

990

Return of Organization Exempt From Income Tax

OMB No. 1545-

0047 2022

Open to Public Inspection

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

Department of the Treasury Internal Revenue Service

A For the 2022 calendar year, or tax year beginning 01-01-2022, and ending 12-31-2022

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

C Name of organization: PHELAN MCDERMID SYNDROME FOUNDATION. Doing business as. Number and street (or P.O. box if mail is not delivered to street address): 8 Sorrento Drive. Room/suite. City or town, state or province, country, and ZIP or foreign postal code: Osprey, FL 34229

D Employer identification number: 04-3673104. E Telephone number: (941) 485-8000. G Gross receipts \$ 856,254

F Name and address of principal officer: Rhonda Blumenthal, 8 Sorrento Drive, Osprey, FL 34229

H(a) Is this a group return for subordinates? Yes No. H(b) Are all subordinates included? Yes No. H(c) Group exemption number

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

J Website: pmsf.org

K Form of organization: Corporation, Trust, Association, Other

L Year of formation: 2002. M State of legal domicile: FL

Part I Summary

Table with 4 main sections: Activities & Governance, Revenue, Expenses, and Net Assets or Fund Balances. Includes rows for mission statement, voting members, revenue, expenses, and assets.

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.

Signature of officer: Rhonda Blumenthal, Chief Executive Officer. Date: 2023-03-10

Paid Preparer Use Only. Fields for Preparer's name, signature, date, firm's name, EIN, and phone number.

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:

The mission of the Phelan-McDermid Syndrome Foundation is to improve the quality of life of people affected by Phelan-McDermid Syndrome worldwide by accelerating research, providing family support and raising awareness.

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 \$ **235,949** including grants of \$ **20,900**) (Revenue \$ **15,366**)

RESEARCH SUPPORT: The Phelan-McDermid Syndrome Foundation (PMSF) works closely with researchers, pharmacological companies, biotechnology, academic institutions, and other external scientists with the ultimate goal of finding effective treatments for Phelan-McDermid syndrome (PMS). The PMSF contributes to research by breaking down barriers to patient participation. We provide information and access to research opportunities as well as offer financial assistance for travel costs to certain research sites. We work with our international scientific advisory committee (SAC) to set strategic goals in research and science for the PMSF and to stay informed of international PMS projects and research.

4b (Code:) (Expenses \$ **160,847** including grants of \$ **0**) (Revenue \$ **19,009**)

FAMILY SUPPORT: The Phelan-McDermid Syndrome Foundation (PMSF) is the largest patient advocacy group (PAG) for Phelan-McDermid syndrome (PMS) in the world. The PMSF was established to provide critical information and support to empower families affected by this rare condition. The PMSF and our entire community of families, researchers, clinicians, and friends share everything we know about PMS and provide connections to a global community. We have created a worldwide virtual and local community. The PMSF receives daily contact from families, extended families, clinicians, and researchers through email, social media, phone, and other avenues. Every two years, families, researchers, clinicians, and others who support people with Phelan-McDermid syndrome come together at the International Family Conference to laugh, share and learn. Families report that the PMSF International Family Conference is life-changing. In non-conference years, the PMSF strives to create a virtual or in-person regional conference. We partner with a clinical care center in a major city and invite speakers to present their work to our families. The PMSF Regional REPs coordinate periodic in-person gatherings to help families create connections, share stories and support each other.

4c (Code:) (Expenses \$ **43,010** including grants of \$ **0**) (Revenue \$ **0**)

ADVOCACY AND AWARENESS: Everyone in the Phelan-McDermid community is an advocate who increases awareness, hope, and action toward our Foundation's mission. Our program goal is to raise awareness and to empower stakeholders to advocate for research, funding, support services, and legislative initiatives that improve the lives of everyone affected by PMS. This program is focused on sharing information and establishing partnerships within the medical, research, and corporate, pharmaceutical, and rare disease communities. Program objectives include (1) enlisting support in the advancement of research and research funding by participating in national and international forums focused on developing treatments, therapies, and cures for rare diseases. (2) Developing collaborations with national organizations focused in improving the quality of life and quality of services for people with disabilities and disseminating information to the PMS community. (3) Developing legislative priorities for the PMS community and working collaboratively with local, state, country and international bodies to share the PMS patient voice on legislative issues that affect our population.

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

(Expenses \$ **0** including grants of \$ **0**) (Revenue \$ **0**)

4e **Total program service expenses** **439,806**

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)? <i>If "Yes," complete Schedule A</i>	Yes	
2	Is the organization required to complete <i>Schedule B, Schedule of Contributors</i> ? See instructions.	Yes	
3	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? <i>If "Yes," complete Schedule C, Part I</i>		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? <i>If "Yes," complete Schedule C, Part II</i>		No
5	Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Rev. Proc. 98-19? <i>If "Yes," complete Schedule C, Part III</i>		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? <i>If "Yes," complete Schedule D, Part I</i>		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? <i>If "Yes," complete Schedule D, Part II</i>		No
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If "Yes," complete Schedule D, Part III</i>		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? <i>If "Yes," complete Schedule D, Part IV</i>		No
10	Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi endowments? <i>If "Yes," complete Schedule D, Part V</i>	Yes	
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? <i>If "Yes," complete Schedule D, Part VI</i>	Yes	
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? <i>If "Yes," complete Schedule D, Part VII</i>		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? <i>If "Yes," complete Schedule D, Part VIII</i>		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? <i>If "Yes," complete Schedule D, Part IX</i>		No
e	Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X</i>		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)?		No
12a	Did the organization obtain separate, independent audited financial statements for the tax year? <i>If "Yes," complete Schedule D, Parts XI and XII</i>	Yes	
b	Was the organization included in consolidated, independent audited financial statements for the tax year? <i>If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional</i>		No
13	Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E</i>		No
14a	Did the organization maintain an office, employees, or agents outside of the United States?		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? <i>If "Yes," complete Schedule F, Parts I and IV</i>		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? <i>If "Yes," complete Schedule F, Parts II and IV</i>		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? <i>If "Yes," complete Schedule F, Parts III and IV</i>		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? <i>If "Yes," complete Schedule G, Part I</i> . See instructions.		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? <i>If "Yes," complete Schedule G, Part II</i>	Yes	
19	Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? <i>If "Yes," complete Schedule G, Part III</i>		No
20a	Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H</i>		No
b	If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?		
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? <i>If "Yes," complete Schedule I, Parts I and II</i>	Yes	

Part IV Checklist of Required Schedules (continued)

Table with 3 columns: Question ID, Question Text, Yes, No. Rows include questions 22 through 38 regarding tax-exempt bond issues, excess benefit transactions, and controlled entities.

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

Table with 3 columns: Question ID, Question Text, Yes, No. Rows include questions 1a, 1b, and 1c regarding Form 1096, Forms W-2G, and backup withholding rules.

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

Form 990 (2022) Part V Statements Regarding Other IRS Filings and Tax Compliance (continued). Includes sections 2a through 17 with various questions and input fields.

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

Table with 3 columns: Question, Yes, No. Rows include: 1a Enter the number of voting members... 1b Enter the number of voting members... 2 Did any officer, director, trustee... 3 Did the organization delegate control... 4 Did the organization make any significant changes... 5 Did the organization become aware... 6 Did the organization have members... 7a Did the organization have members... 7b Are any governance decisions... 8 Did the organization contemporaneously document... 8a The governing body? 8b Each committee... 9 Is there any officer, director, trustee...

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

Table with 3 columns: Question, Yes, No. Rows include: 10a Did the organization have local chapters... 10b If "Yes," did the organization have written policies... 11a Has the organization provided a complete copy... 11b Describe on Schedule O the process... 12a Did the organization have a written conflict... 12b Were officers, directors, or trustees... 12c Did the organization regularly and consistently... 13 Did the organization have a written whistleblower... 14 Did the organization have a written document... 15 Did the process for determining compensation... 15a The organization's CEO... 15b Other officers or key employees... 16a Did the organization invest in, contribute... 16b If "Yes," did the organization follow a written...

Section C. Disclosure

- 17 List the states with which a copy of this Form 990 is required to be filed: AK, AL, AR, CA, CO, CT, DC, FL, GA, IL, KS, KY, MA, MD, ME, MI, MN, MO, MS, NC, ND, NH, NJ, NM, NV, NY, OH, OK, OR, PA, RI, SC, TN, UT, VA, WA, WI, WV
18 Section 6104 requires an organization to make its Form 1023 (1024 or 1024-A, if applicable), 990, and 990-T (section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.
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: Priscilla Hackstadt 8 Sorrento Drive Osprey, FL 34229 (941) 485-8000

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

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

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

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

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

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

- List the organization's five **current** highest compensated employees (other than an officer, director, trustee or key employee) who received reportable compensation (box 5 of Form W-2, box 6 of Form 1099-MISC, and/or box 1 of Form 1099-NEC) of more than \$100,000 from the organization and any related organizations.

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

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

(A) 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/1099-NEC)	(E) Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee;	Officer	Key employee	Highest compensated employee			
(1) Rhonda Blumenthal Chief Executive Officer	40 0			X	X		107,739	0	3,232
(2) Alycia Halladay President	5 0	X		X			0	0	0
(3) Denise Croden Vice President	5 0	X		X			0	0	0
(4) Michael O'Boyle Treasurer	5 0	X		X			0	0	0
(5) Heidi Grabenstatter Secretary	5 0	X		X			0	0	0
(6) Cynthia Schauss Director	5 0	X					0	0	0
(7) Chris Jauch Director	5 0	X					0	0	0
(8) Catherine Valcourt-Pearce Director	5 0	X					0	0	0
(9) Mike Fraunces Director	5 0	X					0	0	0
(10) Lisa Brown Director	5 0	X					0	0	0

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			0	
1b Membership dues			0	
1c Fundraising events			38,350	
1d Related organizations			0	
1e Government grants (contributions)			17,610	
1f All other contributions, gifts, grants, and similar amounts not included above			688,232	
1g Noncash contributions included in lines 1a - 1f:\$			0	
1g Total. Add lines 1a-1f				744,192

Program Service Revenue		Business Code				
			(A)	(B)	(C)	(D)
2a Registration fees		813212	19,009	19,009	0	0
b Store sales		453220	240	240	0	0
c Travel program reimbursement fees		813212	15,366	15,366	0	0
d						
e						
f All other program service revenue.			0	0	0	0
g Total. Add lines 2a-2f.			34,615			

Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)		-8,775	-8,775	0	0	
	4 Income from investment of tax-exempt bond proceeds		0	0	0	0	
	5 Royalties		0	0	0	0	
	6a Gross rents	(i) Real					
		(ii) Personal					
		6b Less: rental expenses					
		6c Rental income or (loss)		0	0		
	d Net rental income or (loss)						
	7a Gross amount from sales of assets other than inventory	(i) Securities					
		(ii) Other					
		7b Less: cost or other basis and sales expenses					
		7c Gain or (loss)		0	0		
	d Net gain or (loss)						
	8a Gross income from fundraising events (not including \$ 38,350 of contributions reported on line 1c). See Part IV, line 18		86,222				
		8b Less: direct expenses		2,606			
c Net income or (loss) from fundraising events			83,616		0	83,616	
9a Gross income from gaming activities. See Part IV, line 19							
	9b Less: direct expenses						
	c Net income or (loss) from gaming activities						
10a Gross sales of inventory, less returns and allowances							
	10b Less: cost of goods sold						
	c Net income or (loss) from sales of inventory						

Other Revenue Misc Amt		Business Code				
			(A)	(B)	(C)	(D)
11a						
b						
c						
d All other revenue						
e Total. Add lines 11a-11d			0			
12 Total revenue. See instructions			853,648	25,840	0	83,616

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	20,900	20,900		
2 Grants and other assistance to domestic individuals. See Part IV, line 22	0	0		
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16.	0	0		
4 Benefits paid to or for members	0	0		
5 Compensation of current officers, directors, trustees, and key employees	108,000	64,800	21,600	21,600
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	297,525	167,403	62,392	67,730
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	10,503	6,201	2,578	1,724
9 Other employee benefits	642	0	642	
10 Payroll taxes	31,770	18,551	6,375	6,844
11 Fees for services (non-employees):				
a Management				
b Legal				
c Accounting				
d Lobbying				
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)	56,156	31,376	14,351	10,429
12 Advertising and promotion	5,571	3,725		1,846
13 Office expenses	25,332	4,507	9,890	10,935
14 Information technology	53,056	29,595	8,086	15,375
15 Royalties				
16 Occupancy	6,900		6,900	
17 Travel	36,692	36,633	59	
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	55,867	55,378		489
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization				
23 Insurance	5,394	187	5,207	
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				
b				
c				
d				
e All other expenses	955	550	70	335
25 Total functional expenses. Add lines 1 through 24e	715,263	439,806	138,150	137,307
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 <input type="checkbox"/> 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	1,352,848	1	1,550,551
	2 Savings and temporary cash investments		2	
	3 Pledges and grants receivable, net		3	
	4 Accounts receivable, net	10,000	4	
	5 Loans and other receivables from any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		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	3,036	9	3,937
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	13,017		
	b Less: accumulated depreciation	13,017	0	0
	11 Investments—publicly traded securities	574,500	11	559,432
	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		15	
16 Total assets: Add lines 1 through 15 (must equal line 33)	1,940,384	16	2,113,920	
Liabilities	17 Accounts payable and accrued expenses	24,329	17	48,845
	18 Grants payable		18	
	19 Deferred revenue		19	10,635
	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	24,329	26	59,480
Net Assets or Fund Balances	Organizations that follow FASB ASC 958, check here <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33.			
	27 Net assets without donor restrictions	1,915,050	27	2,054,440
	28 Net assets with donor restrictions	1,005	28	0
	Organizations that do not follow FASB ASC 958, check here <input type="checkbox"/> 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	1,916,055	32	2,054,440
33 Total liabilities and net assets/fund balances	1,940,384	33	2,113,920	

Part XI Reconciliation of Net Assets

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	853,648
2	Total expenses (must equal Part IX, column (A), line 25)	2	715,263
3	Revenue less expenses. Subtract line 2 from line 1	3	138,385
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	1,916,055
5	Net unrealized gains (losses) on investments	5	0
6	Donated services and use of facilities	6	0
7	Investment expenses	7	0
8	Prior period adjustments	8	0
9	Other changes in net assets or fund balances (explain in Schedule O)	9	0
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (A))	10	2,054,440

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: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other _____ If the organization changed its method of accounting from a prior year or checked "Other," explain on Schedule O.		
2a	Were the organization's financial statements compiled or reviewed by an independent accountant? If 'Yes,' check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both: <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		No
b	Were the organization's financial statements audited by an independent accountant? If 'Yes,' check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both: <input checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis	Yes	
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? If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O.	Yes	
3a	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Uniform Guidance, 2 C.F.R. Part 200, Subpart F?		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.		

Additional Data

[Return to Form](#)

Software ID: 22015720

Software Version: v1.00

Form 990, Special Condition Description:

Special Condition Description

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.**

Name of the organization
PHELAN MCDERMID SYNDROME FOUNDATION

Employer identification number
04-3673104

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).)
- 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 on 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?		(v) Amount of monetary support (see instructions)	(vi) Amount of other support (see instructions)
			Yes	No		
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) 2018	(b) 2019	(c) 2020	(d) 2021	(e) 2022	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grant.") . . .	625,444	477,942	471,225	758,981	744,192	3,077,784
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	625,444	477,942	471,225	758,981	744,192	3,077,784
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.						3,077,784

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2018	(b) 2019	(c) 2020	(d) 2021	(e) 2022	(f) Total
7 Amounts from line 4.	625,444	477,942	471,225	758,981	744,192	3,077,784
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	-2,368	6,163	886	123	-8,775	-3,971
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.)	541,843	172,279	88,089	137,898	118,231	1,058,340
11 Total support. Add lines 7 through 10						4,132,153
12 Gross receipts from related activities, etc. (see instructions)					12	
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						<input type="checkbox"/>

Section C. Computation of Public Support Percentage

14 Public support percentage for 2022 (line 6, column (f) divided by line 11, column (f))	14	74.484 %
15 Public support percentage for 2020 Schedule A, Part II, line 14	15	62.241 %
16a 33 1/3% support test—2022. 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	<input checked="" type="checkbox"/>	
b 33 1/3% support test—2021. 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	<input type="checkbox"/>	
17a 10%-facts-and-circumstances test—2022. 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	<input type="checkbox"/>	
b 10%-facts-and-circumstances test—2021. 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	<input type="checkbox"/>	
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	<input type="checkbox"/>	

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

Table with 7 columns: (a) 2018, (b) 2019, (c) 2020, (d) 2021, (e) 2022, (f) Total. Rows include: 1 Gifts, grants, contributions, and membership fees received; 2 Gross receipts from admissions, merchandise sold or services performed; 3 Gross receipts from activities that are not an unrelated trade or business; 4 Tax revenues levied for the organization's benefit; 5 The value of services or facilities furnished by a governmental unit; 6 Total; 7a Amounts included on lines 1, 2, and 3 received from disqualified persons; 7b Amounts included on lines 2 and 3 received from other than disqualified persons; 8 Public support.

Section B. Total Support

Table with 7 columns: (a) 2018, (b) 2019, (c) 2020, (d) 2021, (e) 2022, (f) Total. Rows include: 9 Amounts from line 6; 10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources; 10b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975; 11 Net income from unrelated business activities not included on line 10b; 12 Other income; 13 Total support; 14 First 5 years.

Section C. Computation of Public Support Percentage

Table with 2 columns: Description, Percentage. Row 15: Public support percentage for 2022; Row 16: Public support percentage from 2021 Schedule A, Part III, line 15.

Section D. Computation of Investment Income Percentage

Table with 2 columns: Description, Percentage. Row 17: Investment income percentage for 2022; Row 18: Investment income percentage from 2021 Schedule A, Part III, line 17; Row 19a: 33 1/3% support tests-2022; Row 19b: 33 1/3% support tests-2021; Row 20: Private foundation.

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.		
2	Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? If "Yes," explain in Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).		
3a	Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? If "Yes," answer lines 3b and 3c below.		
b	Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? If "Yes," describe in Part VI when and how the organization made the determination.		
c	Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? If "Yes," explain in Part VI what controls the organization put in place to ensure such use.		
4a	Was any supported organization not organized in the United States ("foreign supported organization")? If "Yes" and if you checked box 12a or 12b in Part I, answer lines 4b and 4c below.		
b	Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? If "Yes," describe in Part VI how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.		
c	Did the organization support any foreign supported organization that does not have an IRS determination under sections 501(c)(3) and 509(a)(1) or (2)? If "Yes," explain in Part VI what controls the organization used to ensure that all support to the foreign supported organization was used exclusively for section 170(c)(2)(B) purposes.		
5a	Did the organization add, substitute, or remove any supported organizations during the tax year? If "Yes," answer lines 5b and 5c below (if applicable). Also, provide detail in Part VI , including (i) the names and EIN numbers of the supported organizations added, substituted, or removed; (ii) the reasons for each such action; (iii) the authority under the organization's organizing document authorizing such action; and (iv) how the action was accomplished (such as by amendment to the organizing document).		
b	Type I or Type II only. Was any added or substituted supported organization part of a class already designated in the organization's organizing document?		
c	Substitutions only. Was the substitution the result of an event beyond the organization's control?		
6	Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? If "Yes," provide detail in Part VI .		
7	Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? If "Yes," complete Part I of Schedule L (Form 990).		
8	Did the organization make a loan to a disqualified person (as defined in section 4958) not described on line 7? If "Yes," complete Part I of Schedule L (Form 990).		
9a	Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons, as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? If "Yes," provide detail in Part VI .		
b	Did one or more disqualified persons (as defined on line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? If "Yes," provide detail in Part VI .		
c	Did a disqualified person (as defined on line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? If "Yes," provide detail in Part VI .		
10a	Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? If "Yes," answer line 10b below.		
b	Did the organization have any excess business holdings in the tax year? (Use Schedule C, Form 4720, to determine whether the organization had excess business holdings).		

Part IV Supporting Organizations (continued)

- 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 on lines 11b and 11c below, the governing body of a supported organization?
 - b** A family member of a person described on 11a above?
 - c** A 35% controlled entity of a person described on line 11a or 11b above? *If "Yes" to 11a, 11b, or 11c, provide detail in Part VI*

	Yes	No
11a		
11b		
11c		

Section B. Type I Supporting Organizations

- 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.*
- 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.*

	Yes	No
1		
2		

Section C. Type II Supporting Organizations

- 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).*

	Yes	No
1		

Section D. All Type III Supporting Organizations

- 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?
- 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).*
- 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.*

	Yes	No
1		
2		
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.**

- a** Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? *If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.*
- b** Did the activities described on line 2a, above constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? *If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.*

	Yes	No
2a		
2b		
3a		
3b		

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

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

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 (<i>explain in detail in Part VI</i>): | | | |
| 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 2022 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-2022	(iii) Distributable Amount for 2022
1 Distributable amount for 2022 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2022 (reasonable cause required-- explain in Part VI). See instructions.			
3 Excess distributions carryover, if any, to 2022:			
a From 2017.			
b From 2018.			
c From 2019.			
d From 2020.			
e From 2021.			
f Total of lines 3a through e			
g Applied to underdistributions of prior years			
h Applied to 2022 distributable amount			
i Carryover from 2017 not applied (see instructions)			
j Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
4 Distributions for 2022 from Section D, line 7: \$			
a Applied to underdistributions of prior years			
b Applied to 2022 distributable amount			
c Remainder. Subtract lines 4a and 4b from line 4.			
5 Remaining underdistributions for years prior to 2022, 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 2022. 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 2023. Add lines 3j and 4c.			
8 Breakdown of line 7:			
a Excess from 2018.			
b Excess from 2019.			
c Excess from 2020.			
d Excess from 2021.			
e Excess from 2022.			

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
Schedule A, Part II, Line 10	Net income from fundraising events, program income from registration fees and contracts

Additional Data

Return to Form

Software ID: 22015720

Software Version: v1.00

Schedule B

Schedule of Contributors

OMB No. 1545-0047

(Form 990)
Department of the Treasury
Internal Revenue Service

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

2022

Name of the organization PHELAN MCDERMID SYNDROME FOUNDATION	Employer identification number 04-3673104
---	--

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 33¹/₃% 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
 PHELAN MCDERMID SYNDROME FOUNDATION

Employer identification number
 04-3673104

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

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
RESTRICTED		\$ RESTRICTED	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)

Name of organization
 PHELAN MCDERMID SYNDROME FOUNDATION

Employer identification number
 04-3673104

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
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____

Name of organization
 PHELAN MCDERMID SYNDROME FOUNDATION

Employer identification number
 04-3673104

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

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Supplemental Financial Statements

2022

Open to Public Inspection

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

Attach to Form 990.

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

Department of the Treasury Internal Revenue Service

Name of the organization PHELAN MCDERMID SYNDROME FOUNDATION

Employer identification number

04-3673104

Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts.

Complete if the organization answered "Yes" on Form 990, Part IV, line 6.

Table with 2 columns: (a) Donor advised funds, (b) Funds and other accounts. Rows include total number at end of year, aggregate value of contributions, grants, and end of year, and two questions about donor/donor advisor notification.

Part II Conservation Easements.

Complete if the organization answered "Yes" on Form 990, Part IV, line 7.

Table with 2 columns: Description, Held at the End of the Year. Rows include purpose(s) of conservation easements, number of easements, acreage, and other details.

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets.

Complete if the organization answered "Yes" on Form 990, Part IV, line 8.

Table with 2 columns: Description, Amount. Rows include questions about reporting art, historical treasures, or other similar assets.

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets (continued)

- 3** Using the organization's acquisition, accession, and other records, check any of the following that are a significant use of its collection items (check all that apply):
- a** Public exhibition
 - b** Scholarly research
 - c** Preservation for future generations
 - d** Loan or exchange programs
 - e** Other
- 4** Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII.
- 5** During the year, did the organization solicit or receive donations of art, historical treasures or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection? . . . **Yes** **No**

Part IV Escrow and Custodial Arrangements.

Complete if the organization answered "Yes" on Form 990, Part IV, line 9, or reported an amount on Form 990, Part X, line 21.

- 1a** Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X? **Yes** **No**
- b** If "Yes," explain the arrangement in Part XIII and complete the following table:
- | | Amount |
|--|-----------|
| c Beginning balance | 1c |
| d Additions during the year | 1d |
| e Distributions during the year | 1e |
| f Ending balance | 1f |
- 2a** Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability? **Yes** **No**
- b** If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided in Part XIII

Part V Endowment Funds.

Complete if the organization answered "Yes" on Form 990, Part IV, line 10.

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1a Beginning of year balance	0	0	37,367	32,588	36,577
b Contributions	0	0	0	0	0
c Net investment earnings, gains, and losses	0	0	-1,592	6,339	-2,383
d Grants or scholarships	0	0	35,693	1,384	1,349
e Other expenditures for facilities and programs	0	0	0	0	0
f Administrative expenses	0	0	82	176	257
g End of year balance	0	0	0	37,367	32,588

- 2** Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
- a** Board designated or quasi-endowment ▶ 100 %
 - b** Permanent endowment ▶ 0 %
 - c** Term endowment ▶ 0 %
- The percentages on lines 2a, 2b, and 2c should equal 100%.

- 3a** Are there endowment funds not in the possession of the organization that are held and administered for the organization by:
- | | Yes | No |
|--|--------|----|
| (i) Unrelated organizations | 3a(i) | No |
| (ii) Related organizations | 3a(ii) | No |
| b If "Yes" on 3a(ii), are the related organizations listed as required on Schedule R? | 3b | |
- 4** Describe in Part XIII the intended uses of the organization's endowment funds.

Part VI Land, Buildings, and Equipment.

Complete if the organization answered "Yes" on Form 990, Part IV, line 11a. See Form 990, Part X, line 10.

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land	0	0		0
b Buildings	0	0	0	0
c Leasehold improvements	0	0	0	0
d Equipment	0	13,017	13,017	0
e Other	0	0	0	0
Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c).) . . . ▶				0

Part VII Investments - Other Securities.

Complete if the organization answered "Yes" on Form 990, Part IV, line 11b. See Form 990, Part X, line 12.

(a) Description of security or category (including name of security)	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1) Financial derivatives		
(2) Closely-held equity interests		
(3) Other _____		
(A)		
(B)		
(C)		
(D)		
(E)		
(F)		
(G)		
(H)		
Total. (Column (b) must equal Form 990, Part X, col. (B) line 12.)		

Part VIII Investments - Program Related.

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

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

Part IX Other Assets.

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

(a) Description	(b) Book value
(1)	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (Column (b) must equal Form 990, Part X, col.(B) line 15.)	

Part X Other Liabilities.

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

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

2. Liability for uncertain tax positions. In Part XIII, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FIN 48 (ASC 740). Check here if the text of the footnote has been provided in Part XIII

Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per Return.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 12a.

1	Total revenue, gains, and other support per audited financial statements		1	856,254
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
a	Net unrealized gains (losses) on investments	2a	0	
b	Donated services and use of facilities	2b	0	
c	Recoveries of prior year grants	2c	0	
d	Other (Describe in Part XIII.)	2d	0	
e	Add lines 2a through 2d			2e 0
3	Subtract line 2e from line 1			3 856,254
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	0	
b	Other (Describe in Part XIII.)	4b	-2,606	
c	Add lines 4a and 4b			4c -2,606
5	Total revenue. Add lines 3 and 4c . (This must equal Form 990, Part I, line 12.)			5 853,648

Part XII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 12a.

1	Total expenses and losses per audited financial statements		1	717,869
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
a	Donated services and use of facilities	2a	0	
b	Prior year adjustments	2b	0	
c	Other losses	2c	0	
d	Other (Describe in Part XIII.)	2d	0	
e	Add lines 2a through 2d			2e 0
3	Subtract line 2e from line 1			3 717,869
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	0	
b	Other (Describe in Part XIII.)	4b	-2,606	
c	Add lines 4a and 4b			4c -2,606
5	Total expenses. Add lines 3 and 4c . (This must equal Form 990, Part I, line 18.)			5 715,263

Part XIII**Supplemental Information**

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

Return Reference	Explanation
Schedule D, Part V, Line 4	The organization will use the quasi-endowment funds which were liquidated in 2020 in specific program initiatives.
Schedule D, Part XI, Line 4b	Fundraising event expenses netted against event revenue
Schedule D, Part XII, Line 4b	Fundraising event expenses netted against event revenue

Additional Data

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**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.

Name of the organization
PHELAN MCDERMID SYNDROME FOUNDATION

Employer identification number
 04-3673104

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 <input type="checkbox"/> Mail solicitations | e <input type="checkbox"/> Solicitation of non-government grants |
| b <input type="checkbox"/> Internet and email solicitations | f <input type="checkbox"/> Solicitation of government grants |
| c <input type="checkbox"/> Phone solicitations | g <input type="checkbox"/> Special fundraising events |
| d <input type="checkbox"/> In-person solicitations | |
- 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.

		(a) Event #1 <u>Phelan Lucky</u> (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	117,656			117,656
	2 Less: Contributions	35,092			35,092
	3 Gross income (line 1 minus line 2)	82,564			82,564
Direct Expenses	4 Cash prizes	0			0
	5 Noncash prizes	0			0
	6 Rent/facility costs	0			0
	7 Food and beverages	0		0	0
	8 Entertainment	0		0	0
	9 Other direct expenses	1,246			1,246
	10 Direct expense summary. Add lines 4 through 9 in column (d) ▶				1,246
11 Net income summary. Subtract line 10 from line 3, column (d) ▶				81,318	

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.

		(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	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> 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

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

**Schedule I
(Form 990)**

**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

2022

**Open to Public
Inspection**

Department of the
Treasury
Internal Revenue Service

Name of the organization
PHELAN MCDERMID SYNDROME FOUNDATION

Employer identification number
04-3673104

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) Icahn School of Medicine at Mount Sinai One Gustave L Levy Place Box 1075 New York, NY 10029	13-6171197	501(c)(#)	20,900				To define and retrospectively characterize the neurobehavioral profile of individuals with Phelan-McDermid syndrome and neuropsychiatric decompensation. To develop clinician and caregiver survey tools for qualitative assessment of clinical outcomes based on recommendations from the Phelan-McDermid syndrome Neuropsychiatric Consultation Group.

- 2** Enter total number of section 501(c)(3) and government organizations listed in the line 1 table 1
- 3** Enter total number of other organizations listed in the line 1 table 0

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
Schedule I, Part I, Line 2	PMSF verifies 501(c)(3) status with those it grants funding to and stipulates that the funds are to be used for the benefit or programs that support individuals with Phelan-McDermid syndrome and their families. Also, the organization has a scientific director and scientific advisory committee that review all grant requests and grant contract awards. The deliverables and expectations set forth in the executed awards may vary according to the size and circumstances of the grant contract.

Additional Data

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SCHEDULE O
(Form 990)Department of the Treasury
Internal Revenue Service**Supplemental Information to Form 990 or 990-EZ****Complete to provide information for responses to specific questions on
Form 990 or 990-EZ or to provide any additional information.****▶ Attach to Form 990 or 990-EZ.****▶ Go to www.irs.gov/Form990 for the latest information.**

OMB No. 1545-0047

2022**Open to Public
Inspection**Name of the organization
PHELAN MCDERMID SYNDROME FOUNDATION**Employer identification number**

04-3673104

Return Reference	Explanation
Form 990, Part VI, Section B, Line 11b	Form 990 and any required supplemental schedules are reviewed in draft form by the finance committee. Finance committee approves and recommends that the board accept the draft of the 990. Board members are provided a draft of the 990 and allowed one week to comment, request changes, and ask questions, after which time the 990 is filed electronically.
Form 990, Part VI, Section B, Line 12c	Board members, committee chairs, and other key volunteers are required to sign an annual statement acknowledging they have received a written conflict of interest policy and are in compliance with the policy.
Form 990, Part VI, Section B, Line 15	Board determines compensation of Chief Executive Officer as part of annual budgeting process for entire organization. Salary of CEO falls within range that would be considered reasonable, given comparability data of other similar organization. Board president performs annual review of CEO. Note that independent review and approval as well as comparability data used is documented in board minutes whenever a salary change is made. CEO determines compensation of other key staff as part of annual budgeting process for entire organization. Salary of these staff people fall within the range that would be considered reasonable given comparability data of other similar organizations.
Form 990, Part VI, Section C, Line 19	The organization makes its audited financial statements and form 990s available on its website. Other documents are made available upon request.

Additional Data

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