

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
2018
Open to Public Inspection

A For the 2019 calendar year, or tax year beginning 01-01-2018, and ending 12-31-2018

- 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 INC

Doing business as

Number and street (or P O box if mail is not delivered to street address) Room/suite
200 CAPRI ISLES BOULEVARD

City or town, state or province, country, and ZIP or foreign postal code
VENICE, FL 34292

D Employer identification number
04-3673104

E Telephone number
(941) 485-8000

G Gross receipts \$ 1,201,176

F Name and address of principal officer
200 CAPRI ISLES BOULEVARD 7F
VENICE, FL 34292

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.PMSF.ORG

K Form of organization Corporation Trust Association Other ▶

L Year of formation 2002

M State of legal domicile FL

Part I Summary

1 Briefly describe the organization's mission or most significant activities
THE MISSION OF 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 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)	8
4 Number of independent voting members of the governing body (Part VI, line 1b)	7
5 Total number of individuals employed in calendar year 2018 (Part V, line 2a)	10
6 Total number of volunteers (estimate if necessary)	250
7a Total unrelated business revenue from Part VIII, column (C), line 12	0
7b Net unrelated business taxable income from Form 990-T, line 34	

	Prior Year	Current Year
8 Contributions and grants (Part VIII, line 1h)	434,983	659,602
9 Program service revenue (Part VIII, line 2g)	648,234	473,175
10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)	5,651	-2,367
11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	74,131	68,668
12 Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)	1,162,999	1,199,078
13 Grants and similar amounts paid (Part IX, column (A), lines 1-3)	108,750	11,394
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)	203,698	314,298
16a Professional fundraising fees (Part IX, column (A), line 11e)		0
b Total fundraising expenses (Part IX, column (D), line 25) ▶49,338		
17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	806,817	573,728
18 Total expenses Add lines 13-17 (must equal Part IX, column (A), line 25)	1,119,265	899,420
19 Revenue less expenses Subtract line 18 from line 12	43,734	299,658
	Beginning of Current Year	End of Year
20 Total assets (Part X, line 16)	1,197,242	1,423,117
21 Total liabilities (Part X, line 26)	163,062	89,279
22 Net assets or fund balances Subtract line 21 from line 20	1,034,180	1,333,838

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: 2019-06-19
SUSAN LOMAS President Type or print name and title

Paid Preparer Use Only
Print/Type preparer's name: Preparer's signature: Date: Check if self-employed PTIN: P00545346
Firm's name: WHITTAKER & ASSOCIATES CPAS PA Firm's EIN: 59-2845665
Firm's address: 304 WEST VENICE AVENUE SUITE 300 VENICE, FL 34285 Phone no: (941) 493-5299

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 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 \$ 405,383 including grants of \$) (Revenue \$ 397,240)
See Additional Data

4b (Code) (Expenses \$ 170,323 including grants of \$ 6,035) (Revenue \$ 75,935)
See Additional Data

4c (Code) (Expenses \$ 49,403 including grants of \$) (Revenue \$)
See Additional Data

4d Other program services (Describe in Schedule O)
(Expenses \$ 45,798 including grants of \$ 5,359) (Revenue \$)

4e Total program service expenses ▶ 670,907

Part IV Checklist of Required Schedules

Table with 3 columns: Question ID, Question Text, Yes, No. Rows include questions 1 through 22 regarding organizational requirements, such as political activities, lobbying, and financial reporting.

Part IV Checklist of Required Schedules (continued)

Table with 3 columns: Question ID, Question Text, and Yes/No columns. Rows include questions 23 through 38 regarding compensation, bond issues, escrow accounts, 501(c)(3) organizations, and other IRS filings.

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, and Yes/No columns. Rows include questions 1a, 1b, and 1c regarding Form 1096, Forms W-2G, and backup withholding rules.

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	10		
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? <i>If "No" to line 3b, provide an explanation in Schedule O</i>		3b			No
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			No
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			No
d If "Yes," indicate the number of Forms 8282 filed during the year		7d			0
e Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?		7e			No
f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?		7f			No
g If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?		7g			No
h If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?		7h			No
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			No
9a Did the sponsoring organization make any taxable distributions under section 4966?		9a			No
b Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?		9b			No
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			No
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			No
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? <i>If "No," provide an explanation in Schedule O</i>		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? If "Yes," see instructions and file Form 4720, Schedule N		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

Table with 3 columns: Question, Yes, No. Rows include: 1a Enter the number of voting members of the governing body at the end of the tax year (8); 1b Enter the number of voting members included in line 1a, above, who are independent (7); 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? (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? (No); 4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed? (No); 5 Did the organization become aware during the year of a significant diversion of the organization's assets? (No); 6 Did the organization have members or stockholders? (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? (No); 7b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body? (No); 8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following: a The governing body? (Yes); b Each committee with authority to act on behalf of the governing body? (No); 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 (No).

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, branches, or affiliates? (No); 10b 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?; 11a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? (Yes); 11b 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 (Yes); 12b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? (Yes); 12c Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done (Yes); 13 Did the organization have a written whistleblower policy? (No); 14 Did the organization have a written document retention and destruction policy? (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 (Yes); b Other officers or key employees of the organization (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? (No); 16b 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?

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, FL, IL, KS, KY, MA, MD, MI, MN, MS, NC, ND, NH, NJ, NM, OK, OR, PA, RI, SC, TN, UT, VA, WI, WV
- 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, [X] 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: PRISCILLA HACKSTADT 200 CAPRI ISLES BOULEVARD SUITE 7F VENICE, FL 34292 (941) 485-8000

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	34,158		
	d Related organizations	1d			
	e Government grants (contributions)	1e			
	f All other contributions, gifts, grants, and similar amounts not included above	1f	625,444		
	g Noncash contributions included in lines 1a - 1f \$		3,700		
	h Total. Add lines 1a-1f		659,602		

Program Service Revenue			Business Code				
	2a CONTRACTUAL INCOME			397,240	397,240		
	b OTH PROG INC-STORE			19,034	19,034		
	c SYMPOSIUM REG FEES			56,901	56,901		
	d _____						
	e _____						
	f All other program service revenue						
g Total. Add lines 2a-2f			473,175				

Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)			-2,367			-2,367
	4 Income from investment of tax-exempt bond proceeds			0			
	5 Royalties			0			
	6a Gross rents	(i) Real	(ii) Personal				
	b Less rental expenses						
	c Rental income or (loss)						
	d Net rental income or (loss)			0			
	7a Gross amount from sales of assets other than inventory	(i) Securities	(ii) Other				
	b Less cost or other basis and sales expenses						
	c Gain or (loss)						
	d Net gain or (loss)			0			
	8a Gross income from fundraising events (not including \$ 34,158 of contributions reported on line 1c) See Part IV, line 18	a		70,766			
	b Less direct expenses	b		2,098			
	c Net income or (loss) from fundraising events			68,668			65,528
	9a Gross income from gaming activities See Part IV, line 19	a					
b Less direct expenses	b						
c Net income or (loss) from gaming activities			0				
10a Gross sales of inventory, less returns and allowances	a						
b Less cost of goods sold	b						
c Net income or (loss) from sales of inventory			0				
Miscellaneous Revenue		Business Code					
11a _____							
b _____							
c _____							
d All other revenue							
e Total. Add lines 11a-11d			0				
12 Total revenue. See Instructions			1,199,078	473,175		63,161	

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

	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.				
1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21.	5,359	5,359		
2 Grants and other assistance to domestic individuals. See Part IV, line 22.	6,035	6,035		
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, line 15 and 16.	0			
4 Benefits paid to or for members.	0			
5 Compensation of current officers, directors, trustees, and key employees.	83,222	25,055	36,204	21,963
6 Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B).	44,288	14,172	30,116	
7 Other salaries and wages.	163,881	110,284	40,854	12,743
8 Pension plan accruals and contributions (include section 401 (k) and 403(b) employer contributions).	0			
9 Other employee benefits.	0			
10 Payroll taxes.	22,907	11,445	9,054	2,408
11 Fees for services (non-employees):				
a Management.	0			
b Legal.	0			
c Accounting.	0			
d Lobbying.	30,076	30,076		
e Professional fundraising services. See Part IV, line 17.	0			
f Investment management fees.	0			
g Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O).	310,494	298,055	6,346	6,093
12 Advertising and promotion.	21,254	21,002	100	152
13 Office expenses.	25,865	6,398	18,736	731
14 Information technology.	40,205	26,420	8,969	4,816
15 Royalties.	0			
16 Occupancy.	13,619		13,619	
17 Travel.	24,023	16,743	6,848	432
18 Payments of travel or entertainment expenses for any federal, state, or local public officials.	0			
19 Conferences, conventions, and meetings.	99,513	98,978	535	
20 Interest.	0			
21 Payments to affiliates.	0			
22 Depreciation, depletion, and amortization.	1,400		1,400	
23 Insurance.	5,798		5,798	
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 MISCELLANEOUS	1,481	885	596	
b				
c				
d				
e All other expenses	0			
25 Total functional expenses. Add lines 1 through 24e.	899,420	670,907	179,175	49,338
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	200,618	1	1,182,531
	2 Savings and temporary cash investments	787,360	2	0
	3 Pledges and grants receivable, net		3	40,000
	4 Accounts receivable, net	151,196	4	77,321
	5 Loans and other receivables from current and former officers, directors, trustees, key employees, and highest compensated employees Complete Part II of Schedule L		5	0
	6 Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing employers and sponsoring organizations of section 501(c)(9) voluntary employees' beneficiary organizations (see instructions) Complete Part II of Schedule L		6	0
	7 Notes and loans receivable, net		7	0
	8 Inventories for sale or use		8	0
	9 Prepaid expenses and deferred charges	10,384	9	3,029
	10a Land, buildings, and equipment cost or other basis Complete Part VI of Schedule D	13,017		
	b Less accumulated depreciation	11,110	3,307	10c 1,907
	11 Investments—publicly traded securities		11	0
	12 Investments—other securities See Part IV, line 11		12	0
	13 Investments—program-related See Part IV, line 11		13	0
	14 Intangible assets		14	0
	15 Other assets See Part IV, line 11	44,377	15	118,329
16 Total assets. Add lines 1 through 15 (must equal line 34)	1,197,242	16	1,423,117	
Liabilities	17 Accounts payable and accrued expenses	142,062	17	89,279
	18 Grants payable	21,000	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 current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons Complete Part II of Schedule L		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	163,062	26	89,279
Net Assets or Fund Balances	27 Organizations that follow SFAS 117 (ASC 958), check here <input checked="" type="checkbox"/> and complete lines 27 through 29, and lines 33 and 34. Unrestricted net assets	1,025,303	27	1,278,016
	28 Temporarily restricted net assets	8,877	28	55,822
	29 Permanently restricted net assets		29	
	30 Organizations that do not follow SFAS 117 (ASC 958), check here <input type="checkbox"/> and complete lines 30 through 34. Capital stock or trust principal, or current funds		30	
	31 Paid-in or capital surplus, or land, building or equipment fund		31	
	32 Retained earnings, endowment, accumulated income, or other funds		32	
	33 Total net assets or fund balances	1,034,180	33	1,333,838
	34 Total liabilities and net assets/fund balances	1,197,242	34	1,423,117

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	1,199,078
2	Total expenses (must equal Part IX, column (A), line 25)	2	899,420
3	Revenue less expenses Subtract line 2 from line 1	3	299,658
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	1,034,180
5	Net unrealized gains (losses) on investments	5	
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 33, column (B))	10	1,333,838

Part XII Financial Statements and Reporting

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

- 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?
 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?
 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?
 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?
- 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

	Yes	No
2a		No
2b	Yes	
2c	Yes	
3a		No
3b		

Additional Data

Software ID: 18007218

Software Version: 2018v3.1

EIN: 04-3673104

Name: PHELAN-MCDERMID SYNDROME FOUNDATION INC

Form 990 (2018)

Form 990, Part III, Line 4a:

The Phelan Mc-Dermid Syndrome International Registry (PMSIR) To move from basic laboratory research to meaningful therapies and treatments related to Phelan-McDermid Syndrome (PMS), the PMSF funds the PMSIR. The PMSIR is important for characterizing and understanding PMS better and provides valuable information for families and doctors to make the best care decisions possible. It is also a tool to help researchers find patients who might be a good match for their studies. In 2014, PMSF entered into a contract with the Patient-Centered Outcomes Research Institute and Harvard Medical School to foster research that more accurately defines genotype (genetics) and phenotype (characteristics) of Phelan-McDermid Syndrome. Since its inception, this contract has provided significant funding to the PMSIR.

Form 990, Part III, Line 4b:

2018 International Family Conference and McPosium In July 2018, 627 Attendees representing approximately 183 families and 9 countries came to a 3-day conference featuring educational sessions, meetings and opportunities for families to connect in person to share and learn from each other. The McPosium was a discrete event during the conference, taking place over two half-days and consisted of 6 sessions of topics of high priority to the patient and caregiver community of PMS in an interactive format

Form 990, Part III, Line 4c:

Other Family Support programs The PMSF creates programs to improve the quality of life of parents, families, caregivers and individuals with PMS through effectively understanding and addressing their needs and strengthening family-to-family and regional supports The PMSF also assists related international associations in supporting their families in many areas, including advocacy and research

SCHEDULE A
(Form 990 or 990-EZ)

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 the latest information.

OMB No 1545-0047

2018

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

Name of the organization

PHELAN-MCDERMID SYNDROME FOUNDATION INC

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 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?		(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), 170(b)(1)(A)(vi), and 170(b)(1)(A)(ix)

(Complete only if you checked the box on line 5, 7, 8, or 9 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

	Calendar year (or fiscal year beginning in) ▶	(a) 2014	(b) 2015	(c) 2016	(d) 2017	(e) 2018	(f) Total
1	Gifts, grants, contributions, and membership fees received (Do not include any "unusual grant.")	456,730	446,650	574,693	424,060	625,444	2,527,577
2	Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						0
3	The value of services or facilities furnished by a governmental unit to the organization without charge						0
4	Total. Add lines 1 through 3	456,730	446,650	574,693	424,060	625,444	2,527,577
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)						0
6	Public support. Subtract line 5 from line 4						2,527,577

Section B. Total Support

	Calendar year (or fiscal year beginning in) ▶	(a) 2014	(b) 2015	(c) 2016	(d) 2017	(e) 2018	(f) Total
7	Amounts from line 4	456,730	446,650	574,693	424,060	625,444	2,527,577
8	Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	2,912	-898	2,564	5,651	-2,368	7,861
9	Net income from unrelated business activities, whether or not the business is regularly carried on						0
10	Other income Do not include gain or loss from the sale of capital assets (Explain in Part VI.)				74,131	68,668	142,799
11	Total support. Add lines 7 through 10						2,678,237
12	Gross receipts from related activities, etc. (see instructions)					12	

13 First five 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 2018 (line 6, column (f) divided by line 11, column (f))	14	94.370%
15	Public support percentage for 2017 Schedule A, Part II, line 14	15	96.020%

16a 33 1/3% support test—2018. 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—2017.** 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—2018.** 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—2017.** 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) 2014	(b) 2015	(c) 2016	(d) 2017	(e) 2018	(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) 2014	(b) 2015	(c) 2016	(d) 2017	(e) 2018	(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 five 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 2018 (line 8, column (f) divided by line 13, column (f))	15	
16	Public support percentage from 2017 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage

17	Investment income percentage for 2018 (line 10c, column (f) divided by line 13, column (f))	17	
18	Investment income percentage from 2017 Schedule A, Part III, line 17	18	

19a 33 1/3% support tests—2018. 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—2017. 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 12a of Part I, complete Sections A and B. If you checked 12b of Part I, complete Sections A and C. If you checked 12c of Part I, complete Sections A, D, and E. If you checked 12d of Part I, complete Sections A and D, and complete Part V.)

Section A. All Supporting Organizations

		Yes	No
1	Are all of the organization's supported organizations listed by name in the organization's governing documents? <i>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.</i>		
2	Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? <i>If "Yes," explain in Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).</i>		
3a	Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? <i>If "Yes," answer (b) and (c) below.</i>		
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)? <i>If "Yes," describe in Part VI when and how the organization made the determination.</i>		
c	Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? <i>If "Yes," explain in Part VI what controls the organization put in place to ensure such use.</i>		
4a	Was any supported organization not organized in the United States ("foreign supported organization")? <i>If "Yes" and if you checked 12a or 12b in Part I, answer (b) and (c) below.</i>		
b	Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? <i>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.</i>		
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)? <i>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.</i>		
5a	Did the organization add, substitute, or remove any supported organizations during the tax year? <i>If "Yes," answer (b) and (c) below (if applicable). Also, provide detail in Part VI, including (i) the names and EIN numbers of the supported organizations added, substituted, or removed, (ii) the reasons for each such action, (iii) the authority under the organization's organizing document authorizing such action, and (iv) how the action was accomplished (such as by amendment to the organizing document).</i>		
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? <i>If "Yes," provide detail in Part VI.</i>		
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? <i>If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).</i>		
8	Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? <i>If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).</i>		
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))? <i>If "Yes," provide detail in Part VI.</i>		
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? <i>If "Yes," provide detail in Part VI.</i>		
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? <i>If "Yes," provide detail in Part VI.</i>		
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)? <i>If "Yes," answer line 10b below.</i>		
b	Did the organization have any excess business holdings in the tax year? <i>(Use Schedule C, Form 4720, to determine whether the organization had excess business holdings.)</i>		

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 (b) and (c) below, the governing body of a supported organization?		
b	A family member of a person described in (a) above?		
c	A 35% controlled entity of a person described in (a) or (b) above? <i>If "Yes" to a, b, or c, provide detail in Part VI</i>		

Section B. Type I Supporting Organizations

		Yes	No
1	Did the directors, trustees, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the tax year? <i>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.</i>		
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? <i>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.</i>		

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)? <i>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).</i>		

Section D. All Type III Supporting Organizations

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

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	<input type="checkbox"/> The organization satisfied the Activities Test. Complete line 2 below.		
b	<input type="checkbox"/> The organization is the parent of each of its supported organizations. Complete line 3 below.		
c	<input type="checkbox"/> The organization supported a governmental entity. Describe in Part VI how you supported a governmental entity (see instructions).		
2	Activities Test Answer (a) and (b) 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? <i>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.</i>		
b	Did the activities described in (a) constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? <i>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.</i>		
3	Parent of Supported Organizations Answer (a) and (b) 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? <i>Provide details in Part VI.</i>		
b	Did the organization exercise a substantial degree of direction over the policies, programs and activities of each of its supported organizations? <i>If "Yes," describe in Part VI the role played by the organization in this regard.</i>		

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

- 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 1-1/2% of line 3 (for greater amount, see instructions)	4	
5	Net value of non-exempt-use assets (subtract line 4 from line 3)	5	
6	Multiply line 5 by .035	6	
7	Recoveries of prior-year distributions	7	
8	Minimum Asset Amount (add line 7 to line 6)	8	
Section C - Distributable Amount			Current Year
1	Adjusted net income for prior year (from Section A, line 8, Column A)	1	
2	Enter 85% of line 1	2	
3	Minimum asset amount for prior year (from Section B, line 8, Column A)	3	
4	Enter greater of line 2 or line 3	4	
5	Income tax imposed in prior year	5	
6	Distributable Amount. Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions)	6	
7	<input type="checkbox"/> 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	
2 Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	
3 Administrative expenses paid to accomplish exempt purposes of supported organizations	
4 Amounts paid to acquire exempt-use assets	
5 Qualified set-aside amounts (prior IRS approval required)	
6 Other distributions (describe in Part VI) See instructions	
7 Total annual distributions. Add lines 1 through 6	
8 Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI) See instructions	
9 Distributable amount for 2018 from Section C, line 6	
10 Line 8 amount divided by Line 9 amount	

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2018	(iii) Distributable Amount for 2018
1 Distributable amount for 2018 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2018 (reasonable cause required-- explain in Part VI) See instructions			
3 Excess distributions carryover, if any, to 2018			
a From 2013.			
b From 2014.			
c From 2015.			
d From 2016.			
e From 2017.			
f Total of lines 3a through e			
g Applied to underdistributions of prior years			
h Applied to 2018 distributable amount			
i Carryover from 2013 not applied (see instructions)			
j Remainder Subtract lines 3g, 3h, and 3i from 3f			
4 Distributions for 2018 from Section D, line 7			
\$			
a Applied to underdistributions of prior years			
b Applied to 2018 distributable amount			
c Remainder Subtract lines 4a and 4b from 4			
5 Remaining underdistributions for years prior to 2018, 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 2018 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 2019. Add lines 3j and 4c			
8 Breakdown of line 7			
a Excess from 2014.			
b Excess from 2015.			
c Excess from 2016.			
d Excess from 2017.			
e Excess from 2018.			

Additional Data

Software ID: 18007218

Software Version: 2018v3.1

EIN: 04-3673104

Name: PHELAN-MCDERMID SYNDROME FOUNDATION INC

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

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

2018
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 PHELAN-MCDERMID SYNDROME FOUNDATION INC	Employer identification number 04-3673104
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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)	30,076													
c	Total lobbying expenditures (add lines 1a and 1b)	30,076													
d	Other exempt purpose expenditures	869,344													
e	Total exempt purpose expenditures (add lines 1c and 1d)	899,420													
f	Lobbying nontaxable amount Enter the amount from the following table in both columns	159,913													
<table border="1" style="width: 100%;"> <thead> <tr> <th style="width: 50%;">If the amount on line 1e, column (a) or (b) is:</th> <th style="width: 50%;">The lobbying nontaxable amount is:</th> </tr> </thead> <tbody> <tr> <td>Not over \$500,000</td> <td>20% of the amount on line 1e</td> </tr> <tr> <td>Over \$500,000 but not over \$1,000,000</td> <td>\$100,000 plus 15% of the excess over \$500,000</td> </tr> <tr> <td>Over \$1,000,000 but not over \$1,500,000</td> <td>\$175,000 plus 10% of the excess over \$1,000,000</td> </tr> <tr> <td>Over \$1,500,000 but not over \$17,000,000</td> <td>\$225,000 plus 5% of the excess over \$1,500,000</td> </tr> <tr> <td>Over \$17,000,000</td> <td>\$1,000,000</td> </tr> </tbody> </table>		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		
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)	39,978													
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?		<input type="checkbox"/> Yes <input checked="" type="checkbox"/> 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) 2015	(b) 2016	(c) 2017	(d) 2018	(e) Total
2a Lobbying nontaxable amount		179,607	186,927	159,913	526,447
b Lobbying ceiling amount (150% of line 2a, column(e))					789,671
c Total lobbying expenditures		30,756	30,056	30,076	90,888
d Grassroots nontaxable amount		44,902	46,732	39,978	131,612
e Grassroots ceiling amount (150% of line 2d, column (e))					197,418
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 1j below, provide in Part IV a detailed description of the lobbying activity

	(a)		(b)
	Yes	No	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?			
b Paid staff or management (include compensation in expenses reported on lines 1c through 1i)?			
c Media advertisements?			
d Mailings to members, legislators, or the public?			
e Publications, or published or broadcast statements?			
f Grants to other organizations for lobbying purposes?			
g Direct contact with legislators, their staffs, government officials, or a legislative body?			
h Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means?			
i Other activities?			
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)?			
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
Part II-B, Line 1i - Other Activities Description	PART II-A, LINES 1 AND 2 THE FOUNDATION'S KEY VOLUNTEERS HAVE BEEN WORKING WITH A LOBBYING CONSULTANT (CRD ASSOCIATES) TOWARDS TWO MAIN LEGISLATIVE GOALS 1) INCLUDING WORDING IN THE ANNUAL DEFENSE APPROPRIATIONS ACT THAT WOULD FUND RESEARCH INTO SEVERAL KEY GENES ASSOCIATED WITH PHELAN-MCDERMID SYNDROME, AND 2) RECRUITING CHAMPIONS IN THE SENATE AND HOUSE TO AUTHOR AND INTRODUCE A "PHELAN-MCDERMID SYNDROME RESEARCH ACT" FUNDING NEW RESEARCH AND SURVEILLANCE ACTIVITIES AT NIH, CDC AND OTHER HHS AGENCIES CRD ASSOCIATES HAS BEEN WORKING WITH A NUMBER OF DIFFERENT US SENATORS TO DEVELOP RELATIONSHIPS WITH KEY PROGRAM MANAGERS AT THE DEPARTMENT OF DEFENSE THE FOUNDATION'S BOARD PRESIDENT, OTHER KEY VOLUNTEERS, AND CRD ASSOCIATES HAVE EMAILED AND SPOKEN DIRECTLY TO US SENATORS AND REPRESENTATTIVES FOR THEIR STATE IN SUPPORT OF THESE GOALS AND HAVE STARTED TO INVENTORY THE POTENTIAL RELATIONSHIPS THAT PHELAN-MCDERMID SYNDROME FOUNDATION'S MOST ACTIVE GRASSROOTS ADVOCATES MAY HAVE WITH THEIR SENATORS

SCHEDULE D
(Form 990)

Department of the Treasury
Internal Revenue Service

Supplemental Financial Statements
▶ Complete if the organization answered "Yes," on Form 990, Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b.
▶ Attach to Form 990.
▶ Go to www.irs.gov/Form990 for the latest information.

OMB No 1545-0047
2018
Open to Public Inspection

Name of the organization
PHELAN-MCDERMID SYNDROME FOUNDATION INC

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.

	(a) Donor advised funds	(b) Funds and other accounts
1 Total number at end of year		
2 Aggregate value of contributions to (during year)		
3 Aggregate value of grants from (during year)		
4 Aggregate value at end of year		
5 Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control?		<input type="checkbox"/> Yes <input type="checkbox"/> No
6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit?		<input type="checkbox"/> Yes <input type="checkbox"/> No

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

1 Purpose(s) of conservation easements held by the organization (check all that apply)

Preservation of land for public use (e g , recreation or education) Preservation of an historically important land area

Protection of natural habitat Preservation of a certified historic structure

Preservation of open space

2 Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year

	Held at the End of the Year	
a Total number of conservation easements	2a	
b Total acreage restricted by conservation easements	2b	
c Number of conservation easements on a certified historic structure included in (a)	2c	
d Number of conservation easements included in (c) acquired after 7/25/06, and not on a historic structure listed in the National Register	2d	

3 Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year ▶ _____

4 Number of states where property subject to conservation easement is located ▶ _____

5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds? Yes No

6 Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing conservation easements during the year ▶ _____

7 Amount of expenses incurred in monitoring, inspecting, handling of violations, and enforcing conservation easements during the year ▶ \$ _____

8 Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)? Yes No

9 In Part XIII, describe how the organization reports conservation easements in its revenue and expense statement, and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements

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.

1a If the organization elected, as permitted under SFAS 116 (ASC 958), not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIII, the text of the footnote to its financial statements that describes these items

b If the organization elected, as permitted under SFAS 116 (ASC 958), to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items

(i) Revenue included on Form 990, Part VIII, line 1 ▶ \$ _____

(ii) Assets included in Form 990, Part X ▶ \$ _____

2 If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under SFAS 116 (ASC 958) relating to these items

a Revenue included on Form 990, Part VIII, line 1 ▶ \$ _____

b Assets included in Form 990, Part X ▶ \$ _____

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 |
|---|--------|
| 1c Beginning balance | |
| 1d Additions during the year | |
| 1e Distributions during the year | |
| 1f Ending balance | |
- 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	36,577	32,654	31,702	34,158	33,585
b Contributions					
c Net investment earnings, gains, and losses	-2,383	5,431	1,113	-2,286	746
d Grants or scholarships	1,349	1,334			
e Other expenditures for facilities and programs					
f Administrative expenses	257	174	161	170	173
g End of year balance	32,588	36,577	32,654	31,702	34,158

- 2** Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as
- a** Board designated or quasi-endowment ▶
 - b** Permanent endowment ▶
 - c** Temporarily restricted endowment ▶
- 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 | No |
- 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				
b Buildings				
c Leasehold improvements				
d Equipment		13,017	11,110	1,907
e Other				
Total. Add lines 1a through 1e (Column (d) must equal Form 990, Part X, column (B), line 10(c)) . . . ▶				1,907

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) AGENCY ENDOWMENT FUND	32,588
(2) OTHER RECEIVABLES	4,600
(3) UNBILLED CONTRACT REVENUE	81,141
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (Column (b) must equal Form 990, Part X, col (B) line 15)	118,329

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	1,199,809
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12			
a	Net unrealized gains (losses) on investments	2a		
b	Donated services and use of facilities	2b	731	
c	Recoveries of prior year grants	2c		
d	Other (Describe in Part XIII)	2d		
e	Add lines 2a through 2d		2e	731
3	Subtract line 2e from line 1		3	1,199,078
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		
b	Other (Describe in Part XIII)	4b		
c	Add lines 4a and 4b		4c	
5	Total revenue Add lines 3 and 4c . (This must equal Form 990, Part I, line 12)		5	1,199,078

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	900,151
2	Amounts included on line 1 but not on Form 990, Part IX, line 25			
a	Donated services and use of facilities	2a	731	
b	Prior year adjustments	2b		
c	Other losses	2c		
d	Other (Describe in Part XIII)	2d		
e	Add lines 2a through 2d		2e	731
3	Subtract line 2e from line 1		3	899,420
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		
b	Other (Describe in Part XIII)	4b		
c	Add lines 4a and 4b		4c	
5	Total expenses Add lines 3 and 4c . (This must equal Form 990, Part I, line 18)		5	899,420

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	
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Part XIII **Supplemental Information (continued)**

Return Reference	Explanation
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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

2018

Open to Public Inspection

Name of the organization
PHELAN-MCDERMID SYNDROME FOUNDATION INC

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** 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 ten 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		(a) Event #1	(b) Event #2	(c) Other events	(d)
		PL TSHIRTS (event type)	IN IT TO WIN IT (event type)	(total number)	Total events (add col (a) through col (c))
Revenue	1 Gross receipts	98,290	6,634		104,924
	2 Less Contributions	30,664	3,494		34,158
	3 Gross income (line 1 minus line 2)	67,626	3,140		70,766
Direct Expenses	4 Cash prizes				
	5 Noncash prizes				
	6 Rent/facility costs				
	7 Food and beverages				
	8 Entertainment				
	9 Other direct expenses	2,098			2,098
	10 Direct expense summary Add lines 4 through 9 in column (d) ▶				2,098
11 Net income summary Subtract line 10 from line 3, column (d) ▶				68,668	

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		(a) Bingo	(b) Pull tabs/Instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col (a) through col (c))
		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
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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**

OMB No 1545-0047

2018

**Open to Public
Inspection**

Department of the
Treasury
Internal Revenue Service

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.

Name of the organization
PHELAN-MCDERMID SYNDROME FOUNDATION INC

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)							
(2)							
(3)							
(4)							
(5)							
(6)							
(7)							
(8)							
(9)							
(10)							
(11)							
(12)							

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

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) TRAVEL ASSIST-INT'L BIENNIAL CONF	5	2,710		BOOK	
(2) FACILI & NOTETAKER STIPEND MCPOSIUM	19	2,825		BOOK	
(3) POSTER STIPEND YOUNG INVEST MCPOSIU	1	500		BOOK	
(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
Grantmaker's Description of How Grants are Used	A LETTER OF AGREEMENT WHICH OUTLINES THE TERMS OF GRANTS IS PREPARED BY THE PHELAN-MCDERMID SYNDROME FOUNDATION AND SIGNED BY THE GRANTEE BEFORE THE FUNDS ARE DISBURSED THE AGREEMENT OUTLINES ANY STIPULATIONS FOR HOW THE FUNDS MUST BE USED AWARDS ARE PAID FOR IN INSTALLMENTS AND SUBSEQUENT INSTALLMENTS ARE PAID ONLY AFTER GRANTEE PROGRESS AND FINANCIAL REPORTS ARE REVIEWED BY A PHELAN-MCDERMID APPROVED INVESTIGATOR

SCHEDULE O
(Form 990 or 990-EZ)

Supplemental Information to Form 990 or 990-EZ

OMB No 1545-0047

2018

Open to Public Inspection

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.

Department of the Treasury

Name of the organization

PHELAN-MCDERMID SYNDROME FOUNDATION INC

Employer identification number

04-3673104

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990, Part III, Line 4d Other Program Services Description	OTHER PROGRAM SERVICES 4 2018 International Family Conference and McPosium In July 2018, 627 Attendees representing approximately 183 families and 9 countries came to a 3-day conference featuring educational sessions, meetings and opportunities for families to connect in person to share and learn from each other The McPosium was a discrete event during the conference, taking place over two half-days and consisted of 6 sessions of topics of high priority to the patient and caregiver community of PMS in an interactive format

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990, Part VI, Line 11b Form 990 Review Process	CPA PREPARES A DRAFT OF FORM 990 AND REQUIRED SUPPLEMENTAL SCHEDULES FINANCE DIRECTOR REVIEWS IN DETAIL AND CPA PREPARES A SECOND DRAFT WHICH IS DISTRIBUTED TO ALL FINANCE COMMITTEE MEMBERS FOR REVIEW AND APPROVAL AFTER FINANCE COMMITTEE APPROVAL, DRAFT IS DISTRIBUTED TO ALL CURRENT BOARD MEMBERS BOARD MEMBERS ARE ALLOWED ONE WEEK TO COMMENT, REQUEST CHANGES, AND/OR ASK QUESTIONS BOARD MEMBERS E-SIGN A DOCUMENT THAT CONFIRMS THEIR REVIEW OF THE 990 PRIOR TO FILING

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990, Part VI, Line 12c Explanation of Monitoring and Enforcement of Conflicts	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

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990, Part VI, Line 15a Compensation Review & Approval Process - CEO, Top Management	BOARD DETERMINES COMPENSATION OF EXECUTIVE DIRECTOR AS PART OF ANNUAL BUDGETING PROCESS FOR ENTIRE ORGANIZATION SALARY OF EXECUTIVE DIRECTOR FALLS WITHIN RANGE THAT WOULD BE CONSIDERED REASONABLE GIVEN COMPARABILITY DATA OF OTHER SIMILAR ORGANIZATIONS BOARD PRESIDENT PERFORMS ANNUAL REVIEW OF EXECUTIVE DIRECTOR NOTE THAT INDEPENDENT REVIEW AND APPROVAL AS WELL AS COMPARABILITY DATA USED IS DOCUMENTED IN BOARD MINUTES

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990, Part VI, Line 15b Compensation Review and Approval Process for Officers and Key Employees	EXECUTIVE DIRECTOR DETERMINES COMPENSATION OF OTHER KEY STAFF AS PART OF ANNUAL BUDGETING PROCESS FOR ENTIRE ORGANIZATION SALARY OF THESE STAFF PEOPLE FALL WITHIN RANGE THAT WOULD BE CONSIDERED REASONABLE GIVEN COMPARABILITY DATA OF OTHER SIMILAR ORGANIZATIONS

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990, Part VI, Line 18 Explanation of Other Means Forms Available For Public Inspection	990 IS MADE AVAILABLE ON FOUNDATION'S WEBSITE AND OTHER DOCUMENTS UPON REQUEST

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990, Part VI, Line 19 Other Organization Documents Publicly Available	ANNUAL AUDIT REPORT AND FORM 990 IS MADE AVAILABLE ON FOUNDATION'S WEBSITE OTHER DOCUMENTS UPON REQUEST