

**Return of Organization Exempt From Income Tax**

**2010**

**Open to Public Inspection**

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except black lung benefit trust or private foundation)

The organization may have to use a copy of this return to satisfy state reporting requirements.

Department of the Treasury  
Internal Revenue Service

**A For the 2010 calendar year, or tax year beginning** , 2010, and ending ,

**B** Check if applicable:  
 Address change  
 Name change  
 Initial return  
 Terminated  
 Amended return  
 Application pending

**D Employer Identification Number**  
04-3673104

**E Telephone number**  
941-485-8000

**G Gross receipts \$** 402,340.

**F Name and address of principal officer** SUSAN LOMAS  
SAME AS C ABOVE

**H(a)** Is this a group return for affiliates?  Yes  No  
**H(b)** Are all affiliates included?  Yes  No  
 If 'No,' attach a list (see instructions)

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

**J Website:** WWW.PMSF.ORG **H(c) Group exemption number** ▶

**K Form of organization**  Corporation  Trust  Association  Other ▶ **L Year of Formation** 2002 **M State of legal domicile** SC

Part I Summary		Prior Year	Current Year
Activities & Governance	1 Briefly describe the organization's mission or most significant activities <u>TO BUILD AN INTERNATIONAL ALLIANCE OF FAMILY SUPPORT FOR DIAGNOSED INDIVIDUALS AND TO PROVIDE FAMILIES AND PROFESSIONALS AN OPPORTUNITY FOR SCIENTIFIC EDUCATION AND INFORMATIONAL EXCHANGE. TO IMPROVE THE QUALITY OF LIFE FOR INDIVIDUALS AND FAMILIES AFFECTED BY PHELAN-MCDERMID</u>		
	2 Check this box <input type="checkbox"/> 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	5
	5 Total number of individuals employed in calendar year 2010 (Part V, line 2a)	5	3
	6 Total number of volunteers (estimate if necessary)	6	300
	7a Total unrelated business revenue from Part VIII, column (C), line 12	7a	0.
b Net unrelated business taxable income from Form 990-T, line 34	7b	0.	
Revenue	8 Contributions and grants (Part VIII, line 1h)	67,222.	321,052.
	9 Program service revenue (Part VIII, line 2g)	2,335.	30,638.
	10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)	3,173.	5,153.
	11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	2,632.	17,934.
	12 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	75,362.	374,777.
	13 Grants and similar amounts paid (Part IX, column (A), lines 1-3)		5,000.
	14 Benefits paid to or for members (Part IX, column (B), line 4)		
	15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)		55,097.
	16a Professional fundraising fees (Part IX, column (A), line 11e)		
Expenses	b Total fundraising expenses (Part IX, column (B), line 25) ▶ 29,830.		
	17 Other expenses (Part IX, column (A), lines 11d, 11f-24f)	29,593.	145,288.
	18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	29,593.	205,385.
	19 Revenue less expenses Subtract line 18 from line 12	45,769.	169,392.
Net Assets or Fund Balances	20 Total assets (Part X, line 16)	Beginning of Current Year 249,171.	End of Year 437,640.
	21 Total liabilities (Part X, line 26)	0.	17,815.
	22 Net assets or fund balances Subtract line 21 from line 20	249,171.	419,825.

**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: Susan Lomas Date: 7-27-11

Type or print name and title: SUSAN LOMAS PRESIDENT

**Paid Preparer Use Only**

Print/Type preparer's name: NON-PAID PREPARER Preparer's signature: NON-PAID PREPARER Date:                     

Check  if self employed PTIN:                     

Firm's name:                      Firm's address:                      Firm's EIN:                     

Phone no:                     

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

SCANNED AUG 11 2011

RECEIVED  
AUG 8 2011  
WU  
OPEN UP

*Handwritten initials and marks:* 2-18 23

Part III Statement of Program Service Accomplishments

Check if Schedule O contains a response to any question in this Part III

X

1 Briefly describe the organization's mission

SEE SCHEDULE O

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 X

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 X

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

4 Describe the exempt purpose achievements for each of the organization's three largest program services by expenses. Section 501(c)(3) and 501(c)(4) organizations and section 4947(a)(1) trusts 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 \$ 91,822. including grants of \$ ) (Revenue \$ 30,638.)

HOSTED BIENNIAL CONFERENCE IN GREENVILLE, SC FOR INDIVIDUALS DIAGNOSED WITH PHELAN-MCDERMID SYNDROME AND THEIR FAMILIES. 2010 CONFERENCE WAS THE MOST COMPREHENSIVE EVER SINCE FOUNDATION WAS INCORPORATED, STRETCHING OUT OVER FOUR DAYS. NEARLY 500 ATTENDEES AND 20 RESEARCHERS FROM NINE DIFFERENT COUNTRIES WERE REPRESENTED. EDUCATIONAL SESSIONS FOCUSED ON PARENTING, TOILETING, MEDICAL ISSUES, LEGAL/FINANCIAL ISSUES, TRANSITIONAL SERVICES FOR ADULTS WITH PMS, COMMUNICATION, BASIC GENETICS AND GENERAL AWARENESS. PROMISING NEW DIRECTIONS IN CURRENT RESEARCH EFFORTS TOOK A MORE PROMINENT ROLE THAN IN PRIOR CONFERENCES WITH A PANEL OF RESEARCHERS DISCUSSING THE PROGRESS OF THEIR INDIVIDUAL EFFORTS. FOUNDATION GAVE SCHOLARSHIPS IN THE FORM OF REGISTRATION FEE WAIVERS TO ALL ATTENDEES WHO REQUESTED THIS ASSISTANCE. ALSO SOLD AWARENESS-RAISING ITEMS TO FAMILIES.

4b (Code ) (Expenses \$ 12,939. including grants of \$ ) (Revenue \$ )

ENGAGED FAMILIES IN RESEARCH SUPPORT AND EDUCATION ACTIVITIES, INCLUDING ATTENDANCE AT SCIENTIFIC CONFERENCES BY INDIVIDUALS DIAGNOSED WITH PHELAN-MCDERMID SYNDROME AND THEIR FAMILIES. CONFERENCES ATTENDED INCLUDE THOSE SPONSORED BY THE SOCIETY FOR NEUROSCIENCE, THE AMERICAN COLLEGE OF MEDICAL GENETICS, THE AMERICAN SOCIETY OF HUMAN GENETICS, AND THE GENETIC ALLIANCE CONFERENCE.

4c (Code. ) (Expenses \$ 12,562. including grants of \$ ) (Revenue \$ )

STARTED THE PROCESS OF DEVELOPING A FORWARD THINKING INFRASTRUCTURE TO SUSTAIN PHELAN-MCDERMID RESEARCH AND EDUCATION, INCLUDING THE CREATION OF AN INTERNATIONAL REGISTRY FOR RESEARCHERS TO ACCESS. THE REGISTRY IS A CRITICAL STEP TOWARD LEARNING MORE ABOUT THOSE AFFECTED BY THE DISORDER, AS WELL AS THE POSSIBILITY OF IDENTIFYING PROMISING TREATMENTS TO HELP THOSE DIAGNOSED INDIVIDUALS EXPERIENCE LIFE TO THE FULLEST.

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

(Expenses \$ 24,089. including grants of \$ 5,000.) (Revenue \$ )

4e Total program service expenses 141,412.

**Part IV Checklist of Required Schedules**

	Yes	No
1 Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? If 'Yes,' complete Schedule A	X	
2 Is the organization required to complete Schedule B, Schedule of Contributors? (see instructions)	X	
3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If 'Yes,' complete Schedule C, Part I		X
4 <b>Section 501(c)(3) organizations</b> Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? If 'Yes,' complete Schedule C, Part II		X
5 Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? If 'Yes,' complete Schedule C, Part III		
6 Did the organization maintain any donor advised funds or any similar funds or accounts where donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? If 'Yes,' complete Schedule D, Part I		X
7 Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas or historic structures? If 'Yes,' complete Schedule D, Part II		X
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? If 'Yes,' complete Schedule D, Part III		X
9 Did the organization report an amount in Part X, line 21; serve as a custodian for amounts not listed in Part X, or provide credit counseling, debt management, credit repair, or debt negotiation services? If 'Yes,' complete Schedule D, Part IV		X
10 Did the organization, directly or through a related organization, hold assets in term, permanent, or quasi-endowments? If 'Yes,' complete Schedule D, Part V	X	
11 If the organization's answer to any of the following questions is 'Yes,' then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable.		
a Did the organization report an amount for land, buildings and equipment in Part X, line 10? If 'Yes,' complete Schedule D, Part VI		X
b Did the organization report an amount for investments— other securities in Part X, line 12 that is 5% or more of its total assets reported in Part X, line 16? If 'Yes,' complete Schedule D, Part VII		X
c Did the organization report an amount for investments— program related in Part X, line 13 that is 5% or more of its total assets reported in Part X, line 16? If 'Yes,' complete Schedule D, Part VIII		X
d Did the organization report an amount for other assets in Part X, line 15 that is 5% or more of its total assets reported in Part X, line 16? If 'Yes,' complete Schedule D, Part IX	X	
e Did the organization report an amount for other liabilities in Part X, line 25? If 'Yes,' complete Schedule D, Part X		X
f Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? If 'Yes,' complete Schedule D, Part X		X
12a Did the organization obtain separate, independent audited financial statements for the tax year? If 'Yes,' complete Schedule D, Parts XI, XII, and XIII		X
b Was the organization included in consolidated, independent audited financial statements for the tax year? If 'Yes,' and if the organization answered 'No' to line 12a, then completing Schedule D, Parts XI, XII, and XIII is optional		X
13 Is the organization a school described in section 170(b)(1)(A)(ii)? If 'Yes,' complete Schedule E		X
14a Did the organization maintain an office, employees, or agents outside of the United States?		X
b Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, and program service activities outside the United States? If 'Yes,' complete Schedule F, Parts I and IV		X
15 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or assistance to any organization or entity located outside the United States? If 'Yes,' complete Schedule F, Parts II and IV		X
16 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or assistance to individuals located outside the United States? If 'Yes,' complete Schedule F, Parts III and IV		X
17 Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? If 'Yes,' complete Schedule G, Part I (see instructions)		X
18 Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? If 'Yes,' complete Schedule G, Part II	X	
19 Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? If 'Yes,' complete Schedule G, Part III		X
20 a Did the organization operate one or more hospitals? If 'Yes,' complete Schedule H		X
b If 'Yes' to line 20a, did the organization attach its audited financial statements to this return? <b>Note.</b> Some Form 990 filers that operate one or more hospitals must attach audited financial statements (see instructions)		

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

	Yes	No
<b>21</b> Did the organization report more than \$5,000 of grants and other assistance to governments and organizations in the United States on Part IX, column (A), line 1? <i>If 'Yes,' complete Schedule I, Parts I and II</i>		X
<b>22</b> Did the organization report more than \$5,000 of grants and other assistance to individuals in the United States on Part IX, column (A), line 2? <i>If 'Yes,' complete Schedule I, Parts I and III</i>		X
<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>		X
<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, and that was issued after December 31, 2002? <i>If 'Yes,' answer lines 24b through 24d and complete Schedule K. If 'No,' go to line 25</i>		X
<b>24b</b> Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?		
<b>24c</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>24d</b> Did the organization act as an 'on behalf of' issuer for bonds outstanding at any time during the year?		
<b>25a</b> <b>Section 501(c)(3) and 501(c)(4) 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>		X
<b>25b</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>		X
<b>26</b> Was a loan to or by a current or former officer, director, trustee, key employee, highly compensated employee, or disqualified person outstanding as of the end of the organization's tax year? <i>If 'Yes,' complete Schedule L, Part II</i>		X
<b>27</b> Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor, or a grant selection committee member, or to a person related to such an individual? <i>If 'Yes,' complete Schedule L, Part III</i>		X
<b>28</b> Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions)		
<b>28a</b> A current or former officer, director, trustee, or key employee? <i>If 'Yes,' complete Schedule L, Part IV</i>		X
<b>28b</b> A family member of a current or former officer, director, trustee, or key employee? <i>If 'Yes,' complete Schedule L, Part IV</i>		X
<b>28c</b> An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer, director, trustee, or direct or indirect owner? <i>If 'Yes,' complete Schedule L, Part IV</i>		X
<b>29</b> Did the organization receive more than \$25,000 in non-cash contributions? <i>If 'Yes,' complete Schedule M</i>		X
<b>30</b> Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If 'Yes,' complete Schedule M</i>		X
<b>31</b> Did the organization liquidate, terminate, or dissolve and cease operations? <i>If 'Yes,' complete Schedule N, Part I</i>		X
<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>		X
<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? <i>If 'Yes,' complete Schedule R, Part I</i>		X
<b>34</b> Was the organization related to any tax-exempt or taxable entity? <i>If 'Yes,' complete Schedule R, Parts II, III, IV, and V, line 1</i>		X
<b>35</b> Is any related organization a controlled entity within the meaning of section 512(b)(13)?		X
<b>a</b> 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> <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No		
<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>		X
<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>		X
<b>38</b> Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11 and 19? <b>Note.</b> All Form 990 filers are required to complete Schedule O		X

BAA

Form 990 (2010)

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

Check if Schedule O contains a response to any question in this Part V

		Yes	No
<b>1 a</b>	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable		
<b>1 b</b>	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable		
<b>1 c</b>	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	X	
<b>2 a</b>	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		
<b>2 b</b>	If at least one is reported on line 2a, did the organization file all required federal employment tax returns? <b>Note.</b> If the sum of lines 1a and 2a is greater than 250, you may be required to e-file. (see instructions)	X	
<b>3 a</b>	Did the organization have unrelated business gross income of \$1,000 or more during the year?		X
<b>3 b</b>	If 'Yes' has it filed a Form 990-T for this year? If 'No,' provide an explanation in Schedule O		
<b>4 a</b>	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)?		X
<b>4 b</b>	If 'Yes,' enter the name of the foreign country: See instructions for filing requirements for Form TD F 90-22.1, Report of Foreign Bank and Financial Accounts.		
<b>5 a</b>	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?		X
<b>5 b</b>	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?		X
<b>5 c</b>	If 'Yes,' to line 5a or 5b, did the organization file Form 8886-T?		
<b>6 a</b>	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?		X
<b>6 b</b>	If 'Yes,' did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?		
<b>7</b>	<b>Organizations that may receive deductible contributions under section 170(c).</b>		
<b>7 a</b>	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?	X	
<b>7 b</b>	If 'Yes,' did the organization notify the donor of the value of the goods or services provided?	X	
<b>7 c</b>	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?		X
<b>7 d</b>	If 'Yes,' indicate the number of Forms 8282 filed during the year		
<b>7 e</b>	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?		X
<b>7 f</b>	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?		X
<b>7 g</b>	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?		
<b>7 h</b>	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?		
<b>8</b>	<b>Sponsoring organizations maintaining donor advised funds and section 509(a)(3) supporting organizations.</b> Did the supporting organization, or a donor advised fund maintained by a sponsoring organization, have excess business holdings at any time during the year?		
<b>9</b>	<b>Sponsoring organizations maintaining donor advised funds.</b>		
<b>9 a</b>	Did the organization make any taxable distributions under section 4966?		
<b>9 b</b>	Did the organization make a distribution to a donor, donor advisor, or related person?		
<b>10</b>	<b>Section 501(c)(7) organizations.</b> Enter		
<b>10 a</b>	Initiation fees and capital contributions included on Part VIII, line 12		
<b>10 b</b>	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities		
<b>11</b>	<b>Section 501(c)(12) organizations.</b> Enter		
<b>11 a</b>	Gross income from members or shareholders		
<b>11 b</b>	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them)		
<b>12 a</b>	<b>Section 4947(a)(1) non-exempt charitable trusts.</b> Is the organization filing Form 990 in lieu of Form 1041?		
<b>12 b</b>	If 'Yes,' enter the amount of tax-exempt interest received or accrued during the year		
<b>13</b>	<b>Section 501(c)(29) qualified nonprofit health insurance issuers.</b>		
<b>13 a</b>	Is the organization licensed to issue qualified health plans in more than one state? <b>Note.</b> See the instructions for additional information the organization must report on Schedule O.		
<b>13 b</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		
<b>13 c</b>	Enter the amount of reserves on hand		
<b>14 a</b>	Did the organization receive any payments for indoor tanning services during the tax year?		X
<b>14 b</b>	If 'Yes,' has it filed a Form 720 to report these payments? If 'No,' provide an explanation in Schedule O		

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

Check if Schedule O contains a response to any question in this Part VI

**Section A. Governing Body and Management**

		Yes	No
1 a	Enter the number of voting members of the governing body at the end of the tax year		
1 b	Enter the number of voting members included in line 1a, above, who are independent		
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?		X
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?		X
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed? SEE SCH O	X	
5	Did the organization become aware during the year of a significant diversion of the organization's assets?		X
6	Does the organization have members or stockholders?		X
7 a	Does the organization have members, stockholders, or other persons who may elect one or more members of the governing body?		X
7 b	Are any decisions of the governing body subject to approval by members, stockholders, or other persons?		X
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following		
8 a	a The governing body?	X	
8 b	b Each committee with authority to act on behalf of the governing body?		X
9	Is there any officer, director or 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		X

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

	Yes	No
10 a		X
10 b		
11 a	X	
11 b	Describe in Schedule O the process, if any, used by the organization to review this Form 990. SEE SCHEDULE O	
12 a	X	
12 b	X	
12 c	X	
13		X
14		X
15 a		X
15 b		X
15 c	If 'Yes' to line 15a or 15b, describe the process in Schedule O. (See instructions.)	
16 a		X
16 b		

**Section C. Disclosure**

- 17 List the states with which a copy of this Form 990 is required to be filed ► SEE SCHEDULE O
- 18 Section 6104 requires an organization to make its Forms 1023 (or 1024 if applicable), 990, and 990-T (501(c)(3)s only) available for public inspection. Indicate how you make these available. Check all that apply.  
 Own website     Another's website     Upon request
- 19 Describe in Schedule O whether (and if so, how) the organization makes its governing documents, conflict of interest policy, and financial statements available to the public. SEE SCHEDULE O
- 20 State the name, physical address, and telephone number of the person who possesses the books and records of the organization:  
 ► SUSAN LOMAS 200 CAPRI ISLES BLVD 7F VENICE FL 34292 941-485-8000

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

Check if Schedule O contains a response to any question in this Part VII

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

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

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

List persons in the following order: individual trustees or directors; institutional trustees; officers; key employees; highest compensated employees; and former such persons.

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

(A) Name and title	(B) Average hours per week (describe hours for related organizations in Schedule O)	(C) Position (check all that apply)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(1) SUSAN GORDON SECRETARY	2	X		X			0.	0.	0.	
(2) MIKE FRAUNCES DIRECTOR	2	X					0.	0.	0.	
(3) SUSAN LOMAS PRESIDENT	40	X		X	X		13,910.	0.	301.	
(4) NICK ASSENDELFT VICE PRESIDENT	5	X		X			0.	0.	0.	
(5) VICKI CAMARILLO TREASURER	20	X		X			0.	0.	0.	
(6) RANDY RIDDLE DIRECTOR	10	X					0.	0.	0.	
(7) KURT KOESTER DIRECTOR	2	X					0.	0.	0.	
(8) -----										
(9) -----										
(10) -----										
(11) -----										
(12) -----										
(13) -----										
(14) -----										
(15) -----										
(16) -----										
(17) -----										

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

(A) Name and title	(B) Average hours per week (describe hours for related organizations in Sch O)	(C) Position (check all that apply)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(18) -----										
(19) -----										
(20) -----										
(21) -----										
(22) -----										
(23) -----										
(24) -----										
(25) -----										
(26) -----										
(27) -----										
(28) -----										
(29) -----										
<b>1 b Sub-total</b>							13,910.	0.	301.	
<b>c Total from continuation sheets to Part VII, Section A</b>							0.	0.	0.	
<b>d Total (add lines 1b and 1c)</b>							13,910.	0.	301.	

2 Total number of individuals (including but not limited to those listed above) who received more than \$100,000 in reportable compensation from the organization ▶ 0

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

**Section B. Independent Contractors**

1 Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization.

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

2 Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 in compensation from the organization ▶ 0

**Part VIII Statement of Revenue**

		(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512, 513, or 514	
CONTRIBUTIONS, GIFTS, GRANTS AND OTHER SIMILAR AMOUNTS	<b>1 a</b> Federated campaigns	<b>1 a</b>				
	<b>b</b> Membership dues	<b>1 b</b>				
	<b>c</b> Fundraising events	<b>1 c</b> 117,784.				
	<b>d</b> Related organizations	<b>1 d</b>				
	<b>e</b> Government grants (contributions)	<b>1 e</b>				
	<b>f</b> All other contributions, gifts, grants, and similar amounts not included above	<b>1 f</b> 203,268.				
	<b>g</b> Noncash contributions included in lns 1a-1f. \$					
	<b>h Total.</b> Add lines 1a-1f		321,052.			
PROGRAM SERVICE REVENUE	<b>2 a</b> BIENNIAL CONFERENCE	Business Code	30,638.	30,638.		
	<b>b</b> -----					
	<b>c</b> -----					
	<b>d</b> -----					
	<b>e</b> -----					
	<b>f</b> All other program service revenue					
	<b>g Total.</b> Add lines 2a-2f		30,638.			
OTHER REVENUE	<b>3</b> Investment income (including dividends, interest and other similar amounts)		5,153.		5,153.	
	<b>4</b> Income from investment of tax-exempt bond proceeds					
	<b>5</b> Royalties					
	<b>6 a</b> Gross Rents	(i) Real				
		(ii) Personal				
		<b>b</b> Less: rental expenses				
		<b>c</b> Rental income or (loss)				
	<b>d</b> Net rental income or (loss)					
	<b>7 a</b> Gross amount from sales of assets other than inventory	(i) Securities				
		(ii) Other				
		<b>b</b> Less cost or other basis and sales expenses				
		<b>c</b> Gain or (loss)				
	<b>d</b> Net gain or (loss)					
	<b>8 a</b> Gross income from fundraising events (not including \$ 117,784. of contributions reported on line 1c). See Part IV, line 18	<b>a</b> 45,497.				
		<b>b</b> Less: direct expenses	<b>b</b> 27,563.			
<b>c</b> Net income or (loss) from fundraising events			17,934.		17,934.	
<b>9 a</b> Gross income from gaming activities. See Part IV, line 19	<b>a</b>					
	<b>b</b> Less direct expenses	<b>b</b>				
	<b>c</b> Net income or (loss) from gaming activities					
<b>10 a</b> Gross sales of inventory, less returns and allowances	<b>a</b>					
	<b>b</b> Less cost of goods sold	<b>b</b>				
	<b>c</b> Net income or (loss) from sales of inventory					
Miscellaneous Revenue		Business Code				
<b>11 a</b> -----	<b>a</b>					
	<b>b</b> -----					
	<b>c</b> -----					
	<b>d</b> All other revenue					
	<b>e Total.</b> Add lines 11a-11d					
<b>12 Total revenue.</b> See instructions		374,777.	30,638.	0.	23,087.	

**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) but are not required to complete columns (B), (C), and (D).

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to governments and organizations in the U.S. See Part IV, line 21	5,000.	5,000.		
2 Grants and other assistance to individuals in the U.S. See Part IV, line 22				
3 Grants and other assistance to governments, organizations, and individuals outside the U.S. See Part IV, lines 15 and 16				
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	15,257.	12,075.	2,471.	711.
6 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.	0.
7 Other salaries and wages	35,924.	11,514.	8,837.	15,573.
8 Pension plan contributions (include section 401(k) and section 403(b) employer contributions)				
9 Other employee benefits				
10 Payroll taxes	3,916.	1,805.	921.	1,190.
11 Fees for services (non-employees):				
a Management				
b Legal				
c Accounting	4,348.		4,348.	
d Lobbying				
e Professional fundraising services See Part IV, line 17				
f Investment management fees				
g Other	11,496.	11,496.		
12 Advertising and promotion	11,850.	11,070.	24.	756.
13 Office expenses	14,519.	2,395.	8,233.	3,891.
14 Information technology	4,361.	2,204.	791.	1,366.
15 Royalties				
16 Occupancy	10,192.	4,322.	1,811.	4,059.
17 Travel	19,645.	16,659.	2,986.	
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	63,056.	62,460.	227.	369.
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization				
23 Insurance	3,588.	412.	3,176.	
24 Other expenses. Itemize expenses not covered above (List miscellaneous expenses in line 24f. If line 24f amount exceeds 10% of line 25, column (A) amount, list line 24f expenses on Schedule O.)				
a -----	2,233.		318.	1,915.
b -----				
c -----				
d -----				
e -----				
f All other expenses				
25 Total functional expenses. Add lines 1 through 24f	205,385.	141,412.	34,143.	29,830.
26 Joint costs. Check here <input checked="" type="checkbox"/> if following SOP 98-2 (ASC 958-720). Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation	1,219.	792.	256.	171.

BAA

**Part X Balance Sheet**

		(A) Beginning of year		(B) End of year
ASSETS	<b>1</b> Cash – non-interest-bearing	16,864.	<b>1</b>	110,346.
	<b>2</b> Savings and temporary cash investments	210,589.	<b>2</b>	298,384.
	<b>3</b> Pledges and grants receivable, net		<b>3</b>	
	<b>4</b> Accounts receivable, net	21,718.	<b>4</b>	114.
	<b>5</b> Receivables from current and former officers, directors, trustees, key employees, and highest compensated employees. Complete Part II of Schedule L		<b>5</b>	
	<b>6</b> 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)		<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		<b>9</b>	2,500.
	<b>10a</b> Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	<b>10a</b>		
	<b>b</b> Less accumulated depreciation.	<b>10b</b>		<b>10c</b>
	<b>11</b> Investments – publicly traded securities		<b>11</b>	
	<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>	26,296.
<b>16 Total assets.</b> Add lines 1 through 15 (must equal line 34)		249,171.	<b>16</b>	437,640.
LIABILITIES	<b>17</b> Accounts payable and accrued expenses		<b>17</b>	17,042.
	<b>18</b> Grants payable		<b>18</b>	
	<b>19</b> Deferred revenue		<b>19</b>	773.
	<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> Payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons. Complete Part II of Schedule L		<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		<b>24</b>	
	<b>25</b> Other liabilities Complete Part X of Schedule D		<b>25</b>	
	<b>26 Total liabilities.</b> Add lines 17 through 25		0.	<b>26</b>
NET ASSETS OR FUND BALANCES	<b>Organizations that follow SFAS 117, check here</b> <input checked="" type="checkbox"/> <b>and complete lines 27 through 29 and lines 33 and 34.</b>			
	<b>27</b> Unrestricted net assets	249,171.	<b>27</b>	249,445.
	<b>28</b> Temporarily restricted net assets		<b>28</b>	170,380.
	<b>29</b> Permanently restricted net assets		<b>29</b>	
	<b>Organizations that do not follow SFAS 117, check here</b> <input type="checkbox"/> <b>and complete lines 30 through 34.</b>			
	<b>30</b> Capital stock or trust principal, or current funds		<b>30</b>	
	<b>31</b> Paid-in or capital surplus, or land, building, or equipment fund		<b>31</b>	
	<b>32</b> Retained earnings, endowment, accumulated income, or other funds		<b>32</b>	
<b>33</b> Total net assets or fund balances.	249,171.	<b>33</b>	419,825.	
<b>34</b> Total liabilities and net assets/fund balances.	249,171.	<b>34</b>	437,640.	

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Form 990 (2010)

**Part XI Reconciliation of Net Assets**

Check if Schedule O contains a response to any question in this Part XI

1	Total revenue (must equal Part VIII, column (A), line 12)	1	374,777.
2	Total expenses (must equal Part IX, column (A), line 25)	2	205,385.
3	Revenue less expenses. Subtract line 2 from line 1	3	169,392.
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	249,171.
5	Other changes in net assets or fund balances (explain in Schedule O) SEE SCHEDULE O	5	1,262.
6	Net assets or fund balances at end of year. Combine lines 3, 4, and 5 (must equal Part X, line 33, column (B))	6	419,825.

**Part XII Financial Statements and Reporting**

Check if Schedule O contains a response to any question in this Part XII

		Yes	No
1	Accounting method used to prepare the Form 990: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other _____ If the organization changed its method of accounting from a prior year or checked 'Other,' explain in Schedule O.		
2a	Were the organization's financial statements compiled or reviewed by an independent accountant?		X
2b	Were the organization's financial statements audited by an independent accountant?		X
2c	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		
2d	If 'Yes' to line 2a or 2b, check a box below to indicate whether the financial statements for the year were issued 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		
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?		X
3b	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.		

BAA

Form 990 (2010)

**SCHEDULE A**  
**(Form 990 or 990-EZ)**

Department of the Treasury  
Internal Revenue Service

**Public Charity Status and Public Support**

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

▶ Attach to Form 990 or Form 990-EZ. ▶ See separate instructions.

OMB No 1545 0047

**2010**

**Open to Public Inspection**

Name of the organization <b>PHELAN-MCDERMID SYNDROME FOUNDATION</b>	Employer identification number <b>04-3673104</b>
--	---

**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 11, 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.)
- 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 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.)
- 10  An organization organized and operated exclusively to test for public safety See **section 509(a)(4).**
- 11  An organization organized and operated exclusively for the benefit of, to perform the functions of, or 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 that describes the type of supporting organization and complete lines 11e through 11h.
  - a  Type I      b  Type II      c  Type III – Functionally integrated      d  Type III – Other
- e  By checking this box, I certify that the organization is not controlled directly or indirectly by one or more disqualified persons other than foundation managers and other than one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2).
- f If the organization received a written determination from the IRS that is a Type I, Type II or Type III supporting organization, check this box
- g Since August 17, 2006, has the organization accepted any gift or contribution from any of the following persons?

	Yes	No
<b>11 g (i)</b>		
<b>11 g (ii)</b>		
<b>11 g (iii)</b>		

- (i) A person who directly or indirectly controls, either alone or together with persons described in (ii) and (iii) below, the governing body of the supported organization?
- (ii) A family member of a person described in (i) above?
- (iii) A 35% controlled entity of a person described in (i) or (ii) above?

	(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1-9 above or IRC section (see instructions))	(iv) Is the organization in column (i) listed in your governing document?		(v) Did you notify the organization in column (i) of your support?		(vi) Is the organization in column (i) organized in the U.S.?		(vii) Amount of support
				Yes	No	Yes	No	Yes	No	
(A)										
(B)										
(C)										
(D)										
(E)										
<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 fails to qualify under the tests listed below, please complete Part III.)

**Section A. Public Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2006	(b) 2007	(c) 2008	(d) 2009	(e) 2010	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include 'unusual grants'.)	86,703.	83,630.	67,686.	67,222.	325,052.	630,293.
<b>2</b> Tax revenues levied for the organization's benefit and either paid to it or expended on its behalf						0.
<b>3</b> The value of services or facilities furnished by a governmental unit to the organization without charge						0.
<b>4 Total.</b> Add lines 1 through 3	86,703.	83,630.	67,686.	67,222.	325,052.	630,293.
<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).						21,543.
<b>6 Public support.</b> Subtract line 5 from line 4						608,750.

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2006	(b) 2007	(c) 2008	(d) 2009	(e) 2010	(f) Total
<b>7</b> Amounts from line 4	86,703.	83,630.	67,686.	67,222.	325,052.	630,293.
<b>8</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources		1,308.	3,415.	3,173.	5,153.	13,049.
<b>9</b> Net income from unrelated business activities, whether or not the business is regularly carried on						0.
<b>10</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.) SEE PART IV		266.		2,632.	17,934.	20,832.
<b>11 Total support.</b> Add lines 7 through 10						664,174.
<b>12</b> Gross receipts from related activities, etc (see instructions)					12	0.

**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**

<b>14</b> Public support percentage for 2010 (line 6, column (f) divided by line 11, column (f))	<b>14</b>	91.7 %
<b>15</b> Public support percentage from 2009 Schedule A, Part II, line 14	<b>15</b>	0.0 %

**16a 33-1/3% support test – 2010.** If the organization did not check the box on line 13, and the 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 – 2009.** 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 – 2010.** 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 IV how the organization meets the 'facts-and-circumstances' test. The organization qualifies as a publicly supported organization ▶

**b 10%-facts-and-circumstances test – 2009.** 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 IV 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 9 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 yr beginning in) ▶	(a) 2006	(b) 2007	(c) 2008	(d) 2009	(e) 2010	(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 yr beginning in) ▶	(a) 2006	(b) 2007	(c) 2008	(d) 2009	(e) 2010	(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 in 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 IV.)						
<b>13 Total support.</b> (Add lns 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**

<b>15</b> Public support percentage for 2010 (line 8, column (f) divided by line 13, column (f))	<b>15</b>	%
<b>16</b> Public support percentage from 2009 Schedule A, Part III, line 15	<b>16</b>	%

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

<b>17</b> Investment income percentage for <b>2010</b> (line 10c, column (f) divided by line 13, column (f))	<b>17</b>	%
<b>18</b> Investment income percentage from <b>2009</b> Schedule A, Part III, line 17	<b>18</b>	%

**19a 33-1/3% support tests – 2010.** 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 – 2009.** 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  ▶



2010

SCHEDULE A, PART IV - SUPPLEMENTAL INFORMATION PAGE 5

CLIENT PHELAN

PHELAN-MCDERMID SYNDROME FOUNDATION

04-3673104

7/07/11

09 22AM

**PART II, LINE 10 - OTHER INCOME**

<u>NATURE AND SOURCE</u>	<u>2010</u>	<u>2009</u>	<u>2008</u>	<u>2007</u>	<u>2006</u>
NET INCOME FROM FR EVENTS	17,934.				
OTHER MISCELLANEOUS INCOME		2,632.		266.	
TOTAL	<u>\$ 17,934.</u>	<u>\$ 2,632.</u>	<u>\$ 0.</u>	<u>\$ 266.</u>	<u>\$ 0.</u>

**SCHEDULE D  
(Form 990)**

Department of the Treasury  
Internal Revenue Service

**Supplemental Financial Statements**

▶ **Complete if the organization answered 'Yes,' to Form 990, Part IV, lines 6, 7, 8, 9, 10, 11, or 12.**  
▶ **Attach to Form 990. ▶ See separate instructions.**

OMB No 1545-0047

**2010**

**Open to Public Inspection**

Name of the organization

Employer identification number

PHELAN-MCDERMID SYNDROME FOUNDATION

04-3673104

**Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts.** Complete if the organization answered 'Yes' to Form 990, Part IV, line 6.

	(a) Donor advised funds	(b) Funds and other accounts
1 Total number at end of year		
2 Aggregate contributions to (during year)		
3 Aggregate 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' to Form 990, Part IV, line 7.

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

<input type="checkbox"/> Preservation of land for public use (e.g., recreation or education)	<input type="checkbox"/> Preservation of an historically important land area
<input type="checkbox"/> Protection of natural habitat	<input type="checkbox"/> Preservation of a certified historic structure
<input type="checkbox"/> 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 Tax 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 8/17/06, 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, and enforcing conservation easements during the year ▶ \_\_\_\_\_

7 Amount of expenses incurred in monitoring, inspecting, 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 XIV, 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' to Form 990, Part IV, line 8.

- 1 a 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 XIV, 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) Revenues included in 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 Revenues included in 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 XIV.
- 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 organization answered 'Yes' to 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 XIV and complete the following table
- |                                 | Amount |
|---------------------------------|--------|
| c Beginning balance             | 1c     |
| d Additions during the year     | 1d     |
| e Distributions during the year | 1e     |
| f Ending balance                | 1f     |
- 2a Did the organization include an amount on Form 990, Part X, line 21?  Yes  No
- b If 'Yes,' explain the arrangement in Part XIV

**Part V Endowment Funds.** Complete if the organization answered 'Yes' to 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	23,561.	13,778.	9,987.		
b Contributions		5,000.	10,000.		
c Net investment earnings, gains, and losses	2,856.	4,950.	-6,112.		
d Grants or scholarships					
e Other expenditures for facilities and programs					
f Administrative expenses	121.	167.	97.		
g End of year balance	26,296.	23,561.	13,778.		

- 2 Provide the estimated percentage of the year end balance held as:
- a Board designated or quasi-endowment ▶ 100.00 %
  - b Permanent endowment ▶ \_\_\_\_\_ %
  - c Term endowment ▶ \_\_\_\_\_ %
- 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 | X   |    |
| (ii) related organizations  |     | X  |
- b If 'Yes' to 3a(ii), are the related organizations listed as required on Schedule R?
- 4 Describe in Part XIV the intended uses of the organization's endowment funds.

**Part VI Land, Buildings, and Equipment.** See Form 990, Part X, line 10.

Description of investment	(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				
e Other				
<b>Total.</b> Add lines 1a through 1e (Column (d) must equal Form 990, Part X, column (B), line 10(c).)				0.

BAA

<b>Part VII Investments—Other Securities.</b> See Form 990, Part X, line 12. N/A		
(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) -----		
(I) -----		
<b>Total.</b> (Column (b) must equal Form 990 Part X, column (B) line 12.) ▶		

<b>Part VIII Investments—Program Related.</b> (See Form 990, Part X, line 13) N/A		
(a) Description of investment type	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1)		
(2)		
(3)		
(4)		
(5)		
(6)		
(7)		
(8)		
(9)		
(10)		
<b>Total.</b> (Column (b) must equal Form 990, Part X, column (B) line 13.) ▶		

<b>Part IX Other Assets.</b> (See Form 990, Part X, line 15)		(b) Book value
(a) Description		
(1) AGENCY ENDMT FDWITH GULF COAST COMM FDN		26,296.
(2)		
(3)		
(4)		
(5)		
(6)		
(7)		
(8)		
(9)		
(10)		
<b>Total.</b> (Column (b) must equal Form 990, Part X, column(B), line 15) ▶		26,296.

<b>Part X Other Liabilities.</b> (See Form 990, Part X, line 25)	
(a) Description of liability	(b) Amount
(1) Federal income taxes	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
(10)	
(11)	
<b>Total.</b> (Column (b) must equal Form 990, Part X, column (B) line 25) ▶	

2. FIN 48 (ASC 740) Footnote. In Part XIV, 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).

<b>Part XI Reconciliation of Change in Net Assets from Form 990 to Audited Financial Statements</b>		N/A
1	Total revenue (Form 990, Part VIII, column (A), line 12)	
2	Total expenses (Form 990, Part IX, column (A), line 25)	
3	Excess or (deficit) for the year. Subtract line 2 from line 1	
4	Net unrealized gains (losses) on investments	
5	Donated services and use of facilities	
6	Investment expenses	
7	Prior period adjustments	
8	Other (Describe in Part XIV)	
9	Total adjustments (net). Add lines 4 through 8	
10	Excess or (deficit) for the year per audited financial statements. Combine lines 3 and 9	

<b>Part XII Reconciliation of Revenue per Audited Financial Statements With Revenue per Return</b>		N/A
1	Total revenue, gains, and other support per audited financial statements	1
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12	
	a Net unrealized gains on investments	2a
	b Donated services and use of facilities	2b
	c Recoveries of prior year grants	2c
	d Other (Describe in Part XIV)	2d
	e Add lines 2a through 2d	2e
3	Subtract line 2e from line 1	3
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:	
	a Investments expenses not included on Form 990, Part VIII, line 7b	4a
	b Other (Describe in Part XIV.)	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

<b>Part XIII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return</b>		N/A
1	Total expenses and losses per audited financial statements	1
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:	
	a Donated services and use of facilities	2a
	b Prior year adjustments	2b
	c Other losses	2c
	d Other (Describe in Part XIV.)	2d
	e Add lines 2a through 2d	2e
3	Subtract line 2e from line 1	3
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:	
	a Investments expenses not included on Form 990, Part VIII, line 7b	4a
	b Other (Describe in Part XIV.)	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

**Part XIV Supplemental Information**

Complete this part to 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, line 8; Part XII, lines 2d and 4b, and Part XIII, lines 2d and 4b. Also complete this part to provide any additional information.

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**SCHEDULE G**  
**(Form 990 or 990-EZ)**

**Supplemental Information Regarding**  
**Fundraising or Gaming Activities**

OMB No 1545-0047

**2010**

**Open to Public**  
**Inspection**

**Complete if the organization answered 'Yes' to 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.** ▶ **See separate instructions.**

Department of the Treasury  
Internal Revenue Service

Name of the organization

Employer identification number

**PHELAN-MCDERMID SYNDROME FOUNDATION**

**04-3673104**

**Part I Fundraising Activities.** Complete if the organization answered 'Yes' to 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 column (i)	(vi) Amount paid to (or retained by) organization
		Yes	No			
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						
<b>Total</b>						0.

**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

AL AK AZ AR CA CT DC GA HI IL KS KY LA ME MD MA MI MN MS MO NH NJ NM NY NC ND OH OR  
PA RI SC TN UT VA WA WV WI CO FL OK

**Part II Fundraising Events.** Complete if the organization answered 'Yes' to 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 6a. List events with gross receipts greater than \$5,000.

		(a) Event #1	(b) Event #2	(c) Other events	(d) Total events		
		GREAT LOVE LUN (event type)	SAMMY'S RUN (event type)	3 (total number)	(add column (a) through column (c))		
REVENUE	1	Gross receipts	81,430.	33,177.	43,753.	158,360.	
	2	Less Charitable contributions	77,430.		35,433.	112,863.	
	3	Gross income (line 1 minus line 2)	4,000.	33,177.	8,320.	45,497.	
DIRECT EXPENSES	4	Cash prizes					
	5	Noncash prizes					
	6	Rent/facility costs			7,767.	7,767.	
	7	Food and beverages		19,372.		19,372.	
	8	Entertainment					
	9	Other direct expenses	154.		270.	424.	
	10	Direct expense summary Add lines 4- through 9 in column (d)				▶	27,563.
	11	Net income summary. Combine line 3, column (d), and line 10				▶	17,934.

**Part III Gaming.** Complete if the organization answered 'Yes' to 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 column (a) through column (c))	
		1	Gross revenue			
DIRECT EXPENSES	2	Cash prizes				
	3	Non-cash 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. Combine lines 1, column (d) and line 7				▶	

9 Enter the state(s) in which the organization operates gaming activities \_\_\_\_\_

a Is the organization licensed to operate 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 operate 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 operated in:

- a The organization's facility
- b An outside facility

<b>13a</b>		%
<b>13b</b>		%

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 contact 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 to be distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year ▶ \$ \_\_\_\_\_

**Part IV Supplemental Information.** Complete this part to 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 complete this part to provide any additional information (see instructions).

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**SCHEDULE O**  
**(Form 990 or 990-EZ)**

**Supplemental Information to Form 990 or 990-EZ**

OMB No 1545-0047

**2010**

**Open to Public  
Inspection**

Department of the Treasury  
Internal Revenue Service

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.

Name of the organization

Employer identification number

**PHELAN-MCDERMID SYNDROME FOUNDATION**

**04-3673104**

**EXPLANATION FOR CHANGE IN ACCOUNTING METHOLD**

THE ORGANIZATION CHANGED ITS ACCOUNTING METHOD TO COMPLY WITH THE FINANCIAL  
ACCOUNTING STANDARDS BOARD STATEMENT OF FINANCIAL ACCOUNTING STANDARDS 116,  
ACCOUNTING FOR CONTRIBUTIONS RECEIVED AND CONTRIBUTIONS MADE.

**FORM 990, PART III, LINE 1 - ORGANIZATION MISSION**

TO BUILD AN INTERNATIONAL ALLIANCE OF FAMILY SUPPORT FOR DIAGNOSED INDIVIDUALS AND  
TO PROVIDE FAMILIES AND PROFESSIONALS AN OPPORTUNITY FOR SCIENTIFIC EDUCATION AND  
INFORMATIONAL EXCHANGE. TO IMPROVE THE QUALITY OF LIFE FOR INDIVIDUALS AND FAMILIES  
AFFECTED BY PHELAN-MCDERMID SYNDROME BY FOSTERING SOUND GENETIC, BIOLOGICAL AND  
MEDICAL RESEARCH RELATED TO THE CAUSES, EFFECTS, DIAGNOSIS AND EFFECTIVE TREATMENTS  
OF PHELAN MCDERMID SYNDROME.

**FORM 990, PART III, LINE 4D - OTHER PROGRAM SERVICES DESCRIPTION**

RAISED AWARENESS OF PHELAN-MCDERMID SYNDROME IN THE SCIENTIFIC AND MEDICAL  
COMMUNITIES. IN APRIL 2010, CO-HOSTED A MINI-SYMPOSIUM IN PHILADELPHIA, PA ON  
PHELAN-MCDERMID SYNDROME AT CHILDREN'S HOSPITAL OF PHILADELPHIA. PLANNING  
ACTIVITIES AND GROUNDWORK ACCOMPLISHED FOR HOSTING THE FIRST ANNUAL SYMPOSIUM  
EXCLUSIVE TO PHELAN-MCDERMID SYNDROME IN NEW YORK IN MARCH 2011.

PROMOTED AND CONDUCTED OTHER EDUCATIONAL ACTIVITIES REGARDING PHELAN-MCDERMID  
SYNDROME TO ASSIST FAMILIES OF THOSE DIAGNOSED WITH THE DISORDER.

SUPPORTED THE DEVELOPMENT OF EFFECTIVE THERAPEUTIC TREATMENTS THROUGH SCIENTIFIC  
RESEARCH.

Name of the organization

PHELAN-MCDERMID SYNDROME FOUNDATION

Employer identification number

04-3673104

**FORM 990, PART VI, LINE 4 - SIGNIFICANT CHANGES TO ORGANIZATIONAL DOCUMENTS**

AMENDED ARTICLES OF INCORPORATION AND BYLAWS TO CHANGE NAME FROM "22Q13 DELETION SYNDROME FOUNDATION" TO "PHELAN-MCDERMID SYNDROME FOUNDATION". ALSO CHANGED SECTION 8 (A) OF ORIGINAL ARTICLES OF INCORPORATION AND CORRESPONDING SECTIONS IN BYLAWS TO GENERALIZE CERTAIN MISSION/PURPOSES. SEE ATTACHED COPIES OF AMENDED ARTICLES OF INCORPORATION AND BYLAWS.

**FORM 990, PART VI, LINE 11B - FORM 990 REVIEW PROCESS**

TREASURER PREPARES A DRAFT OF FORM 990 AND DISTRIBUTED A COPY TO ALL BOARD MEMBERS, SOLICITING COMMENTS AND QUESTIONS. AFTER THE RETURN IS REVIEWED INDEPENDENTLY AND REVISED, ANOTHER FINAL COPY IS PROVIDED TO ALL BOARD MEMBERS PRIOR TO FINAL FILING.

**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.

**FORM 990 , PART VI, LINE 17 - LIST OF STATES WHICH THIS RETURN IS FILED**

AL AK AZ AR CA CT DC GA HI IL KS KY LA ME MD MA MI MN MS MO NH NJ NM NY NC ND OH OR PA RI SC TN UT VA WA WV WI CO FL OK

**FORM 990, PART VI, LINE 19 - OTHER ORGANIZATION DOCUMENTS PUBLICLY AVAILABLE**

NO DOCUMENTS AVAILABLE TO THE PUBLIC.

2010

SCHEDULE O - SUPPLEMENTAL INFORMATION

PAGE 1

CLIENT PHELAN

PHELAN-MCDERMID SYNDROME FOUNDATION

04-3673104

7/07/11

09 22AM

**FORM 990, PART XI, LINE 5  
OTHER CHANGES IN NET ASSETS OR FUND BALANCES**

PRIOR PERIOD ADJUSTMENT

TOTAL \$ 1,262.  
\$ 1,262.

**PHELAN-MCDERMID SYNDROME FOUNDATION**

**(A South Carolina nonprofit corporation)**

**AMENDED AND RESTATED BYLAWS**

**Adopted: October 9, 2010**

**ARTICLE I – OFFICES; PURPOSE**

**Section 1.1** Business Office

The board of directors (the “Board”) may change the location of the principal office of Phelan-McDermid Syndrome Foundation, a South Carolina nonprofit corporation (the “Corporation”), which may, but is not required to be in the State of South Carolina. The Corporation shall maintain at its principal office a copy of certain records, as specified in Section 33-31-1601 as amended from time to time, or any successor thereto (the “Act”). The Corporation may have such other offices, either within or without the State of South Carolina, as the Board may designate or as the business of the Corporation may require.

**Section 1.2** Registered Office; Registered Agent

The registered office of the Corporation, required by Section 33-51-501, of the Act may be, but need not be, identical with the principal office if the principal office is in the state of South Carolina, and the address of the registered office and the name of the registered agent may be changed from time to time. The registered office must have the same address as the registered agent required by Section 33-51-501 of the Act.

**Section 1.3** Purposes

The purposes of the Corporation shall be:

- (a) To promote and conduct educational activities regarding Phelan-McDermid Syndrome caused by disorders in and around the 22Q13 genetic region, including the cause of the syndrome and its physical effects upon the persons having the syndrome.
- (b) To conduct periodic conferences and publish literature intended to educate the families of persons affected worldwide by the syndrome, to provide guidance in the care of the affected family members as research progresses, and to further the family members’ understanding of the behavioral and physical effects associated with the syndrome.
- (c) Assist research organizations in their study of the syndrome by, among other things, bringing persons with the syndrome and their families to locations where research organizations may study the behavioral and physical attributes of persons having the syndrome and conduct other research activities.

- (d) To solicit contributions of any kind to this Corporation, provided that the Corporation has the power to reject any gift made subject to any condition which the Corporation believes to be in conflict with its policy or the best interest of this Corporation.
- (e) To make distributions to organizations that themselves qualify as exempt organizations under Section 501(c)(3) of the Internal Revenue Code of 1986 (or the corresponding section of any future Federal Tax code); and
- (f) In addition to the foregoing purposes, to do any and all lawful acts and things and to engage in any and all lawful activities permitted by the Act and permissible for an exempt organization under Section 501(c)(3) of the Internal Revenue Code of 1986 (or the corresponding section of any future Federal tax code) which may be necessary, useful, suitable, desirable, or proper for the furtherance, accomplishment, or attainment of any and all the purposes for which the Corporation is organized.

#### **Section 1.4**    Mission

The mission of this corporation is as follows:

- (a) To educate the families of children with the genetic disorder known as Phelan-McDermid Syndrome and provide them with guidance and emotional support on how to manage the affected children's needs as more information is learned through genetic and behavioral research; and
- (b) To provide medical professionals, including genetic researchers, an opportunity to conduct thorough genetic and behavioral evaluations on, and to monitor progress of setbacks of persons with Phelan-McDermid Syndrome.

### **ARTICLE 2 – BOARD OF DIRECTORS**

#### **Section 2.1**    General Powers

The Corporate power, property, and affairs of the Corporation, except as otherwise provided by law, the Articles of Incorporation of the Corporation, as amended from time to time (the "Articles") or these By-Laws, shall be vested in, exercised by, conducted, controlled, and managed by the Corporation's Board of Directors (the "Board").

#### **Section 2.2**    Composition and Tenure

The Board shall consist of not less than three (3) Directors, and the Board shall by resolution from time to time otherwise determine the number of Directors. The term of office of these Directors shall be three years , and the terms of the Directors shall be staggered so that approximately one-third (1/3) of those in office may be elected in any one year. Notwithstanding the foregoing, any Director shall serve until his or her successor is duly qualified and elected or until his or her earlier death, resignation or removal.

**Section 2.3** Election

The members of the Board shall be elected by the Board at the annual meeting of the Board by the vote of the Directors whose terms do not normally expire at that annual meeting of the Board.

**Section 2.4** Compensation

No Director shall be entitled, as a right, to compensation for attendance at meetings of the Board or for any other services rendered to the Corporation in his or her capacity as Director or as a member of any committee of the Board; provided, however, that the Board in its discretion may pay or reimburse any Director for expenses reasonably and necessarily incurred by him or her in the performance of his or her duties as Director, including attendance at meetings of the Board.

**Section 2.5** Meetings

The annual meeting of the Board shall be held each year for the purpose of electing officers and for considering such other business as may be specified in the notice of the meeting. Other regular meetings of the Board shall be held at least quarterly and from time to time as is deemed necessary for the transaction of the Corporation's business. All meetings shall be held at times and places that are generally convenient for the Directors, and the Board shall determine the time and place of regular meetings. Meetings may be held on-line, via video conference, or by other means of electronic communication. Special meetings may be called by the President or any two Directors who give the President written notice of a desire to call a meeting. The time and place of any special meeting shall be determined by the President. No action may be taken at any properly noticed meeting except and until a quorum of the Board has been achieved. Prior to the calling of a vote on any proposed action, the Directors present at the meeting will strive for a consensus.

**Section 2.6** Notice

Notice of the time and place of any meeting of the Board shall be personally served upon or telephoned to each Director by the President or someone authorized by the President. Notice shall be made either by mailing or written notice of the meeting to each Director at his/her address as it then appears on the record of this Corporation at least seven (7) days before the meeting or by telephone, fax, telegraph, or email to each Director at least two (2) days before the meeting. Notice of annual meetings shall be in writing at least thirty (30) days prior to the time of the meeting. Notice of the time and place of any meeting of the Board may be waived in writing (including via email), either before or after the holding of the meeting, which waiver shall be filed or entered upon the records of the meeting. Attendance of any Director at any meeting without protesting the lack of proper notice shall be deemed a waiver of the notice of the meeting. Notwithstanding any other provision of these Bylaws to the contrary, at least seven (7) days written notice shall be given to all Directors of any meeting of the Board at which an action to remove a Director or to approve a matter that would require approval of the members if the Corporation had members is to be considered by the Board; provided, however, such notice may be waived as provided in this Section 2.6.

**Section 2.7** Quorum; Voting

To constitute a quorum at any meeting of the Board, there shall be present not less than a majority of the Directors in office immediately before the meeting begins. Each Director present at the time any vote or action of the Board is taken upon any matter shall be entitled to cast one vote with respect to that matter. If a quorum is present when a vote is taken, the affirmative vote of a majority of Directors present is the act of the Board unless applicable law, the Articles or these Bylaws specify otherwise. Any Director may participate in any meeting of the Board or any committee of the Board through the use of any means of communication by which all Directors participating in the meeting can hear or understand each other simultaneously during the meeting (including on-line over the internet). A Director participating in a meeting by such means is deemed present in person at the meeting.

**Section 2.8** Action Without a Meeting

Any action which might be taken at a meeting of the Board may be taken without a meeting if authorized by writing or writings signed by all of the Directors; provided that such writing or writings are filed with the Secretary of this Corporation and by him or her inserted into the permanent record or minutes relating to the meetings of the Board. Action taken without a meeting is effective when the last Director signs the consent, unless the consent specifies a different date. Action taken pursuant to this Section 2.8 has the effect of a meeting vote and may be described as such in any document.

**Section 2.9** Vacancies

- (a) A Director may resign at any time by delivering written notice to the Board, the Chairman, the President, or the Secretary. Any such resignation is deemed 'in effect' when the notice is received unless the notice specifies a later effective date. If a resignation is made effective at a later date, the Board may fill the vacancy before the effective date if the Board provides that the successor does not take office until the effective date contained in the resignation.
- (b) Any vacancies occurring on the Board shall be filled by a majority vote of the Directors present and constituting a quorum at any meeting of the Board, and vacancies so filled shall be to complete the unexpired term. If the Directors remaining in office constitute fewer than a quorum of the Board, they may fill the vacancy by the affirmative vote of a majority of all the Directors remaining in office.
- (c) No reduction of the authorized number of Directors shall have the effect of removing any Director from office prior to the expiration of the Director's term in office.

**Section 2.10** Removal of Directors

Any member of the Board may be removed without cause by the affirmative vote of two-thirds (2/3) of the Directors. Any member of the Board may be removed by the affirmative vote of a majority of the Directors for the following reasons:

- (a) Failure to attend, without reason, three consecutive meetings of the Board or any committee of the Corporation of which such Director is a member;

- (b) Conviction (including without limitation conviction resulting from a plea of *nolo contendere* or a plea pursuant to *North Carolina v. Alford*, 400 U.S. 25 (1970)) of any felony or of any misdemeanor involving dishonesty or false statement; or
- (c) Violation of such Director's fiduciary duties to the Corporation.

A person who has been removed for failure to attend three consecutive meetings may request a reinstatement in writing at the next meeting of the Board. Such reinstatement shall be allowed within the sole discretion of the Board.

**Section 2.11 Rights of Inspection**

Every Director shall have the absolute right at any reasonable time to inspect and copy all books, records and documents of every kind and to inspect the physical properties of the Corporation for any purpose reasonably related to such person's interest as a Director of the Corporation.

**Section 2.12 Advisory Board**

The Board of Directors shall have the absolute right to appoint an Advisory Board, the composition, rules and function of which shall be solely at the discretion of the Board of Directors.

**ARTICLE 3 – COMMITTEES OF THE BOARD**

**Section 3.1 Creation of Committees of the Board**

The Board may create standing or temporary committees with the duties assigned thereto by the Board pursuant to the provisions of this Article 3. The creation of any committee, the appointment of members to any committee, and the duties assigned to any committee must be approved by a majority of all of the Directors in office when such action is taken.

**Section 3.2 Committee Members**

Each committee must have at least one Director who serves at the pleasure of the Board and a Director must serve as Chairman or Co-Chairman of any committee.

**Section 3.3 Governance of Committees**

The provisions of Article 2 pertaining to meetings, action without meetings, notice and waiver of notice, and quorum and voting requirements of the Board, apply to committees of the Board as their members as well.

**Section 3.4 Powers Prohibited to Committees**

Notwithstanding any other provision of these Bylaws, no committee of the Board may:

- a) Authorize distributions;
- b) Approve or recommend to members the dissolution, merger, or the sale, pledge, or transfer of substantially all of the Corporation's assets;
- c) Select, appoint, or remove Directors or fill vacancies on the Board or on any of its committees;
- d) Adopt, amend, or repeal the Articles or Bylaws; or
- e) Take any other action prohibited to be taken by a committee of the Board by the Act or any successor law, the Articles, the Bylaws, or the Board.

### **Section 3.5** Committee Records

Every committee of the Board shall keep minutes and records of all of its proceedings and shall submit all of its minutes and records to the Board at the next regular meeting of the Board if such minutes and records have not previously been submitted to the Board.

## **ARTICLE 4 – OFFICERS**

### **Section 4.1** Election of Officers

The Corporation shall have a President, a Secretary, a Treasurer, and such Vice Presidents, Assistant Secretaries, Assistant Treasurers and other officers as the Board shall from time to time designate. The officers shall be elected by the Board at its regular annual meeting, and shall, unless otherwise provided by the Board, hold office for one year or until their respective successors shall have been chosen. One person may hold more than one office. Except as expressly approved by the then current disinterested members of the Board at a duly held meeting, all officers of the Corporation shall be volunteers who receive no salary or benefits other than reimbursement for their reasonable costs and expenses incurred in connection with the conduct of the business of their offices.

### **Section 4.2**

#### President

The President shall preside over all the meetings of the general membership, Board of Directors, and any special meetings. The President shall sign all official documents or instruments of the Corporation as authorized by the Board, shall make reports to the Board, shall perform such other duties as are incident to his or her office and shall have such other powers and perform such other duties as are properly required of him or her by the Board. The President shall sign all contracts and any other obligations on behalf of the Corporation as approved by the Board. The President shall also be authorized to sign checks on the Corporation's bank account. The President shall also assist the Treasurer in annually reviewing a capital budget and preparing an operating budget showing the expected receipts and expenditures, and supervise the business affairs of the Corporation to assure that funds are expended to the best possible advantage.

**Section 4.3** Vice Presidents

The Vice Presidents (in order of their appointment), in the absence or disability of the President, shall serve as the chief volunteer officer for the Corporation and perform all duties that might be performed by the President. The Vice Presidents shall have such powers and perform such duties as may be properly assigned to them by the Board or delegated to them by the President.

**Section 4.4** Secretary

The Secretary shall issue notices for all meetings as provided by these Bylaws, shall keep minutes of all meetings, shall have custody of the books and records of the Corporation, except as they shall have been vested in the Treasurer or some other officer, shall perform such other duties as are incident to his or her office and shall have such other powers and perform such other duties as are properly required of him or her by the Board. If so authorized by the Board, the Secretary may also serve as Treasurer.

**Section 4.6** Treasurer

The Treasurer shall have custody of all monies and securities of the Corporation and shall deposit them in the name of this Corporation in such bank or banks as the Board may designate. He or she shall oversee the disbursement of monies of the Corporation and payment of the just demands of the Corporation or as may be ordered by the Board, and shall render to the Board from time to time as may be required an account of all transactions of the Corporation and of the financial condition of the Corporation, shall perform such other duties as are incident to his or her office and shall have such other powers and perform such other duties as are properly required of him or her by the Board.

**Section 4.7** Resignation and Removal of Officers

Any officer may be removed from office by the Board at any time with or without cause. Any officer may resign at any time by delivering written notice of his or her resignation to the Corporation. A resignation is effective when delivered unless a future effective date is specified.

**ARTICLE 5 – MISCELLANEOUS**

**Section 5.1** No Members

The Corporation shall not have any members. Any action which would otherwise require the approval of members shall only require the approval of the Board. All rights which would otherwise vest in members shall vest in the Board. Notwithstanding the foregoing, nothing in these Bylaws shall limit the right of the Corporation to refer to persons associated with the Corporation as “members” even though the Corporation does not have members within the meaning of the Act, and no such reference shall be deemed to constitute a reference to a member or members within the meaning of the Act.

**Section 5.2** Indemnification

The Corporation shall, to the fullest extent permitted by applicable law, indemnify the Directors and the Officers of the Corporation provided for in Article 4 of these Bylaws and shall

pay for or reimburse the reasonable expenses (including without limitation attorneys fees) incurred by such Director or Officer who is a party to a proceeding in advance of final disposition of the proceeding. The Corporation may, at the sole discretion of the Board up to an extent not exceeding the fullest extent permitted by applicable law, indemnify any other employee or agent of the Corporation and pay for or reimburse the reasonable expenses (including without limitation attorneys fees) incurred by such employee or agent who is party to a proceeding in advance of final disposition of the proceeding. The Board may, but is not required to, purchase Director and Officer liability insurance in such amounts and with such terms as the Board may, in its sole discretion, approve subject to the requirements of applicable law.

**Section 5.3** Dissolution; Distribution on Dissolution

- a) Dissolution must be approved by a vote of a majority of the Directors in office at the time such transaction is approved.
- b) Directors must receive seven (7) days prior written notice of any meeting at which dissolution of the Corporation will be voted on unless such notice is waived as provided for in these Bylaws, and such notice must state that one of the purposes of the meeting is to consider dissolution and contain or be accompanied by a copy or summary of the proposed plan of dissolution.
- c) Any plan of dissolution shall indicate to whom the assets owned or held by the Corporation will be distributed after all creditors have been paid. No Director, Officer or any other private individual shall be entitled to share in the distribution of any of the assets of the Corporation upon dissolution of the Corporation. Upon dissolution of the Corporation, the corporate assets shall be distributed to an entity qualified as exempt under Section 501(c)(3) and 170(c) of the Internal Revenue Code or the corresponding provision of any successor law, or to the U.S. Federal government, the State of South Carolina, a local government in the State of South Carolina or a division, department or agency of any of the foregoing as selected by the Board, to be used exclusively for public purposes.

**Section 5.4** Records

- a) The Corporation shall keep as permanent records minutes of all meetings of the Board, a record of all actions taken by the Board without a meeting, and a record of all actions taken by committees of the Board. The Corporation shall maintain appropriate accounting records. All records of the Corporation shall be maintained in written form or in form capable of conversion into written form within a reasonable time.
- b) The Corporation shall keep a copy of the following records at its principle office:
  - i. Its Articles or restated Articles, and all amendments to them currently in effect;
  - ii. Its Bylaws or restated Bylaws and all amendments to them currently in effect;

- iii. A list of names and business or home addresses of its current Directors and Officers: and,
- iv. Its most recent report of each type required to be filled by it with the South Carolina Secretary of State by the Act.

**Section 5.5** Finance

The proposed annual budget of estimated income and expenditures shall be approved by the Board of Directors. No expense shall be incurred in excess of budgetary appropriation without prior approval from the Board.

**Section 5.6** Interested Party Transactions

Any Director, Officer or employee of the Corporation having an interest in any contract or other transaction presented to the Board for authorization, approval, or ratification shall make prompt, full and frank disclosure of his or her interest to the Board prior to its action on such a contract or transaction. Such disclosure shall include any relevant material facts known to such person about the contract or transaction which may reasonably be construed to be in conflict with the Corporation's interest. The Board shall thereupon determine, by majority vote whether such disclosure shows that a conflict of interest exists or can reasonably be construed to exist. If a conflict is deemed to exist, such person shall not vote on, nor participate in the discussion or deliberations with respect to such contract or transaction (other than to present the information required to be disclosed by this Section 5.6 or respond to questions). For the purposes of this Section 5.6, by way of example and not by way of limitation, a person shall be deemed to have an interest in a contract or other transaction if he, she or a close relative is a party (or one of the parties) contracting or dealing with the Corporation, or is a Director or Officer or has a significant financial or influential interest in the entity contracting or dealing with Corporation.

**Section 5.7** Corporate Seal

The Board may adopt a corporate seal for the Corporation. If so adopted, the corporate seal, to be used in authenticating documents, shall contain the name of the Corporation or a successor name stated in an amendment to the Articles, and shall otherwise be in such form as the Board may determine.

**Section 5.8** Fiscal year

The fiscal year of the Corporation shall be the calendar year unless the Board determines otherwise.

**Section 5.9** Insurance

Financial theft or monetary loss insurance shall be maintained, at the expense of the Corporation in the amount designated by the Board, on every officer or employee of the Corporation who shall handle funds or securities of the Corporation.

**Section 5.10** Amendments

CERTIFICATE OF SECRETARY

I, Susan Gordon, do hereby certify as follows:

1. I am the duly elected and acting Secretary of the Phelan-McDermid Syndrome Foundation, a South Carolina corporation (the "Corporation").
2. The foregoing bylaws, consisting of 10 pages, are the true and correct Bylaws of the Corporation as adopted by the board of directors on October 9, 2010.

IN WITNESS WHEREOF, I have hereunto subscribed my name this October 10, 2010.

  
Susan Gordon, Secretary

CERTIFIED TO BE A TRUE AND CORRECT COPY  
ASTAKEN FROM AND COMPARED WITH THE  
ORIGINAL ON FILE IN THIS OFFICE

FEB 22 2010

STATE OF SOUTH CAROLINA  
SECRETARY OF STATE  
NONPROFIT CORPORATION  
ARTICLES OF AMENDMENT

  
SECRETARY OF STATE OF SOUTH CAROLINA

1. On August 15, 2010, 22q13 Deletion Syndrome Foundation, a South Carolina non-profit corporation, adopted the following amendments to its nonprofit corporation articles of incorporation.

(a) The name of the corporation is hereby amended to be:

“Phelan-McDermid Syndrome Foundation.”

(b) Section 8(a) is hereby deleted in its entirety and replaced by the following:

- i. To promote and conduct educational activities regarding Phelan McDermid Syndrome caused by disorders in and around the 22q13 genetic region, including the cause of the syndrome and its physical effects upon the persons having the syndrome;
- ii. To conduct periodic conferences and publish literature intended to educate the families of persons affected worldwide by the syndrome, to provide guidance in the care of the affected family members as research progresses, and to further the family members’ understanding of the behavioral and physical effects associated with the syndrome;
- iii. Assist research organizations in their study of the syndrome by, among other things, bringing persons with the syndrome and their families to locations where research organizations may study the behavioral and physical attributes of persons having the syndrome and conduct other research activities.
- iv. To solicit contributions of any kind to this corporation, provided that the corporation has the power to reject any gift made subject to any condition which the corporation believes to be in conflict with its policy or the best interests of this corporation.
- v. To make distributions to organizations that themselves qualify as exempt organizations under Section 501(c)(3) of the Internal Revenue Code of 1986 (or the corresponding section of any future Federal tax code); and
- vi. In addition to the foregoing purposes, to do any and all lawful acts and things and to engage in any and all lawful activities permitted by the South Carolina Nonprofit Corporation Act of 1994, as amended from time to time or any successor act, and permissible for an exempt organization under Section 501(c)(3) of the Internal Revenue Code of 1986 (or corresponding section of any future

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PHELAN-McDERMID SYNDROME FOUNDATION  
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Mark Hammond

South Carolina Secretary of State

Federal tax code) which may be necessary, useful, suitable, desirable, or proper for the furtherance, accomplishment, or attainment of any and all the purposes for which the corporation is organized.

2. The corporation has no members; therefore, approval by members is not applicable and was not required. The amendments were approved by the Board of Directors.

22q13 Deletion Syndrome Foundation

Date 2/12/10

Susan Lomas  
Susan Lomas, President