					
11a	a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?										
12a	Did the organization have a written conflict of interest policy? If "No," go to line 13				12a	X					
b	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise				12b	Х					
С	Did the organization regularly and consistently monitor and enforce compliance with the policy? If " γ "	es," d	escribe								
	on Schedule O how this was done				12c	X					
13	Did the organization have a written whistleblower policy?				13	X					
14	Did the organization have a written document retention and destruction policy?				14	Х					
15	Did the process for determining compensation of the following persons include a review and approval	by in	dependent								
	persons, comparability data, and contemporaneous substantiation of the deliberation and decision?										
	The organization's CEO, Executive Director, or top management official				15a	X					
b	Other officers or key employees of the organization				15b		_X_				
	If "Yes" to line 15a or 15b, describe the process on Schedule O. See instructions.										
16a	Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement	nent w	ith a								
	taxable entity during the year?			.	16a		_X_				
b	If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate	•	•								
	in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organi	izatior	ı's								
0	exempt status with respect to such arrangements?				16b						
	tion C. Disclosure	, <u> </u>	T 72 G 72 T 1	<u></u>	3.53	36T	163T				
17	List the states with which a copy of this Form 990 is required to be filed AL, AR, CA, FL, G.										
18	Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, an	id 990	-I (section 501(c)	(3)s	only) a	availab	ole				
	for public inspection. Indicate how you made these available. Check all that apply.										
	X Own website X Another's website X Upon request Other (explain		,		_						
19	Describe on Schedule O whether (and if so, how) the organization made its governing documents, con	nflict d	of interest policy,	and	financ	ial					
	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	ks and	d records								
	GLENRAE BROWN - (202) 944-3285										
	1600 WILSON BOULEVARD, 800, ARLINGTON, VA 22209 12-13-22 SEE SCHEDULE O FOR FULL LIST OF STATES				Г	gan	(0000)				
232006	12-13-22 SEE SCHEDULE O FOR FULL LIST OF STATES				Form	JJU	(2022)				

6

Form **990** (2022)

193407_1

00220930 150872 193407

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

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

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

- 1a Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year.
- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
 - List all of the organization's current key employees, if any. See the instructions for definition of "key employee."
- List the organization's five current highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (box 5 of Form W-2, box 6 of Form 1099-MISC, and/or box 1 of Form 1099-NEC) of more than \$100,000 from the organization and any related organizations.

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

- 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.

(A) Name and title	(B) Average hours per week	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)					one n an	(D) Reportable compensation from	(E) Reportable compensation from related	(F) Estimated amount of other
	(list any hours for related organizations below line)	Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former	the organization (W-2/1099-MISC/ 1099-NEC)	organizations (W-2/1099-MISC/ 1099-NEC)	compensation from the organization and related organizations
(1) SARA STRUWE	37.50			3,7				144 612	0	20 601
PRESIDENT AND CEO	27 50			Х				144,612.	0.	30,681.
(2) MICHAEL WOOD COO	37.50			х				115,000.	0.	28,282.
(3) GLENRAE BROWN	37.50									
CFO	F 00			Х				115,000.	0.	28,240.
(4) MARIA BOURNIAS, ESQ, CPA CHAIR	5.00	Х		х				0.	0.	0.
(5) MICHAEL HARTY, JR.	2.00	<u> </u>							0.1	
IMMEDIATE PAST CHAIR		Х		x				0.	0.	0.
(6) ANSHUL VARMA	2.00								-	-
TREASURER/SECRETARY		Х		Х				0.	0.	0.
(7) NANCY GORE	2.00									
CHAIR-ELECT		Х		Х				0.	0.	0.
(8) DOUG BURNS	2.00									
BOARD MEMBER		Х						0.	0.	0.
(9) DAWNE WIDENER BURROWS	2.00									
BOARD MEMBER		Х						0.	0.	0.
(10) TRACY DINUNZIO	2.00									
BOARD MEMBER		Х						0.	0.	0.
(11) MELISSA MAY	2.00	1								
BOARD MEMBER		Х						0.	0.	0.
(12) JOHN WEINER, MD	2.00	ļ								•
BOARD MEMBER		Х						0.	0.	0.
(13) WILSON NEYLAND	2.00	.,							,	0
BOARD MEMBER		Х						0.	0.	0.
(14) CHASE PHILLIPS	2.00	3,7							0	0
BOARD MEMBER	2 00	Х						0.	0.	0.
(15) KATHRYN SMITH BOARD MEMBER	2.00	Х						0.	0.	0.
(16) MARIE THOMING	2.00	Λ						0.	0.	<u> </u>
BOARD MEMBER	2.00	Х						0.	0.	0.
(17) ERIC TOBIN	2.00	71						0.	0.	<u> </u>
BOARD MEMBER	2.00	Х						0.	0.	0.
	l				l				J •	Form 990 (2022)

Form 990 (2022) SPINA BII	FIDA ASS	OC	ΊA	TI	ON	0	F	AMERICA	58-134	2181 Page 8
Part VII Section A. Officers, Directors, Trus	tees, Key Emp	oloye	ees,			ghes	t C	ompensated Employee	s (continued)	
(A) Name and title	(B) Average hours per week (list any hours for related organizations	box,	not c	Posi heck r ss per d a di	ition more son is irecto	than c s both	an tee)	(D) Reportable compensation from the organization (W-2/1099-MISC/ 1099-NEC)	(E) Reportable compensation from related organizations (W-2/1099-MISC/ 1099-NEC)	(F) Estimated amount of other compensation from the organization and related
	below line)	dividua	stitutio	Officer	key employee	ighest c nployee	Former			organizations
	IIIIO	u	iul	0t	Ke	H.	Po			
1b Subtotal	<u> </u>					L		374,612.	0	87,203.
c Total from continuation sheets to Part VI	I, Section A							374,612.	0	
d Total (add lines 1b and 1c)										07,203.
compensation from the organization										Yes No
3 Did the organization list any former officer,	director, truste	ee, k	еу е	mpl	oye	e, or	hig	hest compensated emp	loyee on	
line 1a? If "Yes," complete Schedule J for s 4 For any individual listed on line 1a, is the su										3 X
and related organizations greater than \$150	0,000? If "Yes,	" co	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," com										5 X
Section B. Independent Contractors	-									
1 Complete this table for your five highest co the organization. Report compensation for	•	•							•	ation from
(A) Name and business			ONE					(B) Description of s		(C) Compensation
Name and pasiness	<u>uuuroso</u>	140)IN E	<u>. </u>				Description of a	ICT VICCO	Сотроновного
							\dashv			
2 Total number of independent contractors (i \$100,000 of compensation from the organic	•	ot lin	nited	to t	thos 0		ted	above) who received mo	ore than	
,									•	Form 990 (2022)

00220930 150872 193407

Form 990 (2022) SPINA B
Part VIII Statement of Revenue

			Check if Schedule O contains a response of	or note to any lin	e in this Part VIII			
					(A)	(B)	(C)	(D) Revenue excluded
					Total revenue	Related or exempt function revenue	Unrelated business revenue	from tax under
						Tanotion Toveride	Business revenue	sections 512 - 514
s s	1	а	Federated campaigns 1a	59,946.				
Contributions, Gifts, Grants and Other Similar Amounts			Membership dues 1b					
<u>@</u> 8			Fundraising events 1c					
ifts Ir A			Related organizations 1d					
i, G			Government grants (contributions)	890,700.				
Sir			All other contributions, gifts, grants, and					
uti Je		•		141,521.				
Ģ.		~	Noncash contributions included in lines 1a-1f	7,430.				
no Du		_	· · · · · · · · · · · · · · · · · · ·		2,092,167.			
OB			Total. Add lines 1a-1f	Business Code	2,002,107			
	_	_	CONFERENCE & MEETINGS	541800	67,671.	67,671.		
Program Service Revenue	2			341000	07,071.	07,071.		
erv ne		b						
n S		С						
zar Sev		d						
6		е						
٩		f	All other program service revenue		4- 4-4			
\rightarrow		g	Total. Add lines 2a-2f		67,671.			
	3		Investment income (including dividends, intere		4			4 000
			other similar amounts)		1,808.			1,808.
	4		Income from investment of tax-exempt bond p	roceeds				
	5		Royalties					
			(i) Real	(ii) Personal				
	6	а	Gross rents 6a					
		b	Less: rental expenses 6b					
			Rental income or (loss) 6c					
			Net rental income or (loss)					
	7		Gross amount from sales of (i) Securities	(ii) Other				
	•	u	assets other than inventory 7a 255, 330.	(-7 =				
		h	Less: cost or other basis					
ω		D	and sales expenses					
ther Revenue		_	Gain or (loss) 7c 1,670.					
eve					1,670.			1,670.
Æ	_		Net gain or (loss)		1,070.			1,070.
the l	8	а	Gross income from fundraising events (not					
Ò			including \$ of					
			contributions reported on line 1c). See					
			Part IV, line 18					
			Less: direct expenses8b					
			Net income or (loss) from fundraising events					
	9	а	Gross income from gaming activities. See					
			Part IV, line 199a					
		b	Less: direct expenses9b					
		С	Net income or (loss) from gaming activities					
	10		Gross sales of inventory, less returns					
			and allowances 10a					
		b	Less: cost of goods sold 10b					
			Net income or (loss) from sales of inventory					
				Business Code				
snc	11	а	MISCELLANEOUS INCOME	900099	20,115.			20,115.
Miscellaneous Revenue		b			,			
ella vei		c						
Sc			All other revenue					
Σ			Total. Add lines 11a-11d		20,115.			
	12		Total revenue. See instructions		2,183,431.	67,671.	0.	23,593.
232009					, , = = = , = = = •	,		Form 990 (2022)

00220930 150872 193407

	Check if Schedule O contains a respons		this Part IX	(C)	(D)
	not include amounts reported on lines 6b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	Management and general expenses	Fundraising expenses
1	Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	2,500.	2,500.		
2	Grants and other assistance to domestic				
	individuals. See Part IV, line 22	34,927.	34,927.		
3	Grants and other assistance to foreign				
	organizations, foreign governments, and foreign				
	individuals. See Part IV, lines 15 and 16				
4 5	Benefits paid to or for members Compensation of current officers, directors,				
J	trustees, and key employees	461,815.	408,472.	37,415.	15,928
6	Compensation not included above to disqualified			0.72201	
_	persons (as defined under section 4958(f)(1)) and				
	persons described in section 4958(c)(3)(B)				
7	Other salaries and wages	674,535.	610,167.	21,695.	42,673
8	Pension plan accruals and contributions (include				
	section 401(k) and 403(b) employer contributions)	4.5.4 =	4.5. =		
9	Other employee benefits	120,708.	109,521.	3,106.	8,081 5,039
0	Payroll taxes	94,990.	85,250.	4,701.	5,039
1	Fees for services (nonemployees):				
а					
b		41 104	24 744	4 726	1 70
С.	<u> </u>	41,184. 45,329.	34,744. 42,697.	4,736.	1,704 1,389
	Lobbying	45,349.	44,097.	1,243.	1,30
e	· · · · · · · · · · · · · · · · · · ·	3,704.		3,704.	
f	Investment management fees	3,704.		3,704.	
9	column (A), amount, list line 11g expenses on Sch 0.)	394,543.	371,634.	10,821.	12,088
2	Advertising and promotion	227.	227.		
3	Office expenses	185,189.	97,209.	26,684.	61,296
4	Information technology	4,551.	3,744.	621.	186
5	Royalties				
3	Occupancy	26,639.	21,621.	3,540.	1,478
7	Travel	108,305.	97,047.	3,203.	8,05
3	Payments of travel or entertainment expenses				
	for any federal, state, or local public officials	04.465	40.550	2 40.5	
)	Conferences, conventions, and meetings	24,165.	19,570.	3,486.	1,109
)	Interest				
1	Payments to affiliates	28,102.		28,102.	
2	Depreciation, depletion, and amortization	11,577.	9,060.	1,942.	575
} -	Other expenses. Itemize expenses not covered	11,3//•	3,000.	1,344.	J / :
•	above. (List miscellaneous 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.)				
а	DITTO AND GUDGOD TRUTONG	15,826.	15,826.		
b	MISCELLANEOUS	11,465.	31.	11,434.	
С	FILING REGISTRATION	9,427.	2,725.	6,677.	25
d	TAXES	4,687.	3,073.	1,267.	34
е	All other expenses	1,419.	662.	426.	331
5_	Total functional expenses. Add lines 1 through 24e	2,305,814.	1,970,707.	174,803.	160,304
3	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)				

Form 990 (2022)

Part X | Balance Sheet

Part X	(Balance Sheet					
		Check if Schedule O contains a response or	note to ar	ny line in this Part X			
					(A) Beginning of year		(B) End of year
1	1	Cash - non-interest-bearing			381,363.	1	297,686
2		Savings and temporary cash investments			293,728.	2	292,412
3	3	Pledges and grants receivable, net			153,998.	3	193,502
4		Accounts receivable, net			4		
5	5	Loans and other receivables from any current	t or forme	r officer, director,			
		trustee, key employee, creator or founder, su	bstantial	contributor, or 35%			
		controlled entity or family member of any of t		5			
6	3	Loans and other receivables from other disqu					
		under section 4958(f)(1)), and persons describ	bed in se	ction 4958(c)(3)(B)		6	
တ္ 7	7	Notes and loans receivable, net				7	
Assets	3	Inventories for sale or use			5,139.	8	
∛ 9	9	Prepaid expenses and deferred charges		······	70,414.	9	126,268
10)a	Land, buildings, and equipment: cost or other					
		basis. Complete Part VI of Schedule D					
	b	Less: accumulated depreciation	10b	250,722.	34,840. 502,392.	10c	9,119 440,670
11		Investments - publicly traded securities		502,392.	11	440,670	
12	2	Investments - other securities. See Part IV, Iir		12			
13	3	Investments - program-related. See Part IV, lin		13			
14	4	Intangible assets			14		
15	5	Other assets. See Part IV, line 11	662.	15	58,320		
16		Total assets. Add lines 1 through 15 (must e			1,442,536.	16	1,417,977
17		Accounts payable and accrued expenses $\ \dots$			57,155.	17	73,910
18		Grants payable		2 522	18	151 000	
19		Deferred revenue	8,532.	19	151,928		
20		Tax-exempt bond liabilities				20	
21		Escrow or custodial account liability. Comple				21	
ဖွ 22		Loans and other payables to any current or fo					
┋╽		trustee, key employee, creator or founder, su		· · · · · · · · · · · · · · · · · · ·			
Liabilities		controlled entity or family member of any of t	-			22	
23		Secured mortgages and notes payable to uni		• • • • • • • • • • • • • • • • • • • •		23	
24		Unsecured notes and loans payable to unrela				24	
25	5	Other liabilities (including federal income tax,					
		parties, and other liabilities not included on li	nes 17-24). Complete Part X	170 047		177 014
	_	of Schedule D		·····	170,847.	25	177,914
26	<u> </u>	Total liabilities. Add lines 17 through 25	· · · ·	re X	236,534.	26	403,752
ဖွ		Organizations that follow FASB ASC 958, o	check he	e 🛕			
<u>ور</u> ا	,	and complete lines 27, 28, 32, and 33.			964,522.	07	77/ 316
27 <u>a</u>					241,480.	27	774,316 239,909
ഷ്ട് 28 യ	5				241,400.	28	239,909
<u>.</u> 5		Organizations that do not follow FASB ASC	. 958, CN	eck nere			
힏		and complete lines 29 through 33.	do			00	
St 29		Capital stock or trust principal, or current fun				29	
30		Paid-in or capital surplus, or land, building, or				30	
Net Assets or Fund Balances 25 28 30 31 32		Retained earnings, endowment, accumulated			1,206,002.	31	1,014,225
_				·····	1,442,536.	32	1,417,977
33	,	Total liabilities and net assets/fund balances			1, 114, JJU •	აა	Form 990 (202

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	2,18					
2	Total expenses (must equal Part IX, column (A), line 25)	2	2,30					
3	Revenue less expenses. Subtract line 2 from line 1	3	-12					
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	1,20	<u>6,0</u> 9,3	02.			
5	5 Net unrealized gains (losses) on investments							
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,							
	column (B))	10	1,01	4,2	25.			
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	2a Were the organization's financial statements compiled or reviewed by an independent accountant?							
	If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed	on a						
	separate basis, consolidated basis, or both:							
	Separate basis Consolidated basis Both consolidated and separate basis							
b	Were the organization's financial statements audited by an independent accountant?		. 2b	X				
	If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate	basis,						
	consolidated basis, or both:							
	X Separate basis Consolidated basis Both consolidated and separate basis							
С	If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the	audit,						
	review, or compilation of its financial statements and selection of an independent accountant?		. 2c	X				
	If the organization changed either its oversight process or selection process during the tax year, explain on Sche	dule O.						
За	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the							
	Uniform Guidance, 2 C.F.R. Part 200, Subpart F?		3a		Х			
b	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the require							
	or audits, explain why on Schedule O and describe any steps taken to undergo such audits		. 3b					
			Form	990	(2022)			

232012 12-13-22

SCHEDULE A

(Form 990)

Total

Department of the Treasury Internal Revenue Service

Public Charity Status and Public Support

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

Attach to Form 990 or Form 990-EZ.

Attach to Form 990 or Form 990-EZ.

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

OMB No. 1545-0047

2022

Open to Public Inspection

Employer identification number Name of the organization SPINA BIFIDA ASSOCIATION OF AMERICA 58-1342181 Reason for Public Charity Status. (All organizations must complete this part.) See instructions. Part I The organization is not a private foundation because it is: (For lines 1 through 12, check only one box.) A church, convention of churches, or association of churches described in section 170(b)(1)(A)(i). A school described in section 170(b)(1)(A)(ii). (Attach Schedule E (Form 990).) 3 A hospital or a cooperative hospital service organization described in section 170(b)(1)(A)(iii). A medical research organization operated in conjunction with a hospital described in section 170(b)(1)(A)(iii). Enter the hospital's name, city, and state: An organization operated for the benefit of a college or university owned or operated by a governmental unit described in section 170(b)(1)(A)(iv). (Complete Part II.) 6 A federal, state, or local government or governmental unit described in section 170(b)(1)(A)(v). X An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in section 170(b)(1)(A)(vi). (Complete Part II.) A community trust described in section 170(b)(1)(A)(vi). (Complete Part II.) An agricultural research organization described in section 170(b)(1)(A)(ix) operated in conjunction with a land-grant college or university or a non-land-grant college of agriculture (see instructions). Enter the name, city, and state of the college or 10 An organization that normally receives (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions, subject to certain exceptions; and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See section 509(a)(2). (Complete Part III.) 11 An organization organized and operated exclusively to test for public safety. See section 509(a)(4). 12 An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2). See section 509(a)(3). Check the box on lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g. Type I. A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization. You must complete Part IV, Sections A and B. Type II. A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s). You must complete Part IV, Sections A and C. Type III functionally integrated. A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions). You must complete Part IV, Sections A, D, and E. Type III non-functionally integrated. A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions). You must complete Part IV, Sections A and D, and Part V. Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization. Enter the number of supported organizations Provide the following information about the supported organization(s). (i) Name of supported (ii) EIN (iii) Type of organization (v) Amount of monetary (vi) Amount of other your governing document? (described on lines 1-10 organization support (see instructions) support (see instructions) No above (see instructions))

Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)

(Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

Sec	ction A. Public Support						
Cale	ndar year (or fiscal year beginning in)	(a) 2018	(b) 2019	(c) 2020	(d) 2021	(e) 2022	(f) Total
1	Gifts, grants, contributions, and						
	membership fees received. (Do not						
	include any "unusual grants.")	2905554.	1718305.	1460028.	2139236.	2092167.	10315290.
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	2905554.	1718305.	1460028.	2139236.	2092167.	10315290.
5	The portion of total contributions						
Ŭ	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,						
							1067537.
_	**						9247753.
	Public support. Subtract line 5 from line 4.						1 3241133.
		(=) 2012	(h) 2010	(a) 2020	(4) 2021	(a) 2022	(f) Total
	ndar year (or fiscal year beginning in)	(a) 2018 2905554.	(b) 2019 1718305.	(c) 2020 1460028.	(d) 2021 2139236.	(e) 2022 202167	(f) Total 10315290.
	Amounts from line 4	2903334.	1/10303.	1400020.	2139230.	2092107.	10313290.
8	Gross income from interest,						
	dividends, payments received on						
	securities loans, rents, royalties,	4 042	21 006	14 227	7 070	1 000	40 762
	and income from similar sources	4,043.	21,806.	14,227.	7,879.	1,808.	49,763.
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.	20,115.	
11	Total support. Add lines 7 through 10						10394048.
12	Gross receipts from related activities,	etc. (see instruction	ons)			12	375,499.
13	First 5 years. If the Form 990 is for the	ne organization's fir	rst, second, third, f	fourth, or fifth tax y	ear as a section 50	01(c)(3)	
_	organization, check this box and stop						
Sec	ction C. Computation of Publi	c Support Per	centage				
14	Public support percentage for 2022 (I	ine 6, column (f), d	ivided by line 11, o	olumn (f))		14	88.97 %
15	Public support percentage from 2021	Schedule A, Part	II, line 14			15	88.20 %
16a	33 1/3% support test - 2022. If the o	organization did no	t check the box or	n line 13, and line 1	14 is 33 1/3% or m	ore, check this bo	
	stop here. The organization qualifies	as a publicly suppo	orted organization				X
b	33 1/3% support test - 2021. If the o	organization did no	t check a box on l	ine 13 or 16a, and	line 15 is 33 1/3%	or more, check th	is box
	and stop here. The organization qual	ifies as a publicly s	supported organiza	ation			
17a	10% -facts-and-circumstances test						
	and if the organization meets the fact	s-and-circumstance	es test, check this	box and stop he	re. Explain in Part	VI how the organiz	zation
	meets the facts-and-circumstances te	st. The organizatio	n qualifies as a pu	blicly supported or	rganization		
b	10% -facts-and-circumstances test	-	•		-		
	more, and if the organization meets the	-					
	organization meets the facts-and-circu						
18	Private foundation. If the organization						
				,,	,		(Form 990) 2022

232022 12-09-22

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

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

Sed	ction A. Public Support	slow, picase comp	oicte i art ii.j				
	ndar year (or fiscal year beginning in)	(a) 2018	(b) 2019	(c) 2020	(d) 2021	(e) 2022	(f) Total
	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 disqualified persons						
b	Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
c	Add lines 7a and 7b						
8	Public support. (Subtract line 7c from line 6.)						
	ndar year (or fiscal year beginning in)	(a) 2018	(b) 2019	(c) 2020	(d) 2021	(e) 2022	(f) Total
	Amounts from line 6	(a) 2010	(6) 2019	(6) 2020	(4) 2021	(6) 2022	(i) iotai
	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						
c	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.)						
13	Total support. (Add lines 9, 10c, 11, and 12.)						
14	First 5 years. If the Form 990 is for the	J		,	•	() ()	· —
	check this box and stop here						
	ction C. Computation of Publi					 	
	Public support percentage for 2022 (li	, ,,,	•	column (f))		15	%
	Public support percentage from 2021					16	%
	ction D. Computation of Inves			. 10 1 (0)		14-1	
	Investment income percentage for 20					17	%
	Investment income percentage from 2					18	% 7 in
198	33 1/3% support tests - 2022. If the						
b	more than 33 1/3%, check this box ar 33 1/3% support tests - 2021. If the	organization did r	not check a box or	line 14 or line 19a	a, and line 16 is m	ore than 33 1/3%, a	and
	line 18 is not more than 33 1/3%, che	ck this box and st	top here. The orga	anization qualifies a	as a publicly supp	orted organization	
20	Private foundation. If the organization	n did not check a	hox on line 14 19	a or 19h check th	nis hox and see in	structions	

232023 12-09-22

Schedule A (Form 990) 2022

Part IV | Supporting Organizations

(Complete only if you checked a box on line 12 of 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.)

	Yes	No
1		
2		
20		
3a		
3b		
Зс		
4a		
4b		
4c		
5a		
5b		
5c		
6		
7		
8		
9a		
Ja		
9b		
9c		
10a		
10b		L

232024 12-09-22

Par	t IV	Supporting Organizations (continued)			<u></u>
		1. Commission		Yes	No
11	Has th	ne organization accepted a gift or contribution from any of the following persons?			
		son who directly or indirectly controls, either alone or together with persons described on lines 11b and			
_	•	elow, the governing body of a supported organization?	11a		
h		ily member of a person described on line 11a above?	11b		
		6 controlled entity of a person described on line 11a or 11b above? If "Yes" to line 11a, 11b, or 11c, provide	115		
·		in Part VI.	11c		
Sec		B. Type I Supporting Organizations	110		
				Yes	No
4	Did th	a governing hady, members of the governing hady, officers esting in their official consoity, or membership of one or		163	NO
1		e 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,			
		ors, or trustees at all times during the tax year? If "No," describe in Part VI how the supported organization(s)			
		ively operated, supervised, or controlled the organization's activities. If the organization had more than one supported			
		ization, describe how the powers to appoint and/or remove officers, directors, or trustees were allocated among the	4		
•	supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year. Did the organization operate for the benefit of any supported organization other than the supported		1		
2					
	organization(s) that operated, supervised, or controlled the supporting organization? If "Yes," explain in				
		how providing such benefit carried out the purposes of the supported organization(s) that operated,			
800		vised, or controlled the supporting organization. C. Type II Supporting Organizations	2		
Sec	LIOIT	5. Type ii Supporting Organizations			
				Yes	No
1		a majority of the organization's directors or trustees during the tax year also a majority of the directors			
	or trus	stees of each of the organization's supported organization(s)? If "No," describe in Part VI how control			
	or mai	nagement of the supporting organization was vested in the same persons that controlled or managed			
800	the su	pported organization(s). D. All Type III Supporting Organizations	1		
Sec	LIOII L	7. All Type III Supporting Organizations		1	
	-			Yes	No
1		e organization provide to each of its supported organizations, by the last day of the fifth month of the			
	•	ization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax			
		(ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the			
•	-	ization's governing documents in effect on the date of notification, to the extent not previously provided?	1		
2		any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported			
		ization(s) or (ii) serving on the governing body of a supported organization? If "No," explain in Part VI how	•		
_	•	ganization maintained a close and continuous working relationship with the supported organization(s).	2		
3	-	ason of the relationship described on line 2, above, did the organization's supported organizations have a			
	-	cant voice in the organization's investment policies and in directing the use of the organization's			
		ne or assets at all times during the tax year? If "Yes," describe in Part VI the role the organization's	•		
Sec	<i>suppo</i> tion E	orted organizations played in this regard. E. Type III Functionally Integrated Supporting Organizations	3		
1		the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions). The organization satisfied the Δctivities Test. Complete line 2 below.			
a b		The organization satisfied the Activities Test. Complete line 2 below. The organization is the parent of each of its supported organizations. Complete line 3 below.			
C		The organization is the parent of each of its supported organizations. Complete line 3 perow. The organization supported a governmental entity. Describe in Part VI how you supported a governmental entity (see ins	tatia	اء	
2		ties Test. Answer lines 2a and 2b below.	truction	Yes	No
a		ubstantially all of the organization's activities during the tax year directly further the exempt purposes of		163	140
u		ipported organization(s) to which the organization was responsive? If "Yes," then in Part VI identify			
		supported organization(s) to which the organization was responsive: If Yes, then if Yes, then the organization was responsive. If Yes, then if Yes,			
		he organization was responsive to those supported organizations, and how the organization determined	2a		
h		nese activities constituted substantially all of its activities. The activities described on line 2a, above, constitute activities that, but for the organization's involvement,	<u> za</u>		
b		· · · · · · · · · · · · · · · · · · ·			
		r more of the organization's supported organization(s) would have been engaged in? If "Yes," explain in			
		If the reasons for the organization's position that its supported organization(s) would have engaged in	2b		
3		activities but for the organization's involvement. t of Supported Organizations. Answer lines 3a and 3b below.	ZU		
		e organization have the power to regularly appoint or elect a majority of the officers, directors, or			
а		es of each of the supported organizations? If "Yes" or "No" provide details in Part VI.	3a		
	แนงเป	oo or odon or the supported organizations: If Yes or INO provide details in Fait VI.	Ja	!	

of its supported organizations? If "Yes." describe in Part VI the role played by the organization in this regard. 232025 12-09-22 Schedule A (Form 990) 2022

b Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each

3b

Pa	Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations				
1	Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970 (explain in Part VI). See instructions.				
	All other Type III non-functionally integrated supporting organizations mu	st complete s	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):				
а	Average monthly value of securities	1a			
b	Average monthly cash balances	1b			
С	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-function	ally integrate	d Type III supporting orga	nization (see	
	instructions).			·	

Schedule A (Form 990) 2022

Schedule A (Form 990) 2022

e Excess from 2022

232028 12-09-22 Schedule A (Form 990) 2022

Schedule A

Identification of Excess Contributions Included on Part II, Line 5

2022

** Do Not File **

*** Not Open to Public Inspection ***

Contributor's Name	Total Contributions	Excess Contributions
SCHOOLS FIRST CREDIT UNION	270,275.	62,394.
CENTER FOR DISEASE CONTROL	1,213,024.	1,005,143.
Total Excess Contributions to Schedule A, Part II, Line 5		1,067,537.

Schedule B

(Form 990)

Department of the Treasury Internal Revenue Service

Schedule of Contributors

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

SPINA BIFIDA ASSOCIATION OF AMERICA

OMB No. 1545-0047

2022

Name of the organization

Employer identification number

58-1342181

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

answer "No" on Part IV, line 2, of its Form 990; or check the box on line H of its Form 990-EZ or on its Form 990-PF, Part I, line 2, to certify

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

that it doesn't meet the filing requirements of Schedule B (Form 990).

Schedule B (Form 990) (2022)

Schedule B (Form 990) (2022)

Name of organization Employer identification number

SPINA BIFIDA ASSOCIATION OF AMERICA

58-1342181

Part I	Contributors (see instructions). Use duplicate copies of Part I if additional	space is needed.	
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
1		\$50,000.	Person X Payroll
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
2		\$138,116.	Person X Payroll
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		\$	Person Payroll Oncash Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		\$	Person Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		\$	Person Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		\$	Person Payroll Noncash (Complete Part II for noncash contributions.)

Name of organization Employer identification number

SPINA BIFIDA ASSOCIATION OF AMERICA

58-1342181

Part II	Noncash Property (see instructions). Use duplicate copies of Part II if additional space is needed.				
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received		
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received		
		\$			
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received		
		\$			
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received		
		\$			
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received		
		\$			
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received		
		 \$			

Name of organization **Employer identification number** SPINA BIFIDA ASSOCIATION OF AMERICA 58-1342181 Part III Exclusively religious, charitable, etc., contributions to organizations described in section 501(c)(7), (8), or (10) that total more than \$1,000 for the year from any one contributor. Complete columns (a) through (e) and the following line entry. For organizations completing Part III, enter the total of exclusively religious, charitable, etc., contributions of \$1,000 or less for the year. (Enter this info. once.) Use duplicate copies of Part III if additional space is needed. (a) No. from (b) Purpose of gift (c) Use of gift (d) Description of how gift is held Part I (e) Transfer of gift Transferee's name, address, and ZIP + 4 Relationship of transferor to transferee (a) No. from (b) Purpose of gift (c) Use of gift (d) Description of how gift is held Part I (e) Transfer of gift Transferee's name, address, and ZIP + 4 Relationship of transferor to transferee (a) No. from (b) Purpose of gift (c) Use of gift (d) Description of how gift is held Part I (e) Transfer of gift Transferee's name, address, and ZIP + 4 Relationship of transferor to transferee (a) No. from (b) Purpose of gift (c) Use of gift (d) Description of how gift is held Part I (e) Transfer of gift Transferee's name, address, and ZIP + 4 Relationship of transferor to transferee

SCHEDULE C (Form 990)

Political Campaign and Lobbying Activities

For Organizations Exempt From Income Tax Under section 501(c) and section 527

Complete if the organization is described below. Attach to Form 990 or Form 990-EZ.

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

OMB No. 1545-0047

2022

Open to Public Inspection

Department of the Treasury Internal Revenue Service

If the organization answered "Yes," on Form 990, Part IV, line 3, or Form 990-EZ, Part V, line 46 (Political Campaign Activities), then

- Section 501(c)(3) organizations: Complete Parts I-A and B. Do not complete Part I-C.
- Section 501(c) (other than section 501(c)(3)) organizations: Complete Parts I-A and C below. Do not complete Part I-B.
- Section 527 organizations: Complete Part I-A only.

If the organization answered "Yes," on Form 990, Part IV, line 4, or Form 990-EZ, Part VI, line 47 (Lobbying Activities), then

- Section 501(c)(3) organizations that have filed Form 5768 (election under section 501(h)): Complete Part II-A. Do not complete Part II-B.
- Section 501(c)(3) organizations that have NOT filed Form 5768 (election under section 501(h)): Complete Part II-B. Do not complete Part II-A.

If the organization answered "Yes," on Form 990, Part IV, line 5 (Proxy Tax) (See separate instructions) or Form 990-EZ, Part V, line 35c (Proxy Tax) (See separate instructions), then

Section 501(c)(4), (5), or (6) organizations: Complete Part III.

• Section 501(c)(4), (5), or (6) organizations: Complete Part III.						
	Employer identification number					
SPINA BIFIDA ASSOCIATION OF AMERICA	58-1342181					
Part I-A Complete if the organization is exempt under section 501(c) or is a section 52	7 organization.					
 1 Provide a description of the organization's direct and indirect political campaign activities in Part IV. 2 Political campaign activity expenditures 3 Volunteer hours for political campaign activities 						
Part I-B Complete if the organization is exempt under section 501(c)(3).						
1 Enter the amount of any excise tax incurred by the organization under section 4955	\$					
2 Enter the amount of any excise tax incurred by organization managers under section 4955						
3 If the organization incurred a section 4955 tax, did it file Form 4720 for this year?	Yes No					
4a Was a correction made?						
b If "Yes," describe in Part IV.						
Part I-C Complete if the organization is exempt under section 501(c), except section 5	01(c)(3).					
1 Enter the amount directly expended by the filing organization for section 527 exempt function activities	\$					
2 Enter the amount of the filing organization's funds contributed to other organizations for section 527						
exempt function activities	\$					
3 Total exempt function expenditures. Add lines 1 and 2. Enter here and on Form 1120-POL,						
line 17b						
4 Did the filing organization file Form 1120-POL for this year?						
5 Enter the names, addresses and employer identification number (EIN) of all section 527 political organizations to	which the filing organization					
made payments. For each organization listed, enter the amount paid from the filing organization's funds. Also ent	•					
contributions received that were promptly and directly delivered to a separate political organization, such as a separate political organization, such as a separate political organization.	parate segregated fund or a					
political action committee (PAC). If additional space is needed, provide information in Part IV.						
(a) Name (b) Address (c) EIN (d) Amount paid fi	1 ' '					
filing organization funds. If none, ente						
Turids. Il riorio, citto	delivered to a separate					
	political organization.					
	If none, enter -0					
	1					

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

Schedule C (Form 990) 2022

LHA

232041 11-08-22

	Schedule C (Form 990) 2022 SPINA BIFIDA ASSOCIATION OF AMERICA 58-1342181 Page 2							
Pa	Part II-A Complete if the organization is exempt under section 501(c)(3) and filed Form 5768 (election under							
	section 501(h)).							
Α	Check if the filing organization belongs to an affiliated group (and list in Part IV each affiliated group member's name, address, EIN,							
	expenses, and share of excess lobbying expenditures).							
В	Check if the filing organization checked box A and "limited control" provisions apply.							
			oying Expenditures eans amounts paid or incurred.)	(a) Filing organization's totals	(b) Affiliate total			
1	a Total lol	bbying expenditures to influence publ	lic opinion (grassroots lobbying)	30,659.				
	b Total lol	bbying expenditures to influence a lec	gislative body (direct lobbying)	45,329.				
	c Total lol	bbying expenditures (add lines 1a and	d 1b)	75,988.				
				2,229,826.				
	e Total ex	empt purpose expenditures (add lines		2,305,814.				
	f Lobbyin	ng nontaxable amount. Enter the amou	unt from the following table in both columns.	265,291.				
	If the am	nount on line 1e, column (a) or (b) is:	The lobbying nontaxable amount is:					
	Not ove	r \$500,000	20% of the amount on line 1e.					
	Over \$5	00,000 but not over \$1,000,000	\$100,000 plus 15% of the excess over \$500,000.					
	Over \$1	,000,000 but not over \$1,500,000	\$175,000 plus 10% of the excess over \$1,000,000.					
	Over \$1	,500,000 but not over \$17,000,000	\$225,000 plus 5% of the excess over \$1,500,000.					
	Over \$1	7,000,000	\$1,000,000.					
	- 0	ata na atawahla anaa int (antai OFO), af	See 46	66,323.				
	•	ots nontaxable amount (enter 25% of	,	00,323.				
		t line 1g from line 1a. If zero or less, e		0.				
			nter -0-	U • 1				
			r line 1h or line 1i, did the organization file Form 4720	Г	¬,,	—ъ .		
	reportin	-		L	Yes	No		
			4-Year Averaging Period Under Section 501(h)	. £ 41. a £1 a a l	la			
	(Some organizations that made a section 501(h) election do not have to complete all of the five columns below.							

See the separate instructions for lines 2a through 2f.)

Lobbying Expenditures During 4-Year Averaging Period						
Calendar year (or fiscal year beginning in)	(a) 2019	(b) 2020	(c) 2021	(d) 2022	(e) Total	
2a Lobbying nontaxable amount	261,515.	252,712.	251,651.	265,291.	1,031,169.	
b Lobbying ceiling amount (150% of line 2a, column(e))					1,546,754.	
c Total lobbying expenditures	206,315.	141,188.	159,288.	75,988.	582,779.	
d Grassroots nontaxable amount	65,379.	63,178.	62,913.	66,323.	257,793.	
e Grassroots ceiling amount (150% of line 2d, column (e))					386,690.	
f Grassroots lobbying expenditures	6,000.	6,000.	5,775.	30,659.	48,434.	

Schedule C (Form 990) 2022

Schedule C (Form 990) 2022 SPINA BIFIDA ASSOCIATION OF AMERICA 58-13421 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)).

	or each "Yes" response on lines 1a through 1i below, provide in Part IV a detailed description			(b)	
f the lobbying activity.			No	Amo	ount
1 [During the year, did the filing organization attempt to influence foreign, national, state, or				
le	local legislation, including any attempt to influence public opinion on a legislative matter				
c	or referendum, through the use of:				
a ∖	Volunteers?				
	Paid staff or management (include compensation in expenses reported on lines 1c through 1i)?				
c N	Media advertisements?				
	Mailings to members, legislators, or the public?				
	Publications, or published or broadcast statements?				
f (Grants to other organizations for lobbying purposes?				
_	Direct contact with legislators, their staffs, government officials, or a legislative body?				
h F	Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means?				
	Other activities?				
	Total. Add lines 1c through 1i				
	Did the activities in line 1 cause the organization to be not described in section 501(c)(3)?				
	If "Yes," enter the amount of any tax incurred under section 4912			<u> </u>	
	If "Yes," enter the amount of any tax incurred by organization managers under section 4912				
	If the filing organization incurred a section 4912 tax, did it file Form 4720 for this year?		05.00	tion	
	III-A Complete if the organization is exempt under section 501(c)(4), section 501(c)(6).	11 30 1 (6)(3)	, or se	Stion	
art					
art	00.(0)(0).			Yes	N
	Were substantially all (90% or more) dues received nondeductible by members?		1	Yes	N
1 V				Yes	N
1 V 2 [Were substantially all (90% or more) dues received nondeductible by members? Did the organization make only in-house lobbying expenditures of \$2,000 or less? Did the organization agree to carry over lobbying and political campaign activity expenditures from the 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	e prior year? n 501(c)(5)	2 3), or se	ction	
1 V 2 [3 [Part	Were substantially all (90% or more) dues received nondeductible by members? Did the organization make only in-house lobbying expenditures of \$2,000 or less? Did the organization agree to carry over lobbying and political campaign activity expenditures from the 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." Dues, assessments and similar amounts from members	e prior year? n 501(c)(5) 'No" OR (l), or see b) Part	ction	
1 V 2 [3 [Part	Were substantially all (90% or more) dues received nondeductible by members? Did the organization make only in-house lobbying expenditures of \$2,000 or less? Did the organization agree to carry over lobbying and political campaign activity expenditures from the 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." Dues, assessments and similar amounts from members Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenditures)	e prior year? n 501(c)(5) 'No" OR (l), or see b) Part	ction	
1 V 2 [3 [2 art	Were substantially all (90% or more) dues received nondeductible by members? Did the organization make only in-house lobbying expenditures of \$2,000 or less? Did the organization agree to carry over lobbying and political campaign activity expenditures from the lill-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." Dues, assessments and similar amounts from members Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of politic expenses for which the section 527(f) tax was paid).	e prior year? n 501(c)(5) 'No" OR (l	2 3), or se b) Part	ction	
1 V 2 [3 [2 art	Were substantially all (90% or more) dues received nondeductible by members? Did the organization make only in-house lobbying expenditures of \$2,000 or less? Did the organization agree to carry over lobbying and political campaign activity expenditures from the 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." Dues, assessments and similar amounts from members Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid). Current year	e prior year? n 501(c)(5) 'No" OR (l	2 3), or se b) Part	ction	
1 V 2 [3 [2 art	Were substantially all (90% or more) dues received nondeductible by members? Did the organization make only in-house lobbying expenditures of \$2,000 or less? Did the organization agree to carry over lobbying and political campaign activity expenditures from the lill-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." Dues, assessments and similar amounts from members Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of politic expenses for which the section 527(f) tax was paid).	e prior year? n 501(c)(5) 'No" OR (l	2 3), or see b) Part	ction	
11 V 22 [233 [2art] 11 [22	Were substantially all (90% or more) dues received nondeductible by members? Did the organization make only in-house lobbying expenditures of \$2,000 or less? Did the organization agree to carry over lobbying and political campaign activity expenditures from the 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." Dues, assessments and similar amounts from members Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of politic expenses for which the section 527(f) tax was paid). Current year Carryover from last year	e prior year? n 501(c)(5) 'No" OR (l	2 3), or sec b) Part	ction	
1 V 2 [3 [2 c 4 c l 3 /	Were substantially all (90% or more) dues received nondeductible by members? Did the organization make only in-house lobbying expenditures of \$2,000 or less? Did the organization agree to carry over lobbying and political campaign activity expenditures from the 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." Dues, assessments and similar amounts from members Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of politic expenses for which the section 527(f) tax was paid). Current year Carryover from last year Total Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues	e prior year? n 501(c)(5 'No" OR (l	2 3), or sec b) Part	ction	3, is
1 V 22 [33 [22 st 4 1 1 1 1 1 1 1 1 1	Were substantially all (90% or more) dues received nondeductible by members? Did the organization make only in-house lobbying expenditures of \$2,000 or less? Did the organization agree to carry over lobbying and political campaign activity expenditures from the solid the organization agree to carry over lobbying and political campaign activity expenditures from the solid 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." Dues, assessments and similar amounts from members Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of politic expenses for which the section 527(f) tax was paid). Current year Carryover from last year Total Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the exceeds	e prior year? n 501(c)(5) 'No" OR (l	2 3), or sec b) Part	ction	
1 V 2 [3] 3 2 3 4 1 3 4 1 3 4 1 3 4 1 3 4 1 3 4 1 3 4 4 1 3 4 4 1 4 4 4 4 4 4 4	Were substantially all (90% or more) dues received nondeductible by members? Did the organization make only in-house lobbying expenditures of \$2,000 or less? Did the organization agree to carry over lobbying and political campaign activity expenditures from the source of \$2,000 or less? Did the organization agree to carry over lobbying and political campaign activity expenditures from the source of \$2,000 or less? Did the organization agree to carry over lobbying and political campaign activity expenditures from the source of \$2,000 or less? Did the organization agree to carry over lobbying and political campaign activity expenditures from the section \$01(c)(4), section 501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered answered "Yes." Dues, assessments and similar amounts from members Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid). Current year Carryover from last year Total Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the exceeds the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expension agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditures (do not include amounts of political expenditures).	e prior year? n 501(c)(5) 'No" OR (l	2 3), or sec b) Part	ction	
11 V 2 [33 [33 [34] 4]	Were substantially all (90% or more) dues received nondeductible by members? Did the organization make only in-house lobbying expenditures of \$2,000 or less? Did the organization agree to carry over lobbying and political campaign activity expenditures from the solid the organization agree to carry over lobbying and political campaign activity expenditures from the solid 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." Dues, assessments and similar amounts from members Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of politic expenses for which the section 527(f) tax was paid). Current year Carryover from last year Total Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the exceeds	e prior year? n 501(c)(5) 'No" OR (l	2 3), or sec b) Part	ction	

SCHEDULE D (Form 990)

Department of the Treasury Internal Revenue Service

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

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

OMB No. 1545-0047 Inspection

Name of the organization

SPINA BIFIDA ASSOCIATION OF AMERICA

Employer identification number 58-1342181

Par	t I Organizations Maintaining Donor Advised Funds or	r Other Similar Funds	s or Accounts. Complete if the			
	organization answered "Yes" on Form 990, Part IV, line 6.					
	(a) Do	onor 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	e assets held in donor advi	sed funds			
	are the organization's property, subject to the organization's exclusive legal	al control?	Yes No			
6	Did the organization inform all grantees, donors, and donor advisors in writ	ting that grant funds can be	e used only			
	for charitable purposes and not for the benefit of the donor or donor advisor	or, or for any other purpose	e conferring			
	impermissible private benefit?					
Par	t II Conservation Easements. Complete if the organization ans	swered "Yes" on Form 990,	, Part IV, line 7.			
1	Purpose(s) of conservation easements held by the organization (check all t					
	Preservation of land for public use (for example, recreation or educated)	tion) Preservation of	of a historically important land area			
	Protection of natural habitat	Preservation o	of a certified historic structure			
	Preservation of open space					
2	Complete lines 2a through 2d if the organization held a qualified conservat	tion contribution in the form				
	day of the tax year.		Held at the End of the Tax Year			
_	Total number of conservation easements					
b						
C	Number of conservation easements on a certified historic structure include	()	2c			
d	Number of conservation easements included in (c) acquired after July 25,2					
•						
3	Number of conservation easements modified, transferred, released, extingu	uished, or terminated by th	e organization during the tax			
	year	.11				
4	Number of states where property subject to conservation easement is local		-			
5	Does the organization have a written policy regarding the periodic monitori					
6	violations, and enforcement of the conservation easements it holds? Staff and volunteer hours devoted to monitoring, inspecting, handling of vi	iolations, and enforcing con				
U	Stan and volunteer nours devoted to monitoring, inspecting, nanding or vi	iolations, and emoroling con	iservation easements during the year			
7	Amount of expenses incurred in monitoring, inspecting, handling of violatic	ons, and enforcing conserva	ation easements during the year			
•	, amount of expenses mounted in monitoring, inspecting, manaling of violatic	one, and emorally conserve	ation describing dailing the year			
8	Does each conservation easement reported on line 2(d) above satisfy the re	requirements of section 170	O(h)(4)(B)(i)			
_	and section 170(h)(4)(B)(ii)?					
9	In Part XIII, describe how the organization reports conservation easements					
	balance sheet, and include, if applicable, the text of the footnote to the org	•				
	organization's accounting for conservation easements.					
Par	t III Organizations Maintaining Collections of Art, Histo	rical Treasures, or O	ther Similar Assets.			
	Complete if the organization answered "Yes" on Form 990, Part IV,	line 8.				
1a	If the organization elected, as permitted under FASB ASC 958, not to repo	ort in its revenue statement	and balance sheet works			
	of art, historical treasures, or other similar assets held for public exhibition,	, education, or research in f	furtherance of public			
	service, provide in Part XIII the text of the footnote to its financial statements that describes these items.					
b	If the organization elected, as permitted under FASB ASC 958, to report in	its revenue statement and	balance sheet works of			
	art, historical treasures, or other similar assets held for public exhibition, ed	ducation, or research in furt	therance of public service,			
	provide the following amounts relating to these items:					
	(i) Revenue included on Form 990, Part VIII, line 1		\$			
	(ii) Assets included in Form 990, Part X		\$			
2	If the organization received or held works of art, historical treasures, or oth					
	the following amounts required to be reported under FASB ASC 958 relating	ng to these items:				
а	Revenue included on Form 990, Part VIII, line 1		\$			
b	Assets included in Form 990, Part X		\$			
LHA	For Paperwork Reduction Act Notice, see the Instructions for Form 99	0.	Schedule D (Form 990) 2022			

193407_1

	t III Organizations Maintaining C	ollections of Art	t, Historical Tre	asures, or Othe	er Similai	r Assets	(continu	ıed)
3	Using the organization's acquisition, accession						(**************************************	
	collection items (check all that apply):	·	•	· ·	Ū			
а	Public exhibition	d	Loan or exc	nange program				
b	Scholarly research	е						
С	Preservation for future generations							
4	Provide a description of the organization's co	ollections and explain	how they further th	e organization's exe	empt purpo	se in Part	XIII.	
5	During the year, did the organization solicit o	r receive donations o	of art, historical treas	ures, or other simila	ar assets			
	to be sold to raise funds rather than to be ma	aintained as part of th	ne organization's col	lection?			Yes	☐ No
Pai	t IV Escrow and Custodial Arran	gements. Comple	ete if the organizatio	n answered "Yes" o	n Form 990), Part IV, I	ine 9, or	
	reported an amount on Form 990, Par							
1a	Is the organization an agent, trustee, custodia	an or other intermedi	ary for contributions	or other assets no	t included			
	on Form 990, Part X?						Yes	☐ No
b	If "Yes," explain the arrangement in Part XIII	and complete the fol	lowing table:					
							Amount	
С	Beginning balance				1c			
	Additions during the year							
	Distributions during the year							
f	Ending balance				1f			
2a	Did the organization include an amount on Fo						Yes	☐ No
b	If "Yes," explain the arrangement in Part XIII.							
Pai	t V Endowment Funds. Complete i		swered "Yes" on Fo	rm 990, Part IV, line	10.			
		(a) Current year	(b) Prior year	(c) Two years back	(d) Three y	ears back/	(e) Four	years back
1a	Beginning of year balance	71,135.	67,903.	64,564.		62,552.		62,563.
b	Contributions							
С	Net investment earnings, gains, and losses	-4,119.	3,232.	3,339.		2,012.		-11.
d	Grants or scholarships							
е	Other expenditures for facilities							
	and programs							
f	Administrative expenses							
g	End of year balance	67,016.	71,135.	67,903.		64,564.		62,552.
2	Provide the estimated percentage of the curr	ent year end balance	e (line 1g, column (a)) held as:				
а	Board designated or quasi-endowment	89.5300	_%					
b	Permanent endowment0000	%						
С	Term endowment10.4690	%						
	The percentages on lines 2a, 2b, and 2c show	uld equal 100%.						
За	Are there endowment funds not in the posses	ssion of the organiza	tion that are held ar	d administered for t	the		_	
	organization 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 Schedule R?				3b	
4	Describe in Part XIII the intended uses of the		wment funds.					
Pai	t VI Land, Buildings, and Equipm							
	Complete if the organization answered	d "Yes" on Form 990	, Part IV, line 11a. S	ee Form 990, Part X	(, line 10.			
	Description of property	(a) Cost or of basis (investment)	` '		Accumulate epreciation	II	(d) Book	value
1a	Land							
b	Buildings							
С	Leasehold improvements			2,484.	134,19			,715.
	Equipment			6,312.	33,2			,079.
	Other		9	1,045.	83,2	90.		,755.
Tota	l. Add lines 1a through 1e. (Column (d) must e	qual Form 990, Part	X. column (B), line 10	Oc.)			9	,119.

Schedule D (Form 990) 2022

Schedule D (Form 990) 2022 SP:	INA BIFIDA	ASSOCIATION	OF	AMERICA	58-1342181 Pa	ge
Part VII Investments - Other S	Securities.					
Complete if the organization	answered "Yes" o	on Form 990, Part IV, line	I1b. S	see Form 990, Part X,	, line 12.	
(a) Description of security or category (include	ding name of security)	(b) Book value	(4	c) Method of valuatio	on: Cost or end-of-year market value	
(1) Financial derivatives						
(2) Closely held equity interests						
(3) Other						
(A)						
(B)						
(C)						
(D)						
(E)						
(F)						
(G)						
(H)						
Total. (Col. (b) must equal Form 990, Part X, o						
Part VIII Investments - Progra	m Related.					

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

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

Total. (Col. (b) must equal Form 990, Part X, col. (B) line 13.) Part IX Other Assets.

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

(a) Description	(b) Book value
(1)	
(2)	
(3)	
(4)	
(5)	
(6)	
(8)	
(9)	

Total. (Column (b) must equal Form 990, Part X, col. (B) line 15.) Other Liabilities.

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

1. (a) Description of liability	(b) Book value
(1) Federal income taxes	
(2) DEFERRED RENT AND LEASEHOLD	
(3) INCENTIVES	177,914.
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (Column (b) must equal Form 990, Part X, col. (B) line 25.)	177,914.

Liability for uncertain tax positions. In Part XIII, provide the text of the footnote to the organization's financial statements that reports the X 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) 2022

Pai	rt XI Reconciliation of Revenue per Audited Financial Statem	nents With F	Revenue per Re	turn.	
	Complete if the organization answered "Yes" on Form 990, Part IV, line 12	2a.			
1	Total revenue, gains, and other support per audited financial statements			1	2,110,333.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:				
а	Net unrealized gains (losses) on investments	2a	-69,394.		
b	Donated services and use of facilities	2b			
С	Recoveries of prior year grants	2c			
d	Other (Describe in Part XIII.)	2d			
е	Add lines 2a through 2d			2e	-69,394.
3	Subtract line 2e from line 1			3	2,179,727.
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	3,704.		
b	Other (Describe in Part XIII.)	4b			
С	Add lines 4a and 4b			4c	3,704. 2,183,431.
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.) rt XII Reconciliation of Expenses per Audited Financial States			5	2,183,431.
Pa	rt XII Reconciliation of Expenses per Audited Financial State	ments With	Expenses per F	Returr	۱.
	Complete if the organization answered "Yes" on Form 990, Part IV, line 12	2a.			
1	Total expenses and losses per audited financial statements			1	2,302,110.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:				
а	Donated services and use of facilities	2a			
b					
С		1 1			
d					
е	Add lines 2a through 2d	•		2e	0.
3	Subtract line 2e from line 1			3	2,302,110.
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:				
а		4a	3,704.		
b			•		
С	Add lines 4a and 4b			4c	3,704.
5	Total expenses. Add lines 3 and 4c. (This must equal Form 990. Part I. line 18.)			5	3,704.
Pa	rt XIII Supplemental Information.				
Provi	ride the descriptions required for Part II, lines 3, 5, and 9; Part III, lines 1a and 4; Pa	art IV. lines 1b a	and 2b: Part V. line 4	: Part X	line 2: Part XI.
	2d and 4b; and Part XII, lines 2d and 4b. Also complete this part to provide any ac			,	,
PAF	RT V, LINE 4:				
THE	E ENDOWMENT FUNDS ARE USED TO FUND SCHOLAR	RSHIPS F	OR PEOPLE	WITE	H SPINA
			-		
BIE	FIDA, FUND GRANTS TO PROMOTE THE PREVENTION	ON AND C	URE OF SPI	NA E	BIFIDA,
	,			-	,
ANI	D TO IMPROVE THE LIVES OF THOSE LIVING WIT	TH SPINA	BIFIDA.		
DΔI	RT X T.TNE 2.				
L 231	RT X, LINE 2:				
тиг	E ASSOCIATION EVALUATED ITS UNCERTAINTY I	N TNCOME	י ייזעדכ דרס	тит	T VEAD
T 111	T ADDOCTATION EVADORIED ITS ONCENTAINIT II	A TIACOME	I TAMES FOR	T 111	TEVI
דואים	DED DECEMBER 31, 2022, AND DETERMINED THAT	י קמשעה יי	MEDE NO MA	ጥጥሮ፤	ос тилт
٢١٢٢	DED DECEMBER SI, 2022, AND DETERMINED INA.	TITERE	MTW ON THE	1 1 L) F	O IIIVI
ผ≀∩т	ULD REQUIRE RECOGNITION IN THE FINANCIAL S	статемем	ושכ אה שהצש	Mas	TAME ANV
VVOC	OND VECORITION IN THE LIMMICIAN !	OIVIENEN	TAUL AO GIL	MW.	TIVA E WINT

Schedule D (Form 990) 2022

EFFECT ON ITS TAX-EXEMPT STATUS.

Schedule D (Form 990) 2022 Part XIII Supplemental Inform	SPINA BIFIDA	ASSOCIATION OF	AMERICA	58-1342181 Page 5
Part XIII Supplemental Inform	mation (continued)			
• • • • • • • • • • • • • • • • • • • •	(continued)			

SCHEDULE I (Form 990)

Department of the Treasury Internal Revenue Service

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

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

Attach to Form 990.

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

2022
Open to Public

Inspection

Schedule I (Form 990) 2022

Name of the organization SPINA BIF	IDA ASSOC	IATION OF A	MERICA				Employer identification number 58-1342181
Part I General Information on Grants a							30 1011101
 Does the organization maintain records to criteria used to award the grants or assist Describe in Part IV the organization's process. 	stance? ocedures for monit	oring the use of grant	funds in the United	l States.	-		X Yes No
Part II Grants and Other Assistance to I recipient that received more than \$\frac{1}{2}\$					anization answered "\	es" on Form 990, Part	t IV, line 21, for any
1 (a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of noncash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
2 Enter total number of section 501(c)(3) a	 nd government ord	 ganizations listed in th	e line 1 table				
3 Enter total number of other organizations	-						

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

3	1,425.	0.		
	·	0.		
3	142			
3	142			
	112.	0.		
1				
1	95.	0.		
1	250.	0.		
required in Part I, line	e 2; Part III, column	(b); and any other ac	dditional information.	
ידאו אאר ספ	OCDAM DEVI	FEW FOR FAC	н срамт	
		FROFER FOR	FOSES AND	
IIE INTENDE	D ODE.			
	IAL AND PR	IAL AND PROGRAM REVI	IAL AND PROGRAM REVIEW FOR EAC	required in Part I, line 2; Part III, column (b); and any other additional information. IAL AND PROGRAM REVIEW FOR EACH GRANT GRANTS ARE USED FOR PROPER PURPOSES AND HE INTENDED USE.

Schedule I	(Form 990)	SPINA	BIFIDA	ASSOCIATION	OF	AMERICA	58-1342181	Page 2
Part IV	Suppler	SPINA mental Information						<u> </u>
-								
-								
-								
-								
-								

SCHEDULE J (Form 990)

Compensation Information

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

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

Attach to Form 990.

ZUZZ

OMB No. 1545-0047

Open to Public Inspection

Department of the Treasury
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 ASSOCIATION OF AMERICA | Questions Regarding Compensation

Yes No 1a Check the appropriate box(es) if the organization provided any of the following to or for a person listed on Form 990, Part VII, Section A, line 1a. Complete Part III to provide any relevant information regarding these items. First-class or charter travel Housing allowance or residence for personal use Travel for companions Payments for business use of personal residence Tax indemnification and gross-up payments Health or social club dues or initiation fees Discretionary spending account Personal services (such as maid, chauffeur, chef) b If any of the boxes on line 1a are checked, did the organization follow a written policy regarding payment or reimbursement or provision of all of the expenses described above? If "No," complete Part III to explain 1b Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all directors, trustees, and officers, including the CEO/Executive Director, regarding the items checked on line 1a? 2 Indicate which, if any, of the following the organization used to establish the compensation of the organization's CEO/Executive Director. Check all that apply. Do not check any boxes for methods used by a related organization to establish compensation of the CEO/Executive Director, but explain in Part III. Written employment contract Compensation committee X Compensation survey or study Independent compensation consultant Form 990 of other organizations X Approval by the board or compensation committee During the year, did any person listed on Form 990, Part VII, Section A, line 1a, with respect to the filing organization or a related organization: X a Receive a severance payment or change-of-control payment? 4a X 4b **b** Participate in or receive payment from a supplemental nonqualified retirement plan? X **c** Participate in or receive payment from an equity-based compensation arrangement? 4c If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III. Only section 501(c)(3), 501(c)(4), and 501(c)(29) organizations must complete lines 5-9. For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation 5 contingent on the revenues of: Х a The organization? 5a X **b** Any related organization? If "Yes" on line 5a or 5b, describe in Part III. For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation 6 contingent on the net earnings of: X a The organization? 6a X **b** Any related organization? 6b If "Yes" on line 6a or 6b, describe in Part III. For persons listed on Form 990, Part VII, Section A, line 1a, did the organization provide any nonfixed payments not described on lines 5 and 6? If "Yes," describe in Part III X 7 Were any amounts reported on Form 990, Part VII, paid or accrued pursuant to a contract that was subject to the Х initial contract exception described in Regulations section 53.4958-4(a)(3)? If "Yes," describe in Part III 8 If "Yes" on line 8, did the organization also follow the rebuttable presumption procedure described in

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

Schedule J (Form 990) 2022

Regulations section 53.4958-6(c)?

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

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

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

(A) Name and Title		(B) Breakdown of W	V-2 and/or 1099-MISO compensation	C and/or 1099-NEC	(C) Retirement and other deferred	(D) Nontaxable benefits			
		(i) Base compensation	(ii) Bonus & incentive compensation	(iii) Other reportable compensation	compensation			reported as deferred on prior Form 990	
(1) SARA STRUWE	(i)	144,612.	0.	0.	0.	30,681.	175,293.	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)							1 1/5 000) 0000	

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 O (Form 990)

Department of the Treasury Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

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

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

OMB No. 1545-0047 Inspection

Name of the organization

SPINA BIFIDA ASSOCIATION OF AMERICA

Employer identification number 58-1342181

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 \$ 175,289. INCLUDING GRANTS OF \$ 142. REVENUE \$ 0.
EXPENSES \$ 48,347. 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
MEMBERS OF THE BOARD OF DIRECTORS AND THE SLATE OF OFFICERS OF THE BOARD. LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ. Schedule O (Form 990) 2022

Schedule O (Form 990) 2022 Page **2**

Name of the organization SPINA BIFIDA ASSOCIATION OF AMERICA

Employer identification number 58-1342181

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

FOR ALL OTHER EMPLOYEES. THE BOARD OF DIRECTORS EMPLOYS A COMBINATION OF

Schedule O (Form 990) 2022 Page **2**

Employer identification number Name of the organization SPINA BIFIDA ASSOCIATION OF AMERICA 58-1342181 PERFORMANCE EVALUATION AND REVIEW OF BOTH LOCAL AND NATIONAL COMPENSATION SURVEYS TO ESTABLISH THE COMPENSATION OF THE CEO. SIMILARLY, 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 LAST TOOK PLACE DURING DECEMBER 2021. 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 OF 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 371,634. MANAGEMENT AND GENERAL EXPENSES 10,821. FUNDRAISING EXPENSES 12,088. TOTAL EXPENSES 394,543. TOTAL OTHER FEES ON FORM 990, PART IX, LINE 11G, COL A 394,543. FORM 990, PART I, LINE 5 & PART V, LINE 2A THE ASSOCIATION HAS CONTRACTED WITH A PROFESSIONAL EMPLOYER ORGANIZATION, COADVANTAGE, TO SERVE AS THE EMPLOYER OF RECORD FOR THE ASSOCIATION'S EMPLOYEES. AS SUCH COADVANTAGE IS RESPONSIBLE FOR TAX Schedule O (Form 990) 2022

Scriedule O (F	omi 990) 2022															age ∠
Name of the or	of the organization SPINA BIFIDA ASSOCIATION OF AMERICA									Employer identification number 58-1342181						
FILINGS	RELATED	то і	EMPLOYE	ES.	COAD	VANTA	GE	ISSUED	16	W-2	FO	RMS	IN	2022		
FOR THE	ASSOCIA	TION	EMPLOY	EES	•											