

990

Return of Organization Exempt From Income Tax

OMB No. 1545-

0047 2021

Open to Public Inspection

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

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

Form 990 Department of the Treasury Internal Revenue Service

For the 2021 calendar year, or tax year beginning 01-01-2021, and ending 12-31-2021

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

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

D Employer identification number: 04-3673104. E Telephone number: (941) 485-8000. G Gross receipts \$ 898,356

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

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

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

J Website: pmsf.org

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

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

Part I Summary

1 Briefly describe the organization's mission or most significant activities: The mission of the Phelan-McDermid Syndrome Foundation is to improve the quality of life of people affected by Phelan-McDermid Syndrome worldwide by accelerating research, providing family support and raising awareness.

Table with 2 columns: Description, Amount. Rows 2-7b: 2 Check this box if the organization discontinued its operations or disposed of more than 25% of its net assets. 3 Number of voting members of the governing body (Part VI, line 1a) 3 7. 4 Number of independent voting members of the governing body (Part VI, line 1b) 4 7. 5 Total number of individuals employed in calendar year 2021 (Part V, line 2a) 5 10. 6 Total number of volunteers (estimate if necessary) 6 50. 7a Total unrelated business revenue from Part VIII, column (C), line 12 7a 0. 7b Net unrelated business taxable income from Form 990-T, Part I, line 11 7b 0.

Table with 3 columns: Description, Prior Year, Current Year. Rows 8-12: 8 Contributions and grants (Part VIII, line 1h) 8 471,225 758,981. 9 Program service revenue (Part VIII, line 2g) 9 15,172 50,947. 10 Investment income (Part VIII, column (A), lines 3, 4, and 7d) 10 886 123. 11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) 11 72,917 86,951. 12 Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12) 12 560,200 897,002.

Table with 3 columns: Description, Prior Year, Current Year. Rows 13-19: 13 Grants and similar amounts paid (Part IX, column (A), lines 1-3) 13 0 11,688. 14 Benefits paid to or for members (Part IX, column (A), line 4) 14 0 0. 15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10) 15 333,451 362,955. 16a Professional fundraising fees (Part IX, column (A), line 11e) 16a 0 0. 16b Total fundraising expenses (Part IX, column (D), line 25) 16b 97,839. 17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e) 17 121,939 122,781. 18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25) 18 455,390 497,424. 19 Revenue less expenses. Subtract line 18 from line 12 19 104,810 399,578.

Table with 3 columns: Description, Beginning of Current Year, End of Year. Rows 20-22: 20 Total assets (Part X, line 16) 20 1,639,670 1,940,384. 21 Total liabilities (Part X, line 26) 21 123,193 24,329. 22 Net assets or fund balances. Subtract line 21 from line 20 22 1,516,477 1,916,055.

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: Rhonda Blumenthal, Chief Executive Officer. Date: 2022-03-09.

Paid Preparer Use Only: Print/Type preparer's name, Preparer's signature, Date, Check if self-employed, PTIN, Firm's name, Firm's EIN, Firm's address, Phone no.

**Part III Statement of Program Service Accomplishments**

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

**1** Briefly describe the organization's mission:

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

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

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

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

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

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

**4a** (Code: ) (Expenses \$ **120,057** including grants of \$ **11,689**) (Revenue \$ **50,000**)  
 RESEARCH SUPPORT: The PMSF Research program was established to improve the quality of life for individuals and families affected by PMS by fostering sound genetic, biological, and medical research related to the cause, effects, diagnosis, and effective treatments of PMS. The goal is to increase stakeholder understanding of the Phelan-McDermid syndrome diagnosis, the genotype-phenotype correlations, natural history, biomarkers, and therapeutics. PMSF is supported by an international Scientific Advisory Committee and has developed strategic partnerships in the research and rare disease community to find ways to generate, support, and sustain the advancement of research in the areas of genetics, neurology, biology, and other disciplines that would benefit those affected by PMS. Central to the Research program, PMSF developed and maintains the largest patient data registry in the world for individuals with Phelan-McDermid Syndrome. PMSF enables families to participate in research by sharing de-identified patient data and helping with research study recruitment to further the understanding of and research in PMS.

**4b** (Code: ) (Expenses \$ **102,717** including grants of \$ ) (Revenue \$ **0**)  
 FAMILY SUPPORT: PMSF supports families by providing a peer-to-peer network of Regional Representatives (REPs) who welcome, inform and support families in the membership, PMSF fosters family interaction through the philosophy that parents of children and adults with PMS have a wealth of knowledge and experience to share with each other. Regional REPs are trained to actively listen to families' concerns, suggest resources and connect them with other families who share their challenges, concerns and interests. REPs help families connect with one another to exchange ideas and information about therapies and medical issues, as they face new challenges. These families have more in common than just having a child with a disability, they share a need for emotional support and understanding from other families that are going through similar challenges every day. A sense of belonging is vital to our families as it provides a connection to others, even though they may be hundreds or thousands of miles away. The Family Support program promotes interaction in many ways including a biennial family conference, monthly newsletters, a website, social networking, fundraising and advocacy events, and regional gatherings.

**4c** (Code: ) (Expenses \$ **31,309** including grants of \$ ) (Revenue \$ **0**)  
 ADVOCACY AND AWARENESS: Everyone in the Phelan-McDermid community is an advocate who increases awareness, hope, and action toward our Foundation's mission. Our program goal is to raise awareness and to empower stakeholders to advocate for research, funding, support services, and legislative initiatives that improve the lives of everyone affected by PMS. This program is focused on sharing information and establishing partnerships within the medical, research, and corporate, pharmaceutical, and rare disease communities. Program objectives include (1) enlisting support in the advancement of research and research funding by participating in national and international forums focused on developing treatments, therapies, and cures for rare diseases. (2) Developing collaborations with national organizations focused in improving the quality of life and quality of services for people with disabilities and disseminating information to the PMS community. (3) Developing legislative priorities for the PMS community and working collaboratively with local, state, country and international bodies to share the PMS patient voice on legislative issues that affect our population.

**4d** Other program services (Describe in Schedule O.)  
 (Expenses \$ **0** including grants of \$ **0**) (Revenue \$ **0**)

**4e** **Total program service expenses** **254,083**

Part IV Checklist of Required Schedules

Table with 3 columns: Question ID, Question Text, Yes, No. Rows include questions 1 through 21 regarding organizational requirements, such as political activities, lobbying, and financial reporting.

**Part IV Checklist of Required Schedules (continued)**

		Yes	No
<b>22</b>	Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III . . . . .</i>	<b>22</b>	No
<b>23</b>	Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5, about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J . . . . .</i>	<b>23</b>	No
<b>24a</b>	Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a . . . . .</i>	<b>24a</b>	No
<b>b</b>	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception? . . . . .	<b>24b</b>	
<b>c</b>	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds? . . . . .	<b>24c</b>	
<b>d</b>	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	<b>24d</b>	
<b>25a</b>	<b>Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations.</b> Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I . . . . .</i>	<b>25a</b>	No
<b>b</b>	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I . . . . .</i>	<b>25b</b>	No
<b>26</b>	Did the organization report any amount on Part X, line 5 or 22 for receivables from or payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons?	<b>26</b>	No
<b>27</b>	Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or employee thereof, a grant selection committee member, or to a 35% controlled entity (including an employee thereof) or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III . . . . .</i>	<b>27</b>	No
<b>28</b>	Was the organization a party to a business transaction with one of the following parties (see the Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions):		
<b>a</b>	A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? <i>If "Yes," complete Schedule L, Part IV . . . . .</i>	<b>28a</b>	No
<b>b</b>	A family member of any individual described in line 28a? <i>If "Yes," complete Schedule L, Part IV . . . . .</i>	<b>28b</b>	No
<b>c</b>	A 35% controlled entity of one or more individuals and/or organizations described in line 28a or 28b? <i>If "Yes," complete Schedule L, Part IV . . . . .</i>	<b>28c</b>	No
<b>29</b>	Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M . . . . .</i>	<b>29</b>	No
<b>30</b>	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions?	<b>30</b>	No
<b>31</b>	Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I . . . . .</i>	<b>31</b>	No
<b>32</b>	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II . . . . .</i>	<b>32</b>	No
<b>33</b>	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3?	<b>33</b>	No
<b>34</b>	Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1 . . . . .</i>	<b>34</b>	No
<b>35a</b>	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	<b>35a</b>	No
<b>b</b>	If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2 . . . . .</i>	<b>35b</b>	
<b>36</b>	<b>Section 501(c)(3) organizations.</b> Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2 . . . . .</i>	<b>36</b>	No
<b>37</b>	Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? <i>If "Yes," complete Schedule R, Part VI . . . . .</i>	<b>37</b>	No
<b>38</b>	Did the organization complete Schedule O and provide explanations on Schedule O for Part VI, lines 11b and 19? <b>Note.</b> All Form 990 filers are required to complete Schedule O. . . . .	<b>38</b>	Yes

**Part V Statements Regarding Other IRS Filings and Tax Compliance**

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

		Yes	No
<b>1a</b>	Enter the number reported in box 3 of Form 1096. Enter -0- if not applicable	<b>1a</b>	6
<b>b</b>	Enter the number of Forms W-2G included on line 1a. Enter -0- if not applicable	<b>1b</b>	0
<b>c</b>	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners? . . . . .	<b>1c</b>	Yes

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

Table with 10 columns: Question ID, Question Text, Sub-column 1, Sub-column 2, Sub-column 3, Sub-column 4, Sub-column 5, Sub-column 6, Sub-column 7, Sub-column 8. Rows include questions 2a through 17 regarding employee reporting, federal employment tax returns, unrelated business gross income, foreign accounts, prohibited tax shelter transactions, charitable contributions, and sponsoring organizations.

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 4 columns: Question, 1a, 1b, Yes, No. Rows include questions about voting members, family relationships, management control, and documentation.

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

Table with 4 columns: Question, Yes, No. Rows include questions about local chapters, written policies, conflict of interest, whistleblower policy, and document retention.

Section C. Disclosure

- 17 List the states with which a copy of this Form 990 is required to be filed. AK, AL, AR, CA, CO, CT, DC, FL, GA, HI, IL, KS, KY, MA, MD, ME, MI, MN, MO, MS, NC, ND, NH, NJ, NM, NV, NY, OH, OK, OR, PA, RI, SC, TN, TX, UT, VA, WA, WI, WV
18 Section 6104 requires an organization to make its Form 1023 (1024 or 1024-A, if applicable), 990, and 990-T (section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.
19 Describe in Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.
20 State the name, address, and telephone number of the person who possesses the organization's books and records: Priscilla Hackstadt 8 Sorrento Drive Osprey, FL 34229 (941) 485-8000





**Part 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 Amt Similar Amounts				
<b>1a</b> Federated campaigns . . . . .			0	
<b>1b</b> Membership dues . . . . .			0	
<b>1c</b> Fundraising events . . . . .			38,372	
<b>1d</b> Related organizations . . . . .			0	
<b>1e</b> Government grants (contributions) . . . . .			144,375	
<b>1f</b> All other contributions, gifts, grants, and similar amounts not included above . . . . .			576,234	
<b>1g</b> Noncash contributions included in lines 1a - 1f:\$ . . . . .			0	
<b>1h Total.</b> Add lines 1a-1f . . . . .				758,981

Program Service Revenue		Business Code				
			(A)	(B)	(C)	(D)
<b>2a</b> GCX contract income		813212	50,000	50,000	0	0
<b>b</b> Store sales		453220	947	947	0	0
<b>c</b>						
<b>d</b>						
<b>e</b>						
<b>f</b> All other program service revenue.			0	0	0	0
<b>g Total.</b> Add lines 2a-2f. . . . .			50,947			

Other Revenue	<b>3</b> Investment income (including dividends, interest, and other similar amounts)		123	123	0	0	
	<b>4</b> Income from investment of tax-exempt bond proceeds		0	0	0	0	
	<b>5</b> Royalties . . . . .		0	0	0	0	
	<b>6a</b> Gross rents	(i) Real					
		(ii) Personal					
		<b>6b</b> Less: rental expenses					
		<b>6c</b> Rental income or (loss)		0	0		
	<b>d</b> Net rental income or (loss) . . . . .						
	<b>7a</b> Gross amount from sales of assets other than inventory	(i) Securities					
		(ii) Other					
		<b>7b</b> Less: cost or other basis and sales expenses					
		<b>7c</b> Gain or (loss)		0	0		
	<b>d</b> Net gain or (loss) . . . . .						
	<b>8a</b> Gross income from fundraising events (not including \$ 38,372 of contributions reported on line 1c). See Part IV, line 18 . . . . .		88,305				
		<b>8b</b> Less: direct expenses		1,354			
	<b>c</b> Net income or (loss) from fundraising events . . . . .			86,951	0	86,951	
	<b>9a</b> Gross income from gaming activities. See Part IV, line 19 . . . . .						
		<b>9b</b> Less: direct expenses . . . . .					
	<b>c</b> Net income or (loss) from gaming activities . . . . .						
	<b>10a</b> Gross sales of inventory, less returns and allowances . . . . .						
<b>10b</b> Less: cost of goods sold . . . . .							
<b>c</b> Net income or (loss) from sales of inventory . . . . .							
Miscellaneous Revenue	Business Code						
<b>11a</b>							
<b>b</b>							
<b>c</b>							
<b>d</b> All other revenue . . . . .							
<b>e Total.</b> Add lines 11a-11d . . . . .			0				
<b>12 Total revenue.</b> See instructions . . . . .			897,002	51,070	0	86,951	

**Part IX Statement of Functional Expenses**

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

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

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
<b>1</b> Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	11,688	11,688		
<b>2</b> Grants and other assistance to domestic individuals. See Part IV, line 22	0	0		
<b>3</b> Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16.	0	0		
<b>4</b> Benefits paid to or for members	0	0		
<b>5</b> Compensation of current officers, directors, trustees, and key employees	101,590	60,954	20,318	20,318
<b>6</b> Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)	0	0	0	
<b>7</b> Other salaries and wages	227,851	108,679	64,283	54,889
<b>8</b> Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	6,776	3,208	1,956	1,612
<b>9</b> Other employee benefits	551	0	551	
<b>10</b> Payroll taxes	26,187	14,002	6,502	5,683
<b>11</b> Fees for services (non-employees):				
<b>a</b> Management				
<b>b</b> Legal	713		713	
<b>c</b> Accounting				
<b>d</b> Lobbying				
<b>e</b> Professional fundraising services. See Part IV, line 17				
<b>f</b> Investment management fees				
<b>g</b> Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O)	24,108	8,630	13,628	1,850
<b>12</b> Advertising and promotion	3,038	2,223		815
<b>13</b> Office expenses	17,019	519	8,271	8,229
<b>14</b> Information technology	38,856	28,786	6,962	3,108
<b>15</b> Royalties				
<b>16</b> Occupancy	6,900		6,900	
<b>17</b> Travel	15,265	15,205	60	
<b>18</b> Payments of travel or entertainment expenses for any federal, state, or local public officials				
<b>19</b> Conferences, conventions, and meetings	11,090	90	10,000	1,000
<b>20</b> Interest				
<b>21</b> Payments to affiliates				
<b>22</b> Depreciation, depletion, and amortization	299		299	
<b>23</b> Insurance	4,776		4,776	
<b>24</b> 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.)				
<b>a</b>				
<b>b</b>				
<b>c</b>				
<b>d</b>				
<b>e</b> All other expenses	717	99	283	335
<b>25</b> Total functional expenses. Add lines 1 through 24e	497,424	254,083	145,502	97,839
<b>26</b> 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
<b>Assets</b>	<b>1</b> Cash-non-interest-bearing . . . . .	1,019,415	<b>1</b>	1,352,848
	<b>2</b> Savings and temporary cash investments		<b>2</b>	
	<b>3</b> Pledges and grants receivable, net . . . . .	13,552	<b>3</b>	
	<b>4</b> Accounts receivable, net . . . . .		<b>4</b>	10,000
	<b>5</b> Loans and other receivables from any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		<b>5</b>	
	<b>6</b> Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B)		<b>6</b>	
	<b>7</b> Notes and loans receivable, net . . . . .		<b>7</b>	
	<b>8</b> Inventories for sale or use . . . . .		<b>8</b>	
	<b>9</b> Prepaid expenses and deferred charges . . . . .	28,962	<b>9</b>	3,036
	<b>10a</b> Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	13,017		
	<b>b</b> Less: accumulated depreciation	13,017	299	<b>10c</b> 0
	<b>11</b> Investments—publicly traded securities . . . . .	577,442	<b>11</b>	574,500
	<b>12</b> Investments—other securities. See Part IV, line 11 . . . . .		<b>12</b>	
	<b>13</b> Investments—program-related. See Part IV, line 11 . . . . .		<b>13</b>	
	<b>14</b> Intangible assets . . . . .		<b>14</b>	
	<b>15</b> Other assets. See Part IV, line 11		<b>15</b>	
<b>16 Total assets:</b> Add lines 1 through 15 (must equal line 33) . . . . .	1,639,670	<b>16</b>	1,940,384	
<b>Liabilities</b>	<b>17</b> Accounts payable and accrued expenses . . . . .	10,993	<b>17</b>	24,329
	<b>18</b> Grants payable . . . . .		<b>18</b>	
	<b>19</b> Deferred revenue . . . . .	40,000	<b>19</b>	
	<b>20</b> Tax-exempt bond liabilities . . . . .		<b>20</b>	
	<b>21</b> Escrow or custodial account liability. Complete Part IV of Schedule D		<b>21</b>	
	<b>22</b> Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		<b>22</b>	
	<b>23</b> Secured mortgages and notes payable to unrelated third parties . . . . .		<b>23</b>	
	<b>24</b> Unsecured notes and loans payable to unrelated third parties . . . . .	72,200	<b>24</b>	
<b>25</b> 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		<b>25</b>		
<b>26 Total liabilities.</b> Add lines 17 through 25 . . . . .	123,193	<b>26</b>	24,329	
<b>Net Assets or Fund Balances</b>	<b>Organizations that follow FASB ASC 958, check here <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33.</b>			
	<b>27</b> Net assets without donor restrictions . . . . .	1,495,808	<b>27</b>	1,915,050
	<b>28</b> Net assets with donor restrictions	20,669	<b>28</b>	1,005
	<b>Organizations that do not follow FASB ASC 958, check here <input type="checkbox"/> and complete lines 29 through 33.</b>			
	<b>29</b> Capital stock or trust principal, or current funds . . . . .		<b>29</b>	
	<b>30</b> Paid-in or capital surplus, or land, building or equipment fund . . . . .		<b>30</b>	
	<b>31</b> Retained earnings, endowment, accumulated income, or other funds		<b>31</b>	
	<b>32</b> Total net assets or fund balances	1,516,477	<b>32</b>	1,916,055
<b>33</b> Total liabilities and net assets/fund balances	1,639,670	<b>33</b>	1,940,384	

**Part XI Reconciliation of Net Assets**

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

<b>1</b>	Total revenue (must equal Part VIII, column (A), line 12)	<b>1</b>	897,002
<b>2</b>	Total expenses (must equal Part IX, column (A), line 25)	<b>2</b>	497,424
<b>3</b>	Revenue less expenses. Subtract line 2 from line 1	<b>3</b>	399,578
<b>4</b>	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	<b>4</b>	1,516,477
<b>5</b>	Net unrealized gains (losses) on investments	<b>5</b>	0
<b>6</b>	Donated services and use of facilities	<b>6</b>	0
<b>7</b>	Investment expenses	<b>7</b>	0
<b>8</b>	Prior period adjustments	<b>8</b>	0
<b>9</b>	Other changes in net assets or fund balances (explain in Schedule O)	<b>9</b>	0
<b>10</b>	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (A))	<b>10</b>	1,916,055

**Part XII Financial Statements and Reporting**

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

		Yes	No
<b>1</b>	Accounting method used to prepare the Form 990: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other _____ If the organization changed its method of accounting from a prior year or checked "Other," explain on Schedule O.		
<b>2a</b>	Were the organization's financial statements compiled or reviewed by an independent accountant? If 'Yes,' check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both: <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		No
<b>b</b>	Were the organization's financial statements audited by an independent accountant? If 'Yes,' check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both: <input checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis	Yes	
<b>c</b>	If "Yes," to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O.	Yes	
<b>3a</b>	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?		No
<b>b</b>	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits.		

**Additional Data**

[Return to Form](#)

**Software ID:** 21013178

**Software Version:** v1.00

**Form 990, Special Condition Description:**

**Special Condition Description**

**Public Charity Status and Public Support**

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.  
 Attach to Form 990 or Form 990-EZ.  
 Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

**Name of the organization**  
PHELAN MCDERMID SYNDROME FOUNDATION

**Employer identification number**  
04-3673104

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

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

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

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

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

**Section A. Public Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grant.") . . .	424,060	625,444	477,942	471,225	758,981	2,757,652
<b>2</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf . . . . .						
<b>3</b> The value of services or facilities furnished by a governmental unit to the organization without charge..						
<b>4 Total.</b> Add lines 1 through 3	424,060	625,444	477,942	471,225	758,981	2,757,652
<b>5</b> 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) . . .						
<b>6 Public support.</b> Subtract line 5 from line 4.						2,757,652

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total
<b>7</b> Amounts from line 4. . . . .	424,060	625,444	477,942	471,225	758,981	2,757,652
<b>8</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources . . . . .	5,651	-2,368	6,163	886	123	10,455
<b>9</b> Net income from unrelated business activities, whether or not the business is regularly carried on . . . . .						
<b>10</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.). . . . .	722,365	541,843	172,279	88,089	137,898	1,662,474
<b>11 Total support.</b> Add lines 7 through 10						4,430,581
<b>12</b> Gross receipts from related activities, etc. (see instructions) . . . . .					<b>12</b>	
<b>13 First 5 years.</b> 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 <b>stop here</b> . . . . .						<input type="checkbox"/>

**Section C. Computation of Public Support Percentage**

<b>14</b> Public support percentage for 2021 (line 6, column (f) divided by line 11, column (f)) . . . . .	<b>14</b>	62.241 %
<b>15</b> Public support percentage for 2020 Schedule A, Part II, line 14 . . . . .	<b>15</b>	53.549 %
<b>16a 33 1/3% support test—2021.</b> If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and <b>stop here.</b> The organization qualifies as a publicly supported organization . . . . .		<input checked="" type="checkbox"/>
<b>b 33 1/3% support test—2020.</b> 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 <b>stop here.</b> The organization qualifies as a publicly supported organization . . . . .		<input type="checkbox"/>
<b>17a 10%-facts-and-circumstances test—2021.</b> 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 <b>stop here.</b> Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization . . . . .		<input type="checkbox"/>
<b>b 10%-facts-and-circumstances test—2020.</b> 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 <b>stop here.</b> Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization . . . . .		<input type="checkbox"/>
<b>18 Private foundation.</b> If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions . . . . .		<input type="checkbox"/>

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

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

**Section A. Public Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") .						
<b>2</b> 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						
<b>3</b> Gross receipts from activities that are not an unrelated trade or business under section 513 . . . . .						
<b>4</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf . . . .						
<b>5</b> The value of services or facilities furnished by a governmental unit to the organization without charge						
<b>6 Total.</b> Add lines 1 through 5						
<b>7a</b> Amounts included on lines 1, 2, and 3 received from disqualified persons						
<b>b</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.						
<b>c</b> Add lines 7a and 7b. .						
<b>8 Public support.</b> (Subtract line 7c from line 6.)						

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total
<b>9</b> Amounts from line 6. . . . .						
<b>10a</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources . . . . .						
<b>b</b> Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975.						
<b>c</b> Add lines 10a and 10b.						
<b>11</b> Net income from unrelated business activities not included on line 10b, whether or not the business is regularly carried on.						
<b>12</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) . . . . .						
<b>13 Total support.</b> (Add lines 9, 10c, 11, and 12.) . . . . .						
<b>14 First 5 years.</b> 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 <b>stop here.</b> . . . . . <input type="checkbox"/>						

**Section C. Computation of Public Support Percentage**

<b>15</b> Public support percentage for 2021 (line 8, column (f) divided by line 13, column (f)) . . . . .	<b>15</b>	
<b>16</b> Public support percentage from 2020 Schedule A, Part III, line 15 . . . . .	<b>16</b>	

**Section D. Computation of Investment Income Percentage**

<b>17</b> Investment income percentage for <b>2021</b> (line 10c, column (f) divided by line 13, column (f)) . . . . .	<b>17</b>	
<b>18</b> Investment income percentage from <b>2020</b> Schedule A, Part III, line 17 . . . . .	<b>18</b>	

**19a 33 1/3% support tests—2021.** 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—2020.** If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3% and line 18 is not more than 33 1/3%, check this box and **stop here.** The organization qualifies as a publicly supported organization . . . . .

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

**Part IV Supporting Organizations**

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

**Section A. All Supporting Organizations**

		Yes	No
<b>1</b>	Are all of the organization's supported organizations listed by name in the organization's governing documents? If "No," describe in <b>Part VI</b> how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.		
<b>2</b>	Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? If "Yes," explain in <b>Part VI</b> how the organization determined that the supported organization was described in section 509(a)(1) or (2).		
<b>3a</b>	Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? If "Yes," answer lines 3b and 3c below.		
<b>b</b>	Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? If "Yes," describe in <b>Part VI</b> when and how the organization made the determination.		
<b>c</b>	Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? If "Yes," explain in <b>Part VI</b> what controls the organization put in place to ensure such use.		
<b>4a</b>	Was any supported organization not organized in the United States ("foreign supported organization")? If "Yes" and if you checked box 12a or 12b in Part I, answer lines 4b and 4c below.		
<b>b</b>	Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? If "Yes," describe in <b>Part VI</b> how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.		
<b>c</b>	Did the organization support any foreign supported organization that does not have an IRS determination under sections 501(c)(3) and 509(a)(1) or (2)? If "Yes," explain in <b>Part VI</b> 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.		
<b>5a</b>	Did the organization add, substitute, or remove any supported organizations during the tax year? If "Yes," answer lines 5b and 5c below (if applicable). Also, provide detail in <b>Part VI</b> , including (i) the names and EIN numbers of the supported organizations added, substituted, or removed; (ii) the reasons for each such action; (iii) the authority under the organization's organizing document authorizing such action; and (iv) how the action was accomplished (such as by amendment to the organizing document).		
<b>b</b>	<b>Type I or Type II only.</b> Was any added or substituted supported organization part of a class already designated in the organization's organizing document?		
<b>c</b>	<b>Substitutions only.</b> Was the substitution the result of an event beyond the organization's control?		
<b>6</b>	Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? If "Yes," provide detail in <b>Part VI</b> .		
<b>7</b>	Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? If "Yes," complete Part I of Schedule L (Form 990).		
<b>8</b>	Did the organization make a loan to a disqualified person (as defined in section 4958) not described on line 7? If "Yes," complete Part I of Schedule L (Form 990).		
<b>9a</b>	Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons, as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? If "Yes," provide detail in <b>Part VI</b> .		
<b>b</b>	Did one or more disqualified persons (as defined on line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? If "Yes," provide detail in <b>Part VI</b> .		
<b>c</b>	Did a disqualified person (as defined on line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? If "Yes," provide detail in <b>Part VI</b> .		
<b>10a</b>	Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? If "Yes," answer line 10b below.		
<b>b</b>	Did the organization have any excess business holdings in the tax year? (Use Schedule C, Form 4720, to determine whether the organization had excess business holdings).		



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

- 1**  Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970 (explain in **Part VI**). See instructions. All other Type III non-functionally integrated supporting organizations must complete Sections A through E.

**Section A - Adjusted Net Income**

(A) Prior Year

(B) Current Year  
(optional)

- |   |          |  |  |
|---|----------|--|--|
| <b>1</b> Net short-term capital gain  | <b>1</b> |  |  |
| <b>2</b> Recoveries of prior-year distributions   | <b>2</b> |  |  |
| <b>3</b> Other gross income (see instructions)  | <b>3</b> |  |  |
| <b>4</b> Add lines 1 through 3  | <b>4</b> |  |  |
| <b>5</b> Depreciation and depletion   | <b>5</b> |  |  |
| <b>6</b> 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) | <b>6</b> |  |  |
| <b>7</b> Other expenses (see instructions)  | <b>7</b> |  |  |
| <b>8 Adjusted Net Income</b> (subtract lines 5, 6 and 7 from line 4)  | <b>8</b> |  |  |

**Section B - Minimum Asset Amount**

(A) Prior Year

(B) Current Year  
(optional)

- |  |           |  |  |
|--|-----------|--|--|
| <b>1</b> Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year): | <b>1</b>  |  |  |
| <b>a</b> Average monthly value of securities   | <b>1a</b> |  |  |
| <b>b</b> Average monthly cash balances   | <b>1b</b> |  |  |
| <b>c</b> Fair market value of other non-exempt-use assets  | <b>1c</b> |  |  |
| <b>d Total</b> (add lines 1a, 1b, and 1c)  | <b>1d</b> |  |  |
| <b>e Discount</b> claimed for blockage or other factors (explain in detail in <b>Part VI</b> ):  |           |  |  |
| <b>2</b> Acquisition indebtedness applicable to non-exempt use assets  | <b>2</b>  |  |  |
| <b>3</b> Subtract line 2 from line 1d  | <b>3</b>  |  |  |
| <b>4</b> Cash deemed held for exempt use. Enter 0.015 of line 3 (for greater amount, see instructions).                                  | <b>4</b>  |  |  |
| <b>5</b> Net value of non-exempt-use assets (subtract line 4 from line 3)  | <b>5</b>  |  |  |
| <b>6</b> Multiply line 5 by 0.035  | <b>6</b>  |  |  |
| <b>7</b> Recoveries of prior-year distributions  | <b>7</b>  |  |  |
| <b>8 Minimum Asset Amount</b> (add line 7 to line 6)   | <b>8</b>  |  |  |

**Section C - Distributable Amount**

Current Year

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

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

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

(continued)

Section D - Distributions		Current Year
<b>1</b> Amounts paid to supported organizations to accomplish exempt purposes	<b>1</b>	
<b>2</b> Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	<b>2</b>	
<b>3</b> Administrative expenses paid to accomplish exempt purposes of supported organizations	<b>3</b>	
<b>4</b> Amounts paid to acquire exempt-use assets	<b>4</b>	
<b>5</b> Qualified set-aside amounts (prior IRS approval required - provide details in <b>Part VI</b> )	<b>5</b>	
<b>6</b> Other distributions (describe in <b>Part VI</b> ). See instructions	<b>6</b>	
<b>7 Total annual distributions.</b> Add lines 1 through 6.	<b>7</b>	
<b>8</b> Distributions to attentive supported organizations to which the organization is responsive (provide details in <b>Part VI</b> ). See instructions	<b>8</b>	
<b>9</b> Distributable amount for 2021 from Section C, line 6	<b>9</b>	
<b>10</b> Line 8 amount divided by Line 9 amount	<b>10</b>	

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2021	(iii) Distributable Amount for 2021
<b>1</b> Distributable amount for 2021 from Section C, line 6			
<b>2</b> Underdistributions, if any, for years prior to 2021 (reasonable cause required-- explain in <b>Part VI</b> ). See instructions.			
<b>3</b> Excess distributions carryover, if any, to 2021:			
<b>a</b> From 2016. . . . .			
<b>b</b> From 2017. . . . .			
<b>c</b> From 2018. . . . .			
<b>d</b> From 2019. . . . .			
<b>e</b> From 2020. . . . .			
<b>f Total</b> of lines 3a through e			
<b>g</b> Applied to underdistributions of prior years			
<b>h</b> Applied to 2021 distributable amount			
<b>i</b> Carryover from 2016 not applied (see instructions)			
<b>j</b> Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
<b>4</b> Distributions for 2021 from Section D, line 7: \$			
<b>a</b> Applied to underdistributions of prior years			
<b>b</b> Applied to 2021 distributable amount			
<b>c</b> Remainder. Subtract lines 4a and 4b from line 4.			
<b>5</b> Remaining underdistributions for years prior to 2021, if any. Subtract lines 3g and 4a from line 2. If the amount is greater than zero, explain in <b>Part VI</b> . See instructions.			
<b>6</b> Remaining underdistributions for 2021. Subtract lines 3h and 4b from line 1. If the amount is greater than zero, explain in <b>Part VI</b> . See instructions.			
<b>7 Excess distributions carryover to 2022.</b> Add lines 3j and 4c.			
<b>8</b> Breakdown of line 7:			
<b>a</b> Excess from 2017. . . . .			
<b>b</b> Excess from 2018. . . . .			
<b>c</b> Excess from 2019. . . . .			
<b>d</b> Excess from 2020. . . . .			
<b>e</b> Excess from 2021. . . . .			

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

### Facts And Circumstances Test

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

## **Additional Data**

**Return to Form**

**Software ID:** 21013178

**Software Version:** v1.00

# Supplemental Financial Statements

# 2021

**Open to Public Inspection**

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

▶ **Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.**

Department of the Treasury  
Internal Revenue Service

**Name of the organization**  
PHELAN MCDERMID SYNDROME FOUNDATION

**Employer identification number**  
04-3673104

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

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

	(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? . . . . .  Yes  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? . . . . .  Yes  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 FASB 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 FASB ASC 958, to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, 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 FASB 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    |
|--|-----------|
| <b>c</b> Beginning balance . . . . .             | <b>1c</b> |
| <b>d</b> Additions during the year . . . . .     | <b>1d</b> |
| <b>e</b> Distributions during the year . . . . . | <b>1e</b> |
| <b>f</b> Ending balance . . . . .                | <b>1f</b> |
- 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
<b>1a</b> Beginning of year balance . . . . .	0	37,367	32,588	36,577	32,654
<b>b</b> Contributions . . . . .	0	0	0	0	0
<b>c</b> Net investment earnings, gains, and losses	0	-1,592	6,339	-2,383	5,431
<b>d</b> Grants or scholarships . . . . .	0	35,693	1,384	1,349	1,334
<b>e</b> Other expenditures for facilities and programs . . . . .	0	0	0	0	0
<b>f</b> Administrative expenses . . . . .	0	82	176	257	174
<b>g</b> End of year balance . . . . .	0	0	37,367	32,588	36,577

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

- 3a** Are there endowment funds not in the possession of the organization that are held and administered for the organization by:
- |  | Yes | No |
|--|-----|----|
| <b>(i)</b> Unrelated organizations . . . . .   | No  | No |
| <b>(ii)</b> Related organizations . . . . .  | No  | No |
| <b>b</b> If "Yes" on 3a(ii), are the related organizations listed as required on Schedule R? . . . . . |     |    |
- 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
<b>1a</b> Land . . . . .	0	0	0	0
<b>b</b> Buildings . . . . .	0	0	0	0
<b>c</b> Leasehold improvements	0	0	0	0
<b>d</b> Equipment . . . . .	0	13,017	13,017	0
<b>e</b> Other . . . . .	0	0	0	0
<b>Total.</b> Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c).) . . . . .				0

**Part VII Investments - Other Securities.**

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

(a) Description of security or category (including name of security)	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1) Financial derivatives . . . . .		
(2) Closely-held equity interests . . . . .		
(3) Other _____		
(A)		
(B)		
(C)		
(D)		
(E)		
(F)		
(G)		
(H)		
<b>Total.</b> (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)		
<b>Total.</b> (Column (b) must equal Form 990, Part X, col.(B) line 13.)		

**Part IX Other Assets.**

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

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

**Part X Other Liabilities.**

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

1. (a) Description of liability	(b) Book value
(1) Federal income taxes	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
<b>Total.</b> (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.

<b>1</b>	Total revenue, gains, and other support per audited financial statements . . . . .		<b>1</b>	898,356
<b>2</b>	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
<b>a</b>	Net unrealized gains (losses) on investments . . . . .	<b>2a</b>	0	
<b>b</b>	Donated services and use of facilities . . . . .	<b>2b</b>	0	
<b>c</b>	Recoveries of prior year grants . . . . .	<b>2c</b>	0	
<b>d</b>	Other (Describe in Part XIII.) . . . . .	<b>2d</b>	0	
<b>e</b>	Add lines <b>2a</b> through <b>2d</b> . . . . .			<b>2e</b> 0
<b>3</b>	Subtract line <b>2e</b> from line <b>1</b> . . . . .			<b>3</b> 898,356
<b>4</b>	Amounts included on Form 990, Part VIII, line 12, but not on line 1:			
<b>a</b>	Investment expenses not included on Form 990, Part VIII, line 7b . . . . .	<b>4a</b>	0	
<b>b</b>	Other (Describe in Part XIII.) . . . . .	<b>4b</b>	-1,354	
<b>c</b>	Add lines <b>4a</b> and <b>4b</b> . . . . .			<b>4c</b> -1,354
<b>5</b>	Total revenue. Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 12.) . . . . .			<b>5</b> 897,002

**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.

<b>1</b>	Total expenses and losses per audited financial statements . . . . .		<b>1</b>	498,778
<b>2</b>	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
<b>a</b>	Donated services and use of facilities . . . . .	<b>2a</b>	0	
<b>b</b>	Prior year adjustments . . . . .	<b>2b</b>	0	
<b>c</b>	Other losses . . . . .	<b>2c</b>	0	
<b>d</b>	Other (Describe in Part XIII.) . . . . .	<b>2d</b>	0	
<b>e</b>	Add lines <b>2a</b> through <b>2d</b> . . . . .			<b>2e</b> 0
<b>3</b>	Subtract line <b>2e</b> from line <b>1</b> . . . . .			<b>3</b> 498,778
<b>4</b>	Amounts included on Form 990, Part IX, line 25, but not on line 1:			
<b>a</b>	Investment expenses not included on Form 990, Part VIII, line 7b . . . . .	<b>4a</b>	0	
<b>b</b>	Other (Describe in Part XIII.) . . . . .	<b>4b</b>	-1,354	
<b>c</b>	Add lines <b>4a</b> and <b>4b</b> . . . . .			<b>4c</b> -1,354
<b>5</b>	Total expenses. Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 18.) . . . . .			<b>5</b> 497,424

**Part XIII****Supplemental Information**

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

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

## **Additional Data**

[\*\*Return to Form\*\*](#)

**Software ID:** 21013178

**Software Version:** v1.00

**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](http://www.irs.gov/Form990) for instructions and the latest information.

Name of the organization  
**PHELAN MCDERMID SYNDROME FOUNDATION**

**Employer identification number**  
 04-3673104

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

- 1** Indicate whether the organization raised funds through any of the following activities. Check all that apply.
- |  |   |
|--|---|
| <b>a</b> <input type="checkbox"/> Mail solicitations               | <b>e</b> <input type="checkbox"/> Solicitation of non-government grants |
| <b>b</b> <input type="checkbox"/> Internet and email solicitations | <b>f</b> <input type="checkbox"/> Solicitation of government grants     |
| <b>c</b> <input type="checkbox"/> Phone solicitations              | <b>g</b> <input type="checkbox"/> Special fundraising events            |
| <b>d</b> <input type="checkbox"/> In-person solicitations          |   |
- 2a** Did the organization have a written or oral agreement with any individual (including officers, directors, trustees or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services?  **Yes**  **No**
- b** If "Yes," list the 10 highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization.

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

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

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

		(a) Event #1 <u>Phelan Lucky</u> (event type)	(b) Event #2 _____ (event type)	(c) Other events _____ (total number)	(d) Total events (add col. (a) through col. (c))
<b>Revenue</b>	<b>1</b> Gross receipts . . . . .	124,308			124,308
	<b>2</b> Less: Contributions . . . . .	37,643			37,643
	<b>3</b> Gross income (line 1 minus line 2) . . . . .	86,665			86,665
<b>Direct Expenses</b>	<b>4</b> Cash prizes . . . . .	0			0
	<b>5</b> Noncash prizes . . . . .	0			0
	<b>6</b> Rent/facility costs . . . . .	0			0
	<b>7</b> Food and beverages . . . . .	0		0	0
	<b>8</b> Entertainment . . . . .	0		0	0
	<b>9</b> Other direct expenses . . . . .	437			437
	<b>10</b> Direct expense summary. Add lines 4 through 9 in column (d) . . . . . ▶				437
<b>11</b> Net income summary. Subtract line 10 from line 3, column (d) . . . . . ▶				86,228	

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

		(a) Bingo	(b) Pull tabs/Instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col.(a) through col.(c))
<b>Revenue</b>	<b>1</b> Gross revenue . . . . .				
<b>Direct Expenses</b>	<b>2</b> Cash prizes . . . . .				
	<b>3</b> Noncash prizes . . . . .				
	<b>4</b> Rent/facility costs . . . . .				
	<b>5</b> Other direct expenses . . . . .				
<b>6</b> 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		
<b>7</b> Direct expense summary. Add lines 2 through 5 in column (d) . . . . . ▶					
<b>8</b> Net gaming income summary. Subtract line 7 from line 1, column (d) . . . . . ▶					

**9** Enter the state(s) in which the organization conducts gaming activities: \_\_\_\_\_

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

**b** If "No," explain: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

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

**b** If "Yes," explain: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

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

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

13 Indicate the percentage of gaming activity conducted in:

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

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

Name ▶ -----

Address ▶ -----

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

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

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

Name ▶ -----

Address ▶ -----

16 Gaming manager information:

Name ▶ -----

Gaming manager compensation ▶ \$ -----

Description of services provided ▶ -----

Director/officer       Employee       Independent contractor

17 Mandatory distributions:

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

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

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

Return Reference	Explanation
------------------	-------------

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

**Schedule I  
(Form 990)**

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

OMB No. 1545-0047

**2021**

**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](http://www.irs.gov/Form990) for the latest information.

Name of the organization  
PHELAN MCDERMID SYNDROME FOUNDATION

**Employer identification number**  
04-3673104

**Part I General Information on Grants and Assistance**

- 1** Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? . . . . .  **Yes**  **No**
- 2** Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States.

**Part II Grants and Other Assistance to Domestic Organizations and Domestic Governments.** Complete if the organization answered "Yes" on Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Part II can be duplicated if additional space is needed.

(a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
(1) Kyle's Angels 13940 Tapestry Lane Saint Robert, MO 65584	85-1554186		11,688				To fund travel assistance for individuals with Phelan-McDermid Syndrome and their families to events hosted by the Phelan-McDermid Syndrome Foundation, most notably the biennial international family conference.

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

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

Part III can be duplicated if additional space is needed.

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

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

Return Reference	Explanation
Schedule I, Part I, Line 2	PMSF verifies 501(c)(3) status with those it grants funding to and stipulates that the funds are to be used for the benefit of programs that support individuals with Phelan-McDermid Syndrome and their families.

## Additional Data

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

OMB No. 1545-0047

**2021****Open to Public  
Inspection**Name of the organization  
PHELAN MCDERMID SYNDROME FOUNDATION**Employer identification number**

04-3673104

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

## **Additional Data**

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