Form **990**

Department of the Treasury
Internal Revenue Service

Return of Organization Exempt From Income Tax

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

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

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

OMB No. 1545-0047

2020

Open to Public Inspection

A For the 2020 calendar year, or tax year beginning 10-01-2020 , and ending 09-30-2021

B Check if applicable:
- ☐ Address change
- ☐ Name change
- ☐ Initial return
- ☐ Final return/terminated
- ☐ Amended return
- ☐ Application pending

C Name of organization
NEUROFIBROMATOSIS MIDWEST

Doing business as

Number and street (or P.O. box if mail is not delivered to street address) | Room/suite
473 DUNHAM ROAD SUITE 3

City or town, state or province, country, and ZIP or foreign postal code
ST CHARLES, IL 60174

D Employer identification number
22-2580173

E Telephone number
(630) 945-3562

G Gross receipts $ 217,392

F Name and address of principal officer:
DIANA HABERKAMP
274 SHAWNEE CIRCLE
BARTLETT,IL 60103

H(a) Is this a group return for subordinates? ☐ Yes ☑ No

H(b) Are all subordinates included? ☐ Yes ☐ No
If "No," attach a list. (see instructions)

H(c) Group exemption number ▶

I Tax-exempt status: ☑ 501(c)(3) ☐ 501(c) ( ) ◀ (insert no.) ☐ 4947(a)(1) or ☐ 527

J Website: ▶ WWW.NFMIDWEST.ORG

K Form of organization: ☑ Corporation ☐ Trust ☐ Association ☐ Other ▶

L Year of formation: 1981

M State of legal domicile: IL

Part I Summary

1 Briefly describe the organization's mission or most significant activities:
EDUCATION AND SUPPORT FOR THOSE WITH NEUROFIBROMATOSIS.

2 Check this box ▶ ☐ if the organization discontinued its operations or disposed of more than 25% of its net assets.

3	Number of voting members of the governing body (Part VI, line 1a)	**3**	6
4	Number of independent voting members of the governing body (Part VI, line 1b)	**4**	6
5	Total number of individuals employed in calendar year 2020 (Part V, line 2a)	**5**	5
6	Total number of volunteers (estimate if necessary)	**6**	50
7a	Total unrelated business revenue from Part VIII, column (C), line 12	**7a**	0
b	Net unrelated business taxable income from Form 990-T, line 39	**7b**	

		Prior Year	Current Year
8	Contributions and grants (Part VIII, line 1h)	140,948	145,261
9	Program service revenue (Part VIII, line 2g)		0
10	Investment income (Part VIII, column (A), lines 3, 4, and 7d)	4,700	2,121
11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	33,923	62,583
12	Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)	179,571	209,965
13	Grants and similar amounts paid (Part IX, column (A), lines 1–3)	43,329	33,500
14	Benefits paid to or for members (Part IX, column (A), line 4)		0
15	Salaries, other compensation, employee benefits (Part IX, column (A), lines 5–10)	92,408	91,576
16a	Professional fundraising fees (Part IX, column (A), line 11e)		0
b	Total fundraising expenses (Part IX, column (D), line 25) ▶20,884		
17	Other expenses (Part IX, column (A), lines 11a–11d, 11f–24e)	79,239	50,852
18	Total expenses. Add lines 13–17 (must equal Part IX, column (A), line 25)	214,976	175,928
19	Revenue less expenses. Subtract line 18 from line 12	-35,405	34,037

		Beginning of Current Year	End of Year
20	Total assets (Part X, line 16)	332,706	351,353
21	Total liabilities (Part X, line 26)	19,781	3,486
22	Net assets or fund balances. Subtract line 21 from line 20	312,925	347,867

Part II Signature Block

Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete. Declaration of preparer (other than officer) is based on all information of which preparer has any knowledge.

Sign Here

Signature of officer — Date: 2022-02-07

DIANA HABERKAMP EXECUTIVE DIRECTOR
Type or print name and title

Paid Preparer Use Only

Print/Type preparer's name	Preparer's signature	Date	Check ☐ if self-employed	PTIN
		2022-03-04		P00046293

Firm's name ▶ KOLNICKI PETERSON & WIRTH CPA'S — Firm's EIN ▶ 36-4119639

Firm's address ▶ 1400 OPUS PLACE SUITE 100
DOWNERS GROVE, IL 60515 — Phone no. (630) 390-1140

May the IRS discuss this return with the preparer shown above? (see instructions) ☑ Yes ☐ No

Part III Statement of Program Service Accomplishments

Check if Schedule O contains a response or note to any line in this Part III . . . . . ☑

1 Briefly describe the organization's mission:

TO IMPROVE THE LIVES OF CHILDREN, ADULTS, AND FAMILIES IMPACTED BY NEUROFIBROMATOSIS BY FOCUSING ON AND IMPROVING CLINICS, AWARENESS, RESEARCH, EDUCATION AND SUPPORT IN THE STATES OF ILLINOIS, INDIANA, IOWA, KENTUCKY, WISCONSIN, AND THE EASTERN HALF OF MISSOURI.

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ? . . . . . ☐ Yes ☑ No

If "Yes," describe these new services on Schedule O.

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services? . . . . . ☐ Yes ☑ No

If "Yes," describe these changes on Schedule O.

4 Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses. Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.

4a (Code:) (Expenses $ 119,279 including grants of $ 21,000) (Revenue $)

RESEARCH/CLINICS/IMPROVED CARE NEUROFIBROMATOSIS MIDWEST PROVIDES DIRECT GRANTS FOR RESEARCH AND RESEARCH SUPPORT. WE ALSO WORK WITH CLINICS IN OUR REGION TO IMPROVE CARE AND ACCESS TO CARE. ADDITIONALLY, WE WORK WITH THE NF COMMUNITY AND MANY OTHER RESOURCES ON ADDITIONAL PROGRAMS OR INITIATIVES TO IMPROVE THE QUALITY OF LIFE AND CARE FOR NF PATIENTS AND THEIR FAMILIES.

4b (Code:) (Expenses $ 12,500 including grants of $ 12,500) (Revenue $)

SUPPORT/EDUCATION/AWARENESS NEUROFIBROMATOSIS MIDWEST PROVIDES EDUCATION TO INDIVIDUALS AND FAMILIES WITH NEUROFIBROMATOSIS, TO THE MEDICAL COMMUNITY AND TO THE PUBLIC THROUGH AN ANNUAL SYMPOSIUM; SMALLER LOCAL MEETINGS; AND PRINTED AND ONLINE MATERIALS. WE PROVIDE FREE PACKETS OF INFORMATION TO NEWLY DIAGNOSED FAMILIES AND PHONE AND ONLINE SUPPORT. AN ANNUAL GRANT IS PROVIDED TO SEND CHILDREN WITH NF TO CAMP. WE ALSO PROVIDE MATERIALS AND OPPORTUNITIES TO RAISE AWARENESS.

4c (Code:) (Expenses $ including grants of $) (Revenue $)

4d Other program services (Describe in Schedule O.)
(Expenses $ including grants of $) (Revenue $)

4e **Total program service expenses** ▶ 131,779

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	Yes	
2	Is the organization required to complete *Schedule B, Schedule of Contributors* (see instructions)?	2	Yes	
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		No
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	Yes	
5	Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? *If "Yes," complete Schedule C, Part III*	5		No
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		No
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		No
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? *If "Yes," complete Schedule D,* Part III	8		No
9	Did the organization report an amount in Part X, line 21 for escrow or custodial account liability; serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? *If "Yes," complete Schedule D, Part IV*	9		No
10	Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi endowments? *If "Yes," complete Schedule D, Part V*	10		No
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.			
a	Did the organization report an amount for land, buildings, and equipment in Part X, line 10? *If "Yes," complete Schedule D,* Part VI.	11a		No
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		No
c	Did the organization report an amount for investments—program related in Part X, line 13 that is 5% or more of its total assets reported in Part X, line 16? *If "Yes," complete Schedule D, Part VIII*	11c		No
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		No
e	Did the organization report an amount for other liabilities in Part X, line 25? *If "Yes," complete Schedule D, Part X*	11e		No
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		No
12a	Did the organization obtain separate, independent audited financial statements for the tax year? *If "Yes," complete Schedule D, Parts XI and XII*	12a		No
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		No
13	Is the organization a school described in section 170(b)(1)(A)(ii)? *If "Yes," complete Schedule E*	13		No
14a	Did the organization maintain an office, employees, or agents outside of the United States?	14a		No
b	Did the organization have aggregate revenues or expenses of more than $10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at $100,000 or more? *If "Yes," complete Schedule F, Parts I and IV*	14b		No
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		No
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		No
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		No
18	Did the organization report more than $15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? *If "Yes," complete Schedule G, Part II*	18	Yes	
19	Did the organization report more than $15,000 of gross income from gaming activities on Part VIII, line 9a? *If "Yes," complete Schedule G, Part III*	19		No
20a	Did the organization operate one or more hospital facilities? *If "Yes," complete Schedule H*	20a		No
b	If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?	20b		
21	Did the organization report more than $5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? *If "Yes," complete Schedule I, Parts I and II*	21	Yes	

Part IV Checklist of Required Schedules *(continued)*

			Yes	No
22	Did the organization report more than $5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? *If "Yes," complete Schedule I, Parts I and III*	22		No
23	Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? *If "Yes," complete Schedule J*	23		No
24a	Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than $100,000 as of the last day of the year, that was issued after December 31, 2002? *If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a*	24a		No
b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		
c	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?	24c		
d	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d		
25a	**Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations.** Did the organization engage in an excess benefit transaction with a disqualified person during the year? *If "Yes," complete Schedule L,* Part I	25a		No
b	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? *If "Yes," complete Schedule L,* Part I	25b		No
26	Did the organization report any amount on Part X, line 5 or 22 for receivables from or payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons? *If "Yes," complete Schedule L, Part II*	26		No
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		No
28	Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions):			
a	A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? *If "Yes," complete Schedule L, Part IV*	28a		No
b	A family member of any individual described in line 28a? *If "Yes," complete Schedule L, Part IV*	28b		No
c	A 35% controlled entity of one or more individuals and/or organizations described in lines 28a or 28b? *If "Yes," complete Schedule L, Part IV*	28c		No
29	Did the organization receive more than $25,000 in non-cash contributions? *If "Yes," complete Schedule M*	29		No
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? *If "Yes," complete Schedule M*	30		No
31	Did the organization liquidate, terminate, or dissolve and cease operations? *If "Yes," complete Schedule N, Part I*	31		No
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? *If "Yes," complete Schedule N, Part II*	32		No
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		No
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		No
35a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a		No
b	If 'Yes' to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? *If "Yes," complete Schedule R, Part V, line 2*	35b		
36	**Section 501(c)(3) organizations.** Did the organization make any transfers to an exempt non-charitable related organization? *If "Yes," complete Schedule R, Part V, line 2*	36		No
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		No
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? **Note.** All Form 990 filers are required to complete Schedule O.	38	Yes	

Part V Statements Regarding Other IRS Filings and Tax Compliance

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

				Yes	No
1a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable	1a	0		
b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable	1b	0		
c	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	1c			

Part V Statements Regarding Other IRS Filings and Tax Compliance *(continued)*

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**	5		
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns? **Note.** If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)			**2b**	Yes
3a	Did the organization have unrelated business gross income of $1,000 or more during the year? . . .			**3a**	No
b	If "Yes," has it filed a Form 990-T for this year? *If "No" to line 3b, provide an explanation in Schedule O* . . .			**3b**	
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?			**4a**	No
b	If "Yes," enter the name of the foreign country: ▶ See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).				
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year? . .			**5a**	No
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?			**5b**	No
c	If "Yes," to line 5a or 5b, did the organization file Form 8886-T?			**5c**	
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? . . .			**6a**	No
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?			**6b**	
7	**Organizations that may receive deductible contributions under section 170(c).**				
a	Did the organization receive a payment in excess of $75 made partly as a contribution and partly for goods and services provided to the payor?			**7a**	
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?			**7b**	
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?			**7c**	
d	If "Yes," indicate the number of Forms 8282 filed during the year	**7d**			
e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?			**7e**	
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?			**7f**	
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?			**7g**	
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?			**7h**	
8	**Sponsoring organizations maintaining donor advised funds.** Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?			**8**	
9	**Sponsoring organizations maintaining donor advised funds.**				
a	Did the sponsoring organization make any taxable distributions under section 4966?			**9a**	
b	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person? . . .			**9b**	
10	**Section 501(c)(7) organizations.** Enter:				
a	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:				
a	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**			
12a	**Section 4947(a)(1) non-exempt charitable trusts.** Is the organization filing Form 990 in lieu of Form 1041?			**12a**	
b	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.**				
a	Is the organization licensed to issue qualified health plans in more than one state? . . . . . **Note.** See the instructions for additional information the organization must report on Schedule O.			**13a**	
b	Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans	**13b**			
c	Enter the amount of reserves on hand	**13c**			
14a	Did the organization receive any payments for indoor tanning services during the tax year?			**14a**	No
b	If "Yes," has it filed a Form 720 to report these payments? *If "No," provide an explanation in Schedule O* . .			**14b**	
15	Is the organization subject to the section 4960 tax on payment(s) of more than $1,000,000 in remuneration or excess parachute payment(s) during the year?			**15**	No
16	Is the organization an educational institution subject to the section 4968 excise tax on net investment income? . . If "Yes," complete Form 4720, Schedule O.			**16**	No

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

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

Section A. Governing Body and Management

				Yes	No
1a	Enter the number of voting members of the governing body at the end of the tax year. If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain in Schedule O.	**1a**	6		
b	Enter the number of voting members included in line 1a, above, who are independent	**1b**	6		
2	Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee?		**2**		No
3	Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors or trustees, or key employees to a management company or other person?		**3**		No
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?		**4**		No
5	Did the organization become aware during the year of a significant diversion of the organization's assets?		**5**		No
6	Did the organization have members or stockholders?		**6**		No
7a	Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body?		**7a**		No
b	Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?		**7b**		No
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:				
a	The governing body?		**8a**	Yes	
b	Each committee with authority to act on behalf of the governing body?		**8b**	Yes	
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? *If "Yes," provide the names and addresses in Schedule O*		**9**		No

Section B. Policies (*This Section B requests information about policies not required by the Internal Revenue Code.*)

			Yes	No
10a	Did the organization have local chapters, branches, or affiliates?	**10a**		No
b	If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes?	**10b**		
11a	Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?	**11a**	Yes	
b	Describe in Schedule O the process, if any, used by the organization to review this Form 990.			
12a	Did the organization have a written conflict of interest policy? *If "No," go to line 13*	**12a**	Yes	
b	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	**12b**	Yes	
c	Did the organization regularly and consistently monitor and enforce compliance with the policy? *If "Yes," describe in Schedule O how this was done*	**12c**		No
13	Did the organization have a written whistleblower policy?	**13**	Yes	
14	Did the organization have a written document retention and destruction policy?	**14**	Yes	
15	Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision?			
a	The organization's CEO, Executive Director, or top management official	**15a**	Yes	
b	Other officers or key employees of the organization	**15b**	Yes	
	If "Yes" to line 15a or 15b, describe the process in Schedule O (see instructions).			
16a	Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year?	**16a**		No
b	If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements?	**16b**		

Section C. Disclosure

17 List the states with which a copy of this Form 990 is required to be filed ▶ IL, IN, WI

18 Section 6104 requires an organization to make its Form 1023 (or 1024-A if applicable), 990, and 990-T (501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.

☑ Own website ☐ Another's website ☑ Upon request ☐ Other (explain in Schedule O)

19 Describe in Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.

20 State the name, address, and telephone number of the person who possesses the organization's books and records: ▶DIANA HABERKAMP 473 DUNHAM RD SUITE 3 3 ST CHARLES, IL 60174 (630) 945-3562

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

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

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

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

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

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

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
(1) GORDON CUMMINGS TREASURER	1.00	X		X				0	0	0
(2) DENISE DULCEAK BOARD CHAIR	1.00	X		X				0	0	0
(3) DIANA HABERKAMP EXECUTIVE DI	40.00	X		X				0	0	0
(4) DENA HASSELBERG SECRETARY	1.00	X		X				0	0	0
(5) GAIL MAVROGENES BOARD MEMBER	1.00	X						0	0	0
(6) GAIL MAVROGENES BOARD MEMBER	1.00	X						0	0	0
(7) PETER OSWALD SR VICE CHAIR	1.00	X		X				0	0	0

Part VII **Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees** *(continued)*

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
1b Sub-Total . . . . . ▶										
c Total from continuation sheets to Part VII, Section A . . . . ▶										
d Total (add lines 1b and 1c) . . . . . ▶										

2 Total number of individuals (including but not limited to those listed above) who received more than $100,000 of reportable compensation from the organization ▶

			Yes	No
3	Did the organization list any **former** officer, director or trustee, key employee, or highest compensated employee on line 1a? *If "Yes," complete Schedule J for such individual*	**3**		No
4	For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than $150,000? *If "Yes," complete Schedule J for such individual*	**4**		No
5	Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? *If "Yes," complete Schedule J for such person*	**5**		No

Section B. Independent Contractors

1 Complete this table for your five highest compensated independent contractors that received more than $100,000 of compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax year.

(A) Name and business address	(B) Description of services	(C) Compensation

2 Total number of independent contractors (including but not limited to those listed above) who received more than $100,000 of compensation from the organization ▶

Part VIII Statement of Revenue

Check if Schedule O contains a response or note to any line in this Part VIII . . . . . ☐

		(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512 - 514
Contributions, Gifts, Grants and Other Similar Amounts					
1a Federated campaigns	1a				
b Membership dues	1b				
c Fundraising events	1c				
d Related organizations	1d				
e Government grants (contributions)	1e	36,400			
f All other contributions, gifts, grants, and similar amounts not included above	1f	108,861			
g Noncash contributions included in lines 1a - 1f:$	1g				
h **Total.** Add lines 1a-1f		145,261			
Program Service Revenue	Business Code				
2a					
b					
c					
d					
e					
f All other program service revenue.					
g **Total.** Add lines 2a–2f					
Other Revenue					
3 Investment income (including dividends, interest, and other similar amounts)		2,121	2,121		
4 Income from investment of tax-exempt bond proceeds					
5 Royalties					
	(i) Real	(ii) Personal			
6a Gross rents	6a				
b Less: rental expenses	6b				
c Rental income or (loss)	6c				
d Net rental income or (loss)					
	(i) Securities	(ii) Other			
7a Gross amount from sales of assets other than inventory	7a				
b Less: cost or other basis and sales expenses	7b				
c Gain or (loss)	7c				
d Net gain or (loss)					
8a Gross income from fundraising events (not including $ _____ of contributions reported on line 1c). See Part IV, line 18	8a	68,555			
b Less: direct expenses	8b	6,341			
c Net income or (loss) from fundraising events		62,214			
9a Gross income from gaming activities. See Part IV, line 19	9a				
b Less: direct expenses	9b				
c Net income or (loss) from gaming activities					
10a Gross sales of inventory, less returns and allowances	10a	1,452			
b Less: cost of goods sold	10b	1,086			
c Net income or (loss) from sales of inventory		366	366		
Miscellaneous Revenue	Business Code				
11a OTHER REVENUE		3			3
b					
c					
d All other revenue					
e **Total.** Add lines 11a–11d		3			
12 **Total revenue.** See instructions		209,965	2,487		3

Part IX Statement of Functional Expenses

Section 501(c)(3) and 501(c)(4) organizations must complete all columns. All other organizations must complete column (A).

Check if Schedule O contains a response or note to any line in this Part IX . . . . . ☐

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	29,500	29,500		
2 Grants and other assistance to domestic individuals. See Part IV, line 22	4,000	4,000		
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16.				
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees				
6 Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)				
7 Other salaries and wages	85,069	57,847	13,611	13,611
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
9 Other employee benefits				
10 Payroll taxes	6,507	4,425	1,041	1,041
11 Fees for services (non-employees):				
a Management				
b Legal				
c Accounting	438	228		210
d Lobbying	10,300	10,300		
e Professional fundraising services. See Part IV, line 17				
f Investment management fees				
g Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O)				
12 Advertising and promotion	403	403		
13 Office expenses	6,587	4,547	1,020	1,020
14 Information technology	10,030	6,921	1,304	1,805
15 Royalties				
16 Occupancy	15,496	9,297	4,649	1,550
17 Travel				
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings				
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization				
23 Insurance	1,140	707	260	173
24 Other expenses. Itemize expenses not covered above (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
a BANK AND CREDIT CARD FEES	3,138	1,098	973	1,067
b TELEPHONE	2,710	1,896	407	407
c NF EDUCATION	561	561		
d SYMPOSIUM	35	35		
e All other expenses	14	14		
25 **Total functional expenses.** Add lines 1 through 24e	175,928	131,779	23,265	20,884
26 **Joint costs.** Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here ▶ ☐ if following SOP 98-2 (ASC 958-720).				

Part X Balance Sheet

Check if Schedule O contains a response or note to any line in this Part IX . . . . . ☐

			(A) Beginning of year		(B) End of year
Assets	1	Cash–non-interest-bearing	79,187	1	108,314
	2	Savings and temporary cash investments		2	
	3	Pledges and grants receivable, net		3	
	4	Accounts receivable, net		4	
	5	Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		5	
	6	Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B)		6	
	7	Notes and loans receivable, net		7	
	8	Inventories for sale or use		8	
	9	Prepaid expenses and deferred charges		9	
	10a	Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D — 10a			
	b	Less: accumulated depreciation — 10b		10c	
	11	Investments—publicly traded securities	252,419	11	241,939
	12	Investments—other securities. See Part IV, line 11		12	
	13	Investments—program-related. See Part IV, line 11		13	
	14	Intangible assets		14	
	15	Other assets. See Part IV, line 11	1,100	15	1,100
	16	**Total assets.** Add lines 1 through 15 (must equal line 33)	332,706	16	351,353
Liabilities	17	Accounts payable and accrued expenses	19,781	17	3,486
	18	Grants payable		18	
	19	Deferred revenue		19	
	20	Tax-exempt bond liabilities		20	
	21	Escrow or custodial account liability. Complete Part IV of Schedule D		21	
	22	Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		22	
	23	Secured mortgages and notes payable to unrelated third parties		23	
	24	Unsecured notes and loans payable to unrelated third parties		24	
	25	Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17 - 24). Complete Part X of Schedule D		25	
	26	**Total liabilities.** Add lines 17 through 25	19,781	26	3,486
Net Assets or Fund Balances		**Organizations that follow FASB ASC 958, check here ▶ ☑ and complete lines 27, 28, 32, and 33.**			
	27	Net assets without donor restrictions	312,925	27	347,867
	28	Net assets with donor restrictions		28	
		Organizations that do not follow FASB ASC 958, check here ▶ ☐ and complete lines 29 through 33.			
	29	Capital stock or trust principal, or current funds		29	
	30	Paid-in or capital surplus, or land, building or equipment fund		30	
	31	Retained earnings, endowment, accumulated income, or other funds		31	
	32	Total net assets or fund balances	312,925	32	347,867
	33	Total liabilities and net assets/fund balances	332,706	33	351,353

Part XI Reconcilliation 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	209,965
2	Total expenses (must equal Part IX, column (A), line 25)	2	175,928
3	Revenue less expenses. Subtract line 2 from line 1	3	34,037
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	312,925
5	Net unrealized gains (losses) on investments	5	905
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain in Schedule O)	9	
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column	10	347,867

Part XII Financial Statements and Reporting

Check if Schedule O contains a response or note to any line in this Part XII . . . . . ☐

			Yes	No
1	Accounting method used to prepare the Form 990: ☐ Cash ☑ Accrual ☐ Other _____ If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule O.			
2a	Were the organization's financial statements compiled or reviewed by an independent accountant?	2a		No
	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		No
	If 'Yes,' check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both: ☐ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis			
c	If "Yes," to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant?	2c		
	If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O.			
3a	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133?	3a		No
b	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits.	3b		

Additional Data

Return to Form

Software ID:

Software Version:

Form 990, Special Condition Description:

Special Condition Description

SCHEDULE A (Form 990 or 990EZ)

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support

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

▶ **Attach to Form 990 or Form 990-EZ.**

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

OMB No. 1545-0047

2020

Open to Public Inspection

Name of the organization
NEUROFIBROMATOSIS MIDWEST

Employer identification number
22-2580173

Part I Reason for Public Charity Status (All organizations must complete this part.) See instructions.

The organization is not a private foundation because it is: (For lines 1 through 12, check only one box.)

1 ☐ A church, convention of churches, or association of churches described in **section 170(b)(1)(A)(i).**

2 ☐ A school described in **section 170(b)(1)(A)(ii).** (Attach Schedule E (Form 990 or 990-EZ).)

3 ☐ A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii).**

4 ☐ A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii).** Enter the hospital's name, city, and state:

5 ☐ An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv).** (Complete Part II.)

6 ☐ A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v).**

7 ☑ 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.)

8 ☐ A community trust described in **section 170(b)(1)(A)(vi)**. (Complete Part II.)

9 ☐ An agricultural research organization described in **170(b)(1)(A)(ix)** operated in conjunction with a land-grant college or university or a non-land grant college of agriculture. See instructions. Enter the name, city, and state of the college or university:

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 in lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g.

a ☐ **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.**

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.**

c ☐ **Type III functionally integrated.** A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions). **You must complete Part IV, Sections A, D, and E.**

d ☐ **Type III non-functionally integrated.** A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions). **You must complete Part IV, Sections A and D, and Part V.**

e ☐ 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.

f Enter the number of supported organizations . . . . . _____

g Provide the following information about the supported organization(s).

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1- 10 above (see instructions))	(iv) Is the organization listed in your governing document? Yes	(iv) No	(v) Amount of monetary support (see instructions)	(vi) Amount of other support (see instructions)
Total						

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 failed to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ▶	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grant.") . .	84,680	137,391	139,726	140,948	145,261	648,006
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
3 The value of services or facilities furnished by a governmental unit to the organization without charge..						
4 **Total.** Add lines 1 through 3	84,680	137,391	139,726	140,948	145,261	648,006
5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f) . .						
6 **Public support.** Subtract line 5 from line 4.						648,006

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
7 Amounts from line 4. .	84,680	137,391	139,726	140,948	145,261	648,006
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources . . .						
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.). .		2,001	1,455	2,683	3	6,142
11 **Total support.** Add lines 7 through 10						654,148

12 Gross receipts from related activities, etc. (see instructions) **12** 424,442

13 **First 5 years.** If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and **stop here** . . . . . ▶ ☐

Section C. Computation of Public Support Percentage

14 Public support percentage for 2020 (line 6, column (f) divided by line 11, column (f))	**14**	99.060 %
15 Public support percentage for 2019 Schedule A, Part II, line 14	**15**	98.560 %

16a **33 1/3% support test—2020.** If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and **stop here.** The organization qualifies as a publicly supported organization . . . . . ▶ ☑

b **33 1/3% support test—2019.** If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and **stop here.** The organization qualifies as a publicly supported organization . . . . . ▶ ☐

17a **10%-facts-and-circumstances test—2020.** If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and **stop here.** Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization . . . . . ▶ ☐

b **10%-facts-and-circumstances test—2019.** If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and **stop here.** Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization . . . . . ▶ ☐

18 **Private foundation.** If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions . . . . . ▶ ☐

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

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

Section A. Public Support

Calendar year (or fiscal year beginning in) ▶	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") .						
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf . . .						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 **Total.** Add lines 1 through 5						
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of $5,000 or 1% of the amount on line 13 for the year.						
c Add lines 7a and 7b. .						
8 **Public support.** (Subtract line 7c from line 6.)						

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
9 Amounts from line 6. . .						
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources . .						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975.						
c Add lines 10a and 10b.						
11 Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on.						
12 Other income. Do not include gain or 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 organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and **stop here**. . . . . ▶☐

Section C. Computation of Public Support Percentage

15	Public support percentage for 2020 (line 8, column (f) divided by line 13, column (f))	15
16	Public support percentage from 2019 Schedule A, Part III, line 15	16

Section D. Computation of Investment Income Percentage

17	Investment income percentage for **2020** (line 10c, column (f) divided by line 13, column (f))	17
18	Investment income percentage from **2019** Schedule A, Part III, line 17	18

19a **33 1/3% support tests—2020.** If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and **stop here.** The organization qualifies as a publicly supported organization . . . . . ▶☐

b **33 1/3% support tests—2019.** If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3% and line 18 is not more than 33 1/3%, check this box and **stop here.** The organization qualifies as a publicly supported organization . . . . ▶☐

20 **Private foundation.** If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions . . . . ▶☐

Part IV Supporting Organizations

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

Section A. All Supporting Organizations

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

Part IV Supporting Organizations (continued)

			Yes	No
11	Has the organization accepted a gift or contribution from any of the following persons?			
a	A person who directly or indirectly controls, either alone or together with persons described in lines 11b and 11c below, the governing body of a supported organization?	**11a**		
b	A family member of a person described in 11a above?	**11b**		
c	A 35% controlled entity of a person described in line 11a or 11b above? *If "Yes" to 11a, 11b, or 11c, provide detail in* ***Part VI****.*	**11c**		

Section B. Type I Supporting Organizations

			Yes	No
1	Did the officers, directors, trustees, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the tax year? *If "No," describe in* ***Part VI*** *how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove directors or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.*	**1**		
2	Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? *If "Yes," explain in* ***Part VI*** *how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised or controlled the supporting organization.*	**2**		

Section C. Type II Supporting Organizations

			Yes	No
1	Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)? *If "No," describe in* ***Part VI*** *how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s).*	**1**		

Section D. All Type III Supporting Organizations

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

Section E. Type III Functionally-Integrated Supporting Organizations

1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year **(see instructions)**:

- **a** ☐ The organization satisfied the Activities Test. Complete **line 2** below.
- **b** ☐ The organization is the parent of each of its supported organizations. Complete **line 3** below.
- **c** ☐ The organization supported a governmental entity. Describe in **Part VI** how you supported a government entity (see instructions)

2 Activities Test. **Answer lines 2a and 2b below.**

			Yes	No
a	Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? *If "Yes," then in* ***Part VI identify those supported organizations and explain*** *how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.*	**2a**		
b	Did the activities described in line 2a constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? *If "Yes," explain in* ***Part VI*** *the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.*	**2b**		

3 Parent of Supported Organizations. **Answer lines 3a and 3b below.**

a	Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? *If "Yes" or "No" provide details in* ***Part VI.***	**3a**		
b	Did the organization exercise a substantial degree of direction over the policies, programs and activities of each of its supported organizations? *If "Yes," describe in* ***Part VI.*** *the role played by the organization in this regard.*	**3b**		

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 must complete Sections A through E.

Section A - Adjusted Net Income

			(A) Prior Year	(B) Current Year (optional)
1	Net short-term capital gain	**1**		
2	Recoveries of prior-year distributions	**2**		
3	Other gross income (see instructions)	**3**		
4	Add lines 1 through 3	**4**		
5	Depreciation and depletion	**5**		
6	Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions)	**6**		
7	Other expenses (see instructions)	**7**		
8	**Adjusted Net Income** (subtract lines 5, 6 and 7 from line 4)	**8**		

Section B - Minimum Asset Amount

			(A) Prior Year	(B) Current Year (optional)
1	Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year):	**1**		
a	Average monthly value of securities	**1a**		
b	Average monthly cash balances	**1b**		
c	Fair market value of other non-exempt-use assets	**1c**		
d	**Total** (add lines 1a, 1b, and 1c)	**1d**		
e	**Discount** claimed for blockage or other factors (*explain in detail in **Part VI***):			
2	Acquisition indebtedness applicable to non-exempt use assets	**2**		
3	Subtract line 2 from line 1d	**3**		
4	Cash deemed held for exempt use. Enter 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**		

Section C - Distributable Amount

			Current Year
1	Adjusted net income for prior year (from Section A, line 8, Column A)	**1**	
2	Enter 85% of line 1	**2**	
3	Minimum asset amount for prior year (from Section B, line 8, Column A)	**3**	
4	Enter greater of line 2 or line 3	**4**	
5	Income tax imposed in prior year	**5**	
6	**Distributable Amount.** Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions)	**6**	

7 ☐ Check here if the current year is the organization's first as a non-functionally-integrated Type III supporting organization (see instructions)

Part V **Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations** (continued)

Section D - Distributions		**Current Year**
1 Amounts paid to supported organizations to accomplish exempt purposes	**1**	
2 Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	**2**	
3 Administrative expenses paid to accomplish exempt purposes of supported organizations	**3**	
4 Amounts paid to acquire exempt-use assets	**4**	
5 Qualified set-aside amounts (*prior IRS approval required - provide details in* ***Part VI***)	**5**	
6 Other distributions (*describe in* ***Part VI***). See instructions	**6**	
7 **Total annual distributions.** Add lines 1 through 6.	**7**	
8 Distributions to attentive supported organizations to which the organization is responsive (*provide details in* ***Part VI***). See instructions	**8**	
9 Distributable amount for 2020 from Section C, line 6	**9**	
10 Line 8 amount divided by Line 9 amount	**10**	

Section E - Distribution Allocations (see instructions)	**(i) Excess Distributions**	**(ii) Underdistributions Pre-2020**	**(iii) Distributable Amount for 2020**
1 Distributable amount for 2020 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2020 (reasonable cause required-- *explain in* ***Part VI***). See instructions.			
3 Excess distributions carryover, if any, to 2020:			
a From 2015.			
b From 2016.			
c From 2017.			
d From 2018.			
e From 2019.			
f **Total** of lines 3a through e			
g Applied to underdistributions of prior years			
h Applied to 2020 distributable amount			
i Carryover from 2015 not applied (see instructions)			
j Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
4 Distributions for 2020 from Section D, line 7: $			
a Applied to underdistributions of prior years			
b Applied to 2020 distributable amount			
c Remainder. Subtract lines 4a and 4b from line 4.			
5 Remaining underdistributions for years prior to 2020, if any. Subtract lines 3g and 4a from line 2. If the amount is greater than zero, *explain in* ***Part VI***. See instructions.			
6 Remaining underdistributions for 2020. Subtract lines 3h and 4b from line 1. If the amount is greater than zero, *explain in* ***Part VI***. See instructions.			
7 **Excess distributions carryover to 2021.** Add lines 3j and 4c.			
8 Breakdown of line 7:			
a Excess from 2016.			
b Excess from 2017.			
c Excess from 2018.			
d Excess from 2019.			
e Excess from 2020.			

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

Facts And Circumstances Test

Return Reference	Explanation
PART II, LINE 10	OTHER INCOME 6,139

Additional Data

Return to Form

Software ID:

Software Version:

Schedule B (Form 990, 990-EZ, or 990-PF)
Department of the Treasury
Internal Revenue Service

Schedule of Contributors

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

OMB No. 1545-0047

2020

Name of the organization
NEUROFIBROMATOSIS MIDWEST

Employer identification number
22-2580173

Organization type (check one):

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

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

General Rule

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

Special Rules

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

☐ For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, total contributions of more than $1,000 *exclusively* for religious, charitable, scientific, literary, or educational purposes, or for the prevention of cruelty to children or animals. Complete Parts I, 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, 990-EZ, or 990-PF), but it **must** answer "No" on Part IV, line 2, of its Form 990; or check the box on line H of its Form 990-EZ or on its Form 990PF, Part I, line 2, to certify that it doesn't meet the filing requirements of Schedule B (Form 990, 990-EZ, or 990-PF).

Name of organization
NEUROFIBROMATOSIS MIDWEST

Employer identification number
22-2580173

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

Contributors

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
RESTRICTED		$ RESTRICTED	☐ Person ☐ Payroll ☐ Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		$	☐ Person ☐ Payroll ☐ Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		$	☐ Person ☐ Payroll ☐ Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		$	☐ Person ☐ Payroll ☐ Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		$	☐ Person ☐ Payroll ☐ Noncash (Complete Part II for noncash contributions.)
(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
NEUROFIBROMATOSIS MIDWEST

Employer identification number
22-2580173

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
NEUROFIBROMATOSIS MIDWEST

Employer identification number
22-2580173

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 $1,000 or less for the year. (Enter this information once. See instructions.)** ▶ **$** _____

Use duplicate copies of Part III if additional space is needed.

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
(e) Transfer of gift: Transferee's name, address, and ZIP 4		Relationship of transferor to transferee	

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
(e) Transfer of gift: Transferee's name, address, and ZIP 4		Relationship of transferor to transferee	

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
(e) Transfer of gift: Transferee's name, address, and ZIP 4		Relationship of transferor to transferee	

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
(e) Transfer of gift: Transferee's name, address, and ZIP 4		Relationship of transferor to transferee	

Additional Data

Return to Form

Software ID:

Software Version:

SCHEDULE C (Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

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

2020

Open to Public Inspection

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.

Name of the organization	Employer identification number
NEUROFIBROMATOSIS MIDWEST	22-2580173

Part I-A Complete if the organization is exempt under section 501(c) or is a section 527 organization.

1 Provide a description of the organization's direct and indirect political campaign activities in Part IV (see instructions for definition of "political campaign activities")

2 Political campaign activity expenditures (see instructions) ▶ $

3 Volunteer hours for political campaign activities (see instructions)

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? ☐ Yes ☐ No

b If "Yes," describe in Part IV.

Part I-C Complete if the organization is exempt under section 501(c), except section 501(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? ☐ Yes ☐ No

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 enter the amount of political contributions received that were promptly and directly delivered to a separate political organization, such as a separate 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 from filing organization's funds. If none, enter -0-.	**(e)** Amount of political contributions received and promptly and directly delivered to a separate political organization. If none, enter -0-.
1					
2					
3					
4					
5					
6					

Part II-A **Complete if the organization is exempt under section 501(c)(3) and filed Form 5768 (election under section 501(h)).**

A 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).

B Check ▶ ☐ if the filing organization checked box A and "limited control" provisions apply.

Limits on Lobbying Expenditures (The term "expenditures" means amounts paid or incurred.)	(a) Filing organization's totals	(b) Affiliated group totals
1a Total lobbying expenditures to influence public opinion (grass roots lobbying)		
b Total lobbying expenditures to influence a legislative body (direct lobbying)		
c Total lobbying expenditures (add lines 1a and 1b)		
d Other exempt purpose expenditures		
e Total exempt purpose expenditures (add lines 1c and 1d)		
f Lobbying nontaxable amount. Enter the amount from the following table in both columns.		

If the amount on line 1e, column (a) or (b) is:	The lobbying nontaxable amount is:
Not over $500,000	20% of the amount on line 1e.
Over $500,000 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 $17,000,000	$1,000,000.

g Grassroots nontaxable amount (enter 25% of line 1f)		
h Subtract line 1g from line 1a. If zero or less, enter -0-.		
i Subtract line 1f from line 1c. If zero or less, enter -0-.		

j If there is an amount other than zero on either line 1h or line 1i, did the organization file Form 4720 reporting section 4911 tax for this year? ☐ **Yes** ☐ **No**

4-Year Averaging Period Under Section 501(h)
(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) 2017	(b) 2018	(c) 2019	(d) 2020	(e) Total
2a Lobbying nontaxable amount					
b Lobbying ceiling amount (150% of line 2a, column(e))					
c Total lobbying expenditures					
d Grassroots nontaxable amount					
e Grassroots ceiling amount (150% of line 2d, column (e))					
f Grassroots lobbying expenditures					

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

For each "Yes" response on lines 1a through 1i below, provide in Part IV a detailed description of the lobbying activity.		(a) Yes	(a) No	(b) Amount
1	During the year, did the filing organization attempt to influence foreign, national, state or local legislation, including any attempt to influence public opinion on a legislative matter or referendum, through the use of:			
a	Volunteers?	Yes		
b	Paid staff or management (include compensation in expenses reported on lines 1c through 1i)?	Yes		
c	Media advertisements?		No	
d	Mailings to members, legislators, or the public?		No	
e	Publications, or published or broadcast statements?		No	
f	Grants to other organizations for lobbying purposes?		No	
g	Direct contact with legislators, their staffs, government officials, or a legislative body?		No	
h	Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means?		No	
i	Other activities?		No	
j	Total. Add lines 1c through 1i			
2a	Did the activities in line 1 cause the organization to be not described in section 501(c)(3)?		No	
b	If "Yes," enter the amount of any tax incurred under section 4912			
c	If "Yes," enter the amount of any tax incurred by organization managers under section 4912			
d	If the filing organization incurred a section 4912 tax, did it file Form 4720 for this year?			

Part III-A Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6).

			Yes	No
1	Were substantially all (90% or more) dues received nondeductible by members?	1		
2	Did the organization make only in-house lobbying expenditures of $2,000 or less?	2		
3	Did the organization agree to carry over lobbying and political expenditures from the prior year?	3		

Part III-B Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered "No" OR (b) Part III-A, line 3, is answered "Yes."

1	Dues, assessments and similar amounts from members	1	
2	Section 162(e) nondeductible lobbying and political expenditures **(do not include amounts of political expenses for which the section 527(f) tax was paid).**		
a	Current year	2a	
b	Carryover from last year	2b	
c	Total	2c	
3	Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues	3	
4	If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditure next year?	4	
5	Taxable amount of lobbying and political expenditures (see instructions)	5	

Part IV Supplemental Information

Provide the descriptions required for Part I-A, line 1; Part I-B, line 4; Part I-C, line 5; Part II-A (affiliated group list); Part II-A, lines 1 and 2 (see instructions), and Part II-B, line 1. Also, complete this part for any additional information.

Return Reference	Explanation
SCHEDULE C, PART II-B, LINE 1	THE ORGANIZATION HIRED A LOBBYING FIRM THAT PUTS THE ORGANIZATION'S PEOPLE AT NEUROFIBROMATOSIS MIDWEST IN CONTACT WITH POLITICIANS.

Additional Data

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SCHEDULE G (Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Supplemental Information Regarding Fundraising or Gaming Activities

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

▶ **Attach to Form 990 or Form 990-EZ.**

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

OMB No. 1545-0047

2020

Open to Public Inspection

Name of the organization
NEUROFIBROMATOSIS MIDWEST

Employer identification number
22-2580173

Part I **Fundraising Activities.** Complete if the organization answered "Yes" on Form 990, Part IV, line 17. Form 990-EZ filers are not required to complete this part.

1 Indicate whether the organization raised funds through any of the following activities. Check all that apply.

- **a** ☐ Mail solicitations
- **b** ☐ Internet and email solicitations
- **c** ☐ Phone solicitations
- **d** ☐ In-person solicitations
- **e** ☐ Solicitation of non-government grants
- **f** ☐ Solicitation of government grants
- **g** ☐ Special fundraising events

2a Did the organization have a written or oral agreement with any individual (including officers, directors, trustees or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services? ☐ **Yes** ☐ **No**

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

	(i) Name and address of individual or entity (fundraiser)	**(ii)** Activity	**(iii)** Did fundraiser have custody or control of contributions?		**(iv)** Gross receipts from activity	**(v)** Amount paid to (or retained by) fundraiser listed in col. **(i)**	**(vi)** Amount paid to (or retained by) organization
			Yes	**No**			
1							
2							
3							
4							
5							
6							
7							
8							
9							
10							
Total ▶							

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

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

Revenue / Direct Expenses		(a) Event #1 GREAT STEPS (event type)	(b) Event #2 (event type)	(c) Other events (total number)	(d) Total events (add col. (a) through col. (c))
Revenue	1 Gross receipts	68,555			68,555
	2 Less: Contributions				
	3 Gross income (line 1 minus line 2)	68,555			68,555
Direct Expenses	4 Cash prizes				
	5 Noncash prizes				
	6 Rent/facility costs				
	7 Food and beverages				
	8 Entertainment				
	9 Other direct expenses	6,341			6,341
	10 Direct expense summary. Add lines 4 through 9 in column (d) ▶				6,341
	11 Net income summary. Subtract line 10 from line 3, column (d) ▶				62,214

Part III **Gaming.** Complete if the organization answered "Yes" on Form 990, Part IV, line 19, or reported more than $15,000 on Form 990-EZ, line 6a.

Revenue / Direct Expenses		(a) Bingo	(b) Pull tabs/Instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col.(a) through col.(c))
Revenue	1 Gross revenue				
Direct Expenses	2 Cash prizes				
	3 Noncash prizes				
	4 Rent/facility costs				
	5 Other direct expenses				
	6 Volunteer labor	☐ Yes ____ % ☐ No	☐ Yes ____ % ☐ No	☐ Yes ____ % ☐ No	
	7 Direct expense summary. Add lines 2 through 5 in column (d) ▶				
	8 Net gaming income summary. Subtract line 7 from line 1, column (d) ▶				

9 Enter the state(s) in which the organization conducts gaming activities: _____

a Is the organization licensed to conduct gaming activities in each of these states? ☐ **Yes** ☐ **No**

b If "No," explain: _____

10a Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year? ☐ **Yes** ☐ **No**

b If "Yes," explain: _____

11 Does the organization conduct gaming activities with nonmembers? . . . . . ☐ Yes ☐ No

12 Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity formed to administer charitable gaming? . . . . . ☐ Yes ☐ No

13 Indicate the percentage of gaming activity conducted in:

a	The organization's facility	**13a**	%
b	An outside facility	**13b**	%

14 Enter the name and address of the person who prepares the organization's gaming/special events books and records:

Name ▶ ----------

Address ▶ ----------

15a Does the organization have a contract with a third party from whom the organization receives gaming revenue? . . . . . ☐ Yes ☐ No

b If "Yes," enter the amount of gaming revenue received by the organization ▶ $ _____ and the amount of gaming revenue retained by the third party ▶ $ _____.

c If "Yes," enter name and address of the third party:

Name ▶ ----------

Address ▶ ----------

16 Gaming manager information:

Name ▶ ----------

Gaming manager compensation ▶ $ ----------

Description of services provided ▶ ----------

☐ Director/officer ☐ Employee ☐ Independent contractor

17 Mandatory distributions:

a Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license? . . . . . ☐ Yes ☐ No

b Enter the amount of distributions required under state law distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year ▶ $

Part IV **Supplemental Information.** Provide the explanations required by Part I, line 2b, columns (iii) and (v); and Part III, lines 9, 9b, 10b, 15b, 15c, 16, and 17b, as applicable. Also provide any additional information. See instructions.

Return Reference	Explanation

Additional Data Return to Form

Software ID:

Software Version:

Note: To capture the full content of this document, please select landscape mode (11" x 8.5") when printing.

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.**

OMB No. 1545-0047

2020

Open to Public Inspection

Name of the organization
NEUROFIBROMATOSIS MIDWEST

Employer identification number
22-2580173

Part I General Information on Grants and Assistance

1 Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? . . . . . ☐ Yes ☑ No

2 Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States.

Part II Grants and Other Assistance to Domestic Organizations and Domestic Governments.

Complete if the organization answered "Yes" on Form 990, Part IV, line 21, for any recipient that received more than $5,000. Part II can be duplicated if additional space is needed.

(a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
(1) BRAINY CAMPS 111 MICHIGAN AVE NW WASHINGTON,DC 20010	27-1547370	X	12,500				SUMMER CAMP
(2) MASSACHUSETTS GENERAL HOSPITAL 55 FRUIT STREET BOSTON,MA 02114	04-1564655	X	10,000				RESEARCH AND STUDIES

2 Enter total number of section 501(c)(3) and government organizations listed in the line 1 table . . . . . ▶

3 Enter total number of other organizations listed in the line 1 table . . . . . ▶

Part III **Grants and Other Assistance to Domestic Individuals.** Complete if the organization answered "Yes" on Form 990, Part IV, line 22. Part III can be duplicated if additional space is needed.

	(a) Type of grant or assistance	**(b)** Number of recipients	**(c)** Amount of cash grant	**(d)** Amount of noncash assistance	**(e)** Method of valuation (book, FMV, appraisal, other)	**(f)** Description of noncash assistance
(1)						
(2)						
(3)						
(4)						
(5)						
(6)						
(7)						

Part IV **Supplemental Information.** Provide the information required in Part I, line 2; Part III, column (b); and any other additional information.

Return Reference	Explanation

Additional Data

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SCHEDULE O (Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

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

▶ **Attach to Form 990 or 990-EZ.**

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

OMB No. 1545-0047

2020

Open to Public Inspection

Name of the organization
NEUROFIBROMATOSIS MIDWEST

Employer identification number
22-2580173

Return Reference	Explanation
FORM 990 - ORGANIZATION'S MISSION	TO IMPROVE THE LIVES OF CHILDREN, ADULTS, AND FAMILIES IMPACTED BY NEUROFIBROMATOSIS BY FOCUSING ON AND IMPROVING CLINICS, AWARENESS, RESEARCH, EDUCATION AND SUPPORT IN THE STATES OF ILLINOIS, INDIANA, IOWA, KENTUCKY, WISCONSIN, AND THE EASTERN HALF OF MISSOURI.
FORM 990, PAGE 6, PART VI, LINE 11B	THE ORGANIZATION'S PRINCIPAL OFFICER WILL REVIEW THE FEDERAL 990 AND IN ADDITION THE TREASURER AND PRESIDENT WILL REVIEW THE FEDERAL 990 PRIOR TO THE ACTUAL IRS FILING.
FORM 990, PAGE 6, PART VI, LINE 15A	THE BOARD OF DIRECTORS DETERMINE THE SALARIES ANNUALLY.
FORM 990, PAGE 6, PART VI, LINE 15B	THE BOARD OF DIRECTORS DETERMINE THE BASE SALARIES.
FORM 990, PAGE 6, PART VI, LINE 19	THE GOVERNING DOCUMENTS ARE AVAILABLE TO THE PUBLICE BY REQUEST,

Additional Data

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