

PHELAN-McDERMID SYNDROME FOUNDATION, INC.
FINANCIAL STATEMENTS
AND
INDEPENDENT AUDITOR'S REPORT
DECEMBER 31, 2017 AND 2016

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INDEPENDENT AUDITOR'S REPORT

To the Board of Directors
Phelan-McDermid Syndrome Foundation, Inc.
Venice, Florida

We have audited the accompanying financial statements of Phelan-McDermid Syndrome Foundation, Inc. (a nonprofit organization), which comprise the statement of financial position as of December 31, 2017 and 2016, and the related statements of activities and cash flows for the years then ended, and the related notes to the financial statements.

Management's Responsibility for the Financial Statements

Management is responsible for the preparation and fair presentation of these financial statements in accordance with accounting principles generally accepted in the United States of America; this includes the design, implementation, and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

Auditor's Responsibility

Our responsibility is to express an opinion on these financial statements based on our audit. We conducted our audit in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. Accordingly, we express no such opinion. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Opinion

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of Phelan-McDermid Syndrome Foundation, Inc. as of December 31, 2017 and 2016, and the changes in its net assets and its cash flows for the years then ended in accordance with accounting principles generally accepted in the United States of America.

Report on Supplementary Information

Our audit was conducted for the purpose of forming an opinion on the financial statements as a whole. The schedules of functional expenses on pages 16 and 17 are presented for purposes of additional analysis and are not required parts of the financial statements. Such information is the responsibility of management

To the Board of Directors
Phelan McDermid Syndrome Foundation, Inc.

and was derived from and relates directly to the underlying accounting and other records used to prepare the financial statements. The information has been subjected to the auditing procedures applied in the audit of the financial statements and certain additional procedures, including comparing and reconciling such information directly to the underlying accounting and other records used to prepare the financial statements or to the financial statements themselves, and other additional procedures in accordance with auditing standards generally accepted in the United States of America. In our opinion, the information is fairly stated in all material respects in relation to the financial statements as a whole.



Dowd Whittaker & Associates
Certified Public Accountants
Venice, Florida

April 20, 2018

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.
STATEMENT OF FINANCIAL POSITION
December 31, 2017

(See Independent Auditor's Report)

| | Assets | | |
|---|---------------------|-------------------------------|---------------------|
| | <u>Unrestricted</u> | <u>Temporarily Restricted</u> | <u>Total</u> |
| Current Assets | | | |
| Cash and cash equivalents | \$ 979,101 | \$ 8,877 | \$ 987,978 |
| Contract billings receivable | 151,196 | - | 151,196 |
| Unbilled contract revenue | 7,800 | - | 7,800 |
| Prepaid insurance | 2,824 | - | 2,824 |
| Deposits | 7,560 | - | 7,560 |
| Total Current Assets | <u>1,148,481</u> | <u>8,877</u> | <u>1,157,358</u> |
| Non Current Assets | | | |
| Investments | 36,577 | - | 36,577 |
| Equipment, net of \$7,499 accumulated depreciation | <u>3,307</u> | <u>-</u> | <u>3,307</u> |
| Total Non Current Assets | <u>39,884</u> | <u>-</u> | <u>39,884</u> |
| Total Assets | <u>\$ 1,188,365</u> | <u>\$ 8,877</u> | <u>\$ 1,197,242</u> |
| Liabilities and Net Assets | | | |
| Current Liabilities | | | |
| Accounts payable | \$ 130,619 | \$ - | \$ 130,619 |
| Grants payable | 21,000 | - | 21,000 |
| Accrued liabilities | 7,800 | - | 7,800 |
| Accrued payroll and related taxes | <u>3,643</u> | <u>-</u> | <u>3,643</u> |
| Total Current Liabilities | <u>163,062</u> | <u>-</u> | <u>163,062</u> |
| Total Liabilities | <u>163,062</u> | <u>-</u> | <u>163,062</u> |
| Net Assets | | | |
| Unrestricted | 1,025,303 | - | 1,025,303 |
| Temporarily restricted | <u>-</u> | <u>8,877</u> | <u>8,877</u> |
| Total Net Assets | <u>1,025,303</u> | <u>8,877</u> | <u>1,034,180</u> |
| Total Liabilities and Net Assets | <u>\$ 1,188,365</u> | <u>\$ 8,877</u> | <u>\$ 1,197,242</u> |

The accompanying notes are an integral part of these financial statements.

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.

STATEMENT OF FINANCIAL POSITION

December 31, 2016

(See Independent Auditor's Report)

| | Assets | | |
|---|---------------------|-----------------------------------|---------------------|
| | <u>Unrestricted</u> | <u>Temporarily Restricted</u> | <u>Total</u> |
| Current Assets | | | |
| Cash and cash equivalents | \$ 880,405 | \$ 11,542 | \$ 891,947 |
| Contract billings receivable | 211,911 | - | 211,911 |
| Unbilled contract revenue | 14,700 | - | 14,700 |
| Contributions receivable | 34,999 | - | 34,999 |
| Prepaid insurance | 3,687 | - | 3,687 |
| Deposits | 200 | - | 200 |
| Total Current Assets | <u>1,145,902</u> | <u>11,542</u> | <u>1,157,444</u> |
| Non Current Assets | | | |
| Investments | 32,654 | - | 32,654 |
| Equipment, net of \$5,557 accumulated depreciation | <u>3,715</u> | <u>-</u> | <u>3,715</u> |
| Total Non Current Assets | <u>36,369</u> | <u>-</u> | <u>36,369</u> |
| Total Assets | <u>\$ 1,182,271</u> | <u>\$ 11,542</u> | <u>\$ 1,193,813</u> |
| Liabilities and Net Assets | | | |
| Current Liabilities | | | |
| Accounts payable | \$ 171,867 | \$ - | \$ 171,867 |
| Grants payable | 14,000 | - | 14,000 |
| Accrued liabilities | 14,700 | - | 14,700 |
| Current portion of capital lease payable | <u>2,800</u> | <u>-</u> | <u>2,800</u> |
| Total Current Liabilities | <u>203,367</u> | <u>-</u> | <u>203,367</u> |
| Total Liabilities | <u>203,367</u> | <u>-</u> | <u>203,367</u> |
| Net Assets | | | |
| Unrestricted | 978,904 | - | 978,904 |
| Temporarily restricted | <u>-</u> | <u>11,542</u> | <u>11,542</u> |
| Total Net Assets | <u>978,904</u> | <u>11,542</u> | <u>990,446</u> |
| Total Liabilities and Net Assets | <u>\$ 1,182,271</u> | <u>\$ 11,542</u> | <u>\$ 1,193,813</u> |

The accompanying notes are an integral part of these financial statements.

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.
STATEMENT OF ACTIVITIES
For the year ended December 31, 2017

(See Independent Auditor's Report)

| | Unrestricted | Temporarily Restricted | Total |
|--------------------------------------|---------------------|-----------------------------------|--------------|
| Support and Revenue: | | | |
| General Contributions: | | | |
| Individuals | \$ 312,363 | 11,923 | \$ 324,286 |
| Businesses and organizations | 90,451 | 7,671 | 98,122 |
| In-kind | 2,754 | - | 2,754 |
| Total General Contributions | 405,568 | 19,594 | 425,162 |
| Special Events: | | | |
| Contributions | 10,923 | - | 10,923 |
| Other event revenue | 77,775 | - | 77,775 |
| Less: direct expenses | (3,644) | - | (3,644) |
| Total Special Events | 85,054 | - | 85,054 |
| Other Revenue: | | | |
| Symposium registration fees | 5,631 | - | 5,631 |
| Contractual income | 638,692 | - | 638,692 |
| Interest income | 394 | - | 394 |
| Investment income | 5,257 | - | 5,257 |
| Store sales | 3,911 | - | 3,911 |
| Total Other Revenue | 653,885 | - | 653,885 |
| Subtotal Support and Revenue | 1,144,507 | 19,594 | 1,164,101 |
| Net assets released from restriction | 22,259 | (22,259) | - |
| Total Support and Revenue | 1,166,766 | (2,665) | 1,164,101 |
| Expenses: | | | |
| Program services | 899,918 | - | 899,918 |
| Management and general | 172,543 | - | 172,543 |
| Fund raising | 47,906 | - | 47,906 |
| Total Expenses | 1,120,367 | - | 1,120,367 |
| Increase (decrease) in net assets | 46,399 | (2,665) | 43,734 |
| Net assets at beginning of year | 978,904 | 11,542 | 990,446 |
| Net assets at end of year | \$ 1,025,303 | \$ 8,877 | \$ 1,034,180 |

The accompanying notes are an integral part of these financial statements.

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.
STATEMENT OF ACTIVITIES
For the year ended December 31, 2016

(See Independent Auditor's Report)

| | Unrestricted | Temporarily Restricted | Total |
|--------------------------------------|---------------------|-----------------------------------|--------------|
| Support and Revenue: | | | |
| General Contributions: | | | |
| Individuals | \$ 167,561 | \$ 18,400 | \$ 185,961 |
| Businesses and organizations | 377,903 | 7,000 | 384,903 |
| In-kind | 5,854 | - | 5,854 |
| Total General Contributions | 551,318 | 25,400 | 576,718 |
| Special Events: | | | |
| Contributions | 3,828 | - | 3,828 |
| Total Special Events | 3,828 | - | 3,828 |
| Other Revenue: | | | |
| Family conference registration fees | 48,076 | - | 48,076 |
| Contractual income | 622,463 | - | 622,463 |
| Interest income | 283 | - | 283 |
| Investment income | 2,281 | - | 2,281 |
| Miscellaneous income | 12,523 | - | 12,523 |
| Store sales | 11,761 | - | 11,761 |
| Total Other Revenue | 697,387 | - | 697,387 |
| Subtotal Support and Revenue | 1,252,533 | 25,400 | 1,277,933 |
| Net assets released from restriction | 35,940 | (35,940) | - |
| Total Support and Revenue | 1,288,473 | (10,540) | 1,277,933 |
| Expenses: | | | |
| Program services | 862,738 | - | 862,738 |
| Management and general | 154,324 | - | 154,324 |
| Fund raising | 34,858 | - | 34,858 |
| Total Expenses | 1,051,920 | - | 1,051,920 |
| Increase (decrease) in net assets | 236,553 | (10,540) | 226,013 |
| Net assets at beginning of year | 742,351 | 22,082 | 764,433 |
| Net assets at end of year | \$ 978,904 | \$ 11,542 | \$ 990,446 |

The accompanying notes are an integral part of these financial statements.

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.
STATEMENT OF CASH FLOWS
For the Years Ended December 31, 2017 and 2016

(See Independent Auditor's Report)

| | <u>2017</u> | <u>2016</u> |
|---|-------------------|-------------------|
| Cash flows from operating activities: | | |
| Increase (decrease) in net assets | \$ 43,734 | \$ 226,013 |
| Adjustments to reconcile increase in net assets to net cash provided by operating activities: | | |
| Depreciation | 2,211 | 1,942 |
| Change in contract billings receivable | 60,715 | (25,911) |
| Change in unbilled contract revenue | 6,900 | 54,601 |
| Change in contributions receivable | 34,999 | 2,340 |
| Change in prepaid insurance | 863 | (4) |
| Change in deposits | (7,360) | 1,000 |
| Change in fixed asset additions | (1,803) | (2,181) |
| Change in accounts payable | (41,248) | 27,678 |
| Change in grants payable | 7,000 | (60,599) |
| Change in accrued liabilities | 7,800 | (48,300) |
| Change in accrued payroll and related taxes | (11,057) | 2,800 |
| Total Adjustments | <u>59,020</u> | <u>(46,634)</u> |
| Net cash provided (used) by operating activities | <u>102,754</u> | <u>179,379</u> |
| Cash flows from investing activities: | | |
| Change in investments | <u>(3,923)</u> | <u>(952)</u> |
| Net cash provided (used) by investing activities | <u>(3,923)</u> | <u>(952)</u> |
| Cash flows from financing activities: | | |
| Payment of Capital lease | <u>(2,800)</u> | <u>(1,353)</u> |
| Net cash provided (used) by financing activities | <u>(2,800)</u> | <u>(1,353)</u> |
| Net increase (decrease) in cash and equivalents | 96,031 | 177,074 |
| Cash and equivalents, beginning of year | <u>891,947</u> | <u>714,873</u> |
| Cash and equivalents, end of year | <u>\$ 987,978</u> | <u>\$ 891,947</u> |
| Supplemental Disclosure: | | |
| Interest paid | \$ - | \$ 69 |

The accompanying notes are an integral part of these financial statements.

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2017 and 2016

(See Independent Auditor's Report)

NOTE 1 - ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

Organization

The Phelan-McDermid Syndrome Foundation, Inc. (the "Organization") is a not-for-profit organization formed under Internal Revenue Code 501(c)(3). Its main office is located in Venice, Florida. The mission of the Phelan-McDermid Syndrome Foundation is to improve the quality of life of people affected by Phelan-McDermid Syndrome worldwide by accelerating research, providing family support and raising awareness. The Organization supports scientific research as a way to find the best medical or clinical practices to help those with Phelan-McDermid Syndrome (PMS). The Organization also strives to be the clearinghouse for information, contacts, collaboration and networking that can help to spread effective practices, practical advice and family support to help those caring for people diagnosed with PMS. The Organization facilitates connections among families through its website, monthly newsletter, regional gatherings and a biennial international conference bringing together families, therapists, caregivers and researchers. The Organization also funds important basic and translational science, a web-based patient registry, and scientific meetings.

Basis of Accounting

The accompanying financial statements have been prepared on an accrual basis in accordance with accounting principles generally accepted in the United States of America.

Financial Statement Presentation

The Phelan-McDermid Syndrome Foundation, Inc. presents its financial statements using guidelines established under Statement of Financial Accounting Standard Codification 958. This standard requires that a non-profit organization provide information regarding the net assets of the organization based on the existence or absence of donor-imposed restrictions. The types of restrictions are described as follows:

Temporarily restricted net assets – The part of net assets of a not-for-profit organization resulting from contributions and other inflows of assets whose use by the organization is limited by donor-imposed stipulations that expire by passage of time or that can be fulfilled by actions of the organization pursuant to those stipulations.

Permanently restricted net assets – The part of net assets of a not-for-profit organization resulting from contributions and other inflows of assets whose use by the organization is limited by donor-imposed stipulations that neither expire by the passage of time nor can be fulfilled or otherwise removed by action of the organization pursuant to those stipulations. The Organization had no permanently restricted net assets as of December 31, 2017 and 2016.

Unrestricted net assets – The part of net assets of a not-for-profit organization that is neither permanently restricted nor temporarily restricted by donor-imposed stipulations.

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS (Continued)

DECEMBER 31, 2017 and 2016

(See Independent Auditor's Report)

NOTE 1 - ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

Revenue Recognition - Contributions

Promises to give are recognized when the donor makes a promise to give to the Organization that is, in substance, unconditional. All other donor-restricted contributions are reported as increases in temporarily or permanently restricted net assets depending on the nature of the restrictions. When a donor restriction expires, that is when a stipulated time restriction ends or purpose restriction is accomplished, temporarily restricted net assets are reclassified to unrestricted net assets and reported in the statement of activities as net assets released from restrictions.

Contributions Receivable

The Organization records contributions receivable at their net realizable value. An allowance for doubtful accounts is established based on specific assessment of all amounts that remain unpaid following normal payment periods. All amounts deemed to be uncollectible are charged against the allowance for doubtful accounts in the period the determination is made. Management considers all contributions receivable to be collectible, therefore no allowance for doubtful accounts has been set up as of December 31, 2017.

Estimates

The preparation of financial statements in conformity with accounting principles generally accepted in the United States of America requires management to make estimates and assumptions that affect certain reported amounts and disclosures. Accordingly, actual results could differ from those estimates.

Volunteer Services

Contributed services are recognized if the services received (a) create or increase non-financial assets or (b) require specialized skills that are provided by individuals possessing those skills and would typically need to be purchased if not provided by donation. The Organization has certain key volunteers that donate significant amounts of time to the family and research support programs. However, no additional in-kind contribution revenue or program expenses are recognized for the work done by these volunteers since it does not meet the described criteria.

Investments

Investments in marketable securities are recorded at their fair values. Fair value is the net asset value for money market and mutual funds, and the closing sale or bid for bonds and common stock. Realized and unrealized gains and losses are included in revenues in the Statement of Activities.

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS (Continued)

DECEMBER 31, 2017 and 2016

(See Independent Auditor's Report)

NOTE 1 - ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

Equipment

Equipment is recorded at cost or at estimated fair value at the date of donation. Depreciation is provided using the straight-line method over the estimated useful lives of the assets. Depreciation expense totaled \$2,211 and \$1,942 respectively for the years ended December 31, 2017 and 2016.

Income Tax Status

The Organization has been determined to be an organization exempt from income tax under Section 501(c)(3) of the Internal Revenue Code. Income, if any, from certain activities not directly related to the Organization's tax-exempt purpose is subject to taxation as unrelated business income.

Cash and Cash Equivalents

For purposes of the Statement of Cash Flows, the Organization considers all unrestricted highly liquid investments with an original maturity of three months or less to be cash equivalents.

Functional Allocation of Expenses

The Organization allocates its expenses on a functional basis among its program and support services. Expenses that can be specifically identified with a program or support services are coded directly according to their natural classifications. Other expenses that are common to several functions are allocated based upon estimates made by management.

Concentrations of Credit Risk

Financial instruments that potentially subject the Organization to credit risk include cash, contributions receivable and investments. The Organization's management attempts to prudently manage cash and cash equivalents and monitors outstanding contributions receivable. Deposit accounts at each commercial financial institution are insured by the Federal Deposit Insurance Corporation ("FDIC") up to \$250,000. At December 31, 2017 and 2016, there were \$718,377 and \$630,541 in deposits that were uninsured, respectively. The Organization maintains balances in a PayPal account that are not protected by the FDIC. Uninsured PayPal account balances at December 31, 2017 and 2016 were \$19,601 and \$11,406 respectively.

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS (Continued)

DECEMBER 31, 2017 and 2016

(See Independent Auditor's Report)

NOTE 2 - FAIR VALUE MEASUREMENTS

FASB ASC Topic 820, *Fair Value Measurements* ("ASC 820") establishes a framework for measuring fair value. That framework provides a fair value hierarchy that prioritizes the inputs to valuation techniques used to measure fair value. The hierarchy gives the highest priority to unadjusted quoted prices in active markets for identical assets or liabilities (level 1 measurements) and the lowest priority to unobservable inputs (level 3 measurements). The three levels of the fair value hierarchy under ASC 820 are described as follows:

Level 1 Inputs to the valuation methodology are unadjusted quoted prices for identical assets or liabilities in active markets that the Organization has the ability to access.

Level 2 Inputs to the valuation methodology include

- Quoted prices for similar assets or liabilities in active markets;
- Quoted prices for identical or similar assets or liabilities in inactive markets;
- Inputs other than quoted prices that are observable for the asset or liability;
- Inputs that are derived principally from or corroborated by observable market data by correlation or other means.

If the asset or liability has a specified (contractual) term, the level 2 inputs must be observable for substantially the full term of the asset or liability.

Level 3 Inputs to the valuation methodology are unobservable and significant to the fair value measurement.

The asset or liability's fair value measurement level within the fair value hierarchy is based on the lowest level of any input that is significant to the fair value measurement. Valuation techniques used need to maximize the use of observable inputs and minimize the use of unobservable inputs.

Following is a description of the valuation methodologies used for assets measured at fair value. There have been no changes in the methodologies used at December 31, 2017 and 2016.

Level 1 measurements: The fair values of cash and cash equivalents, common stock, and mutual funds are based on quoted market prices for those or similar investments.

Level 2 measurements: The fair value of fixed income securities are priced using evaluations which may be matrix or model based and do not necessarily reflect actual trades.

The preceding methods described may produce a fair value calculation that may not be indicative of net realizable value or reflective of future fair values. Furthermore, although the Organization believes its valuation methods are appropriate and consistent with other market participants, the use of different methodologies or assumptions to determine the fair value of certain financial instruments could result in a different fair value measurement at the reporting date.

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS (Continued)

DECEMBER 31, 2017 and 2016

(See Independent Auditor's Report)

NOTE 2 - FAIR VALUE MEASUREMENTS (Continued)

The following table sets forth by level, within the fair value hierarchy, the Organization's financial assets measured at fair value on a recurring basis as of December 31, 2017 and 2016:

| | Assets at fair value as of December 31, 2017 | | | |
|--------------------------------|--|-----------------|---------------|--------------------|
| | Level 1 | Level 2 | Level 3 | Total |
| Cash and cash equivalents | | | | |
| Checking account | \$ 181,017 | \$ - | \$ - | \$ 181,017 |
| Money market account | 787,360 | - | - | 787,360 |
| PayPal account | 19,601 | - | - | 19,601 |
| | <u>987,978</u> | <u>-</u> | <u>-</u> | <u>987,978</u> |
| Available-for-sale securities: | | | | |
| Endowment fund (1) | 33,139 | 3,036 | 402 | 36,577 |
| | <u>\$ 1,021,117</u> | <u>\$ 3,036</u> | <u>\$ 402</u> | <u>\$1,024,555</u> |

| | Assets at fair value as of December 31, 2016 | | | |
|--------------------------------|--|-----------------|---------------|-------------------|
| | Level 1 | Level 2 | Level 3 | Total |
| Cash and cash equivalents | | | | |
| Checking account | \$ 93,559 | \$ - | \$ - | \$ 93,559 |
| Money market account | 786,982 | - | - | 786,982 |
| PayPal account | 11,406 | - | - | 11,406 |
| | <u>891,947</u> | <u>-</u> | <u>-</u> | <u>891,947</u> |
| Available-for-sale securities: | | | | |
| Endowment fund (1) | 29,258 | 2,874 | 522 | 32,654 |
| | <u>\$ 921,205</u> | <u>\$ 2,874</u> | <u>\$ 522</u> | <u>\$ 924,601</u> |

(1) During 2007, the Organization set up an Endowment fund with a local Community Foundation. This Community Foundation invests all funds together and distributes income, gains and losses proportionally. For the years ending December 31, 2017 and 2016, the Foundation considers 90.6% and 89.6% to be invested in Level 1, 8.3% and 8.8% to be invested in Level 2 and 1.1% and 1.6% to be invested in Level 3, respectively.

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS (Continued)

DECEMBER 31, 2017 and 2016

(See Independent Auditor's Report)

NOTE 3 - INVESTMENTS

In 2007, the Organization entered into an agency endowment agreement with the Gulf Coast Community Foundation of Venice (GCCF). Under this agreement, the Organization has transferred a total of \$25,000 to a fund established in the name of Phelan-McDermid Syndrome Foundation, Inc. The Organization is entitled to annual distributions of 4% of the asset value of the agency endowment fund, as determined on a 12 quarter rolling average. Variance power rests with GCCF to consider requests from the Organization for a distribution in excess of 4%. Investments consist of unrestricted net assets and are recorded at fair value.

An analysis of the composition, cost and market values of investments at December 31, 2017 and 2016 are as follows:

| <u>December 31, 2017</u> | | | Net |
|--------------------------|-------------------|------------------|--------------------|
| | <u>Fair Value</u> | <u>Cost</u> | <u>Gain/(Loss)</u> |
| Endowment fund | <u>\$ 36,577</u> | <u>\$ 25,000</u> | <u>\$ 11,577</u> |
| | | | |
| <u>December 31, 2016</u> | | | Net |
| | <u>Fair Value</u> | <u>Cost</u> | <u>Gain/(Loss)</u> |
| Endowment fund | <u>\$ 32,654</u> | <u>\$ 25,000</u> | <u>\$ 7,654</u> |

During the years ended December 31, 2017 and 2016, the Organization had net realized gains (losses) of \$5,257 and \$2,281, respectively.

NOTE 4 - RESTRICTIONS ON NET ASSETS

Temporary restrictions on net assets as of December 31, 2017 and 2016 consisted of the following:

December 31, 2017

| | |
|------------------------------|-----------------|
| PMSF Australia Support | \$ 1,020 |
| 2018 Conference Scholarships | 1,790 |
| 2018 Conference Lodging | 6,067 |
| | <u>\$ 8,877</u> |

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS (Continued)

DECEMBER 31, 2017 and 2016

(See Independent Auditor's Report)

NOTE 4 - RESTRICTIONS ON NET ASSETS (Continued)

December 31, 2016

| | |
|------------------------------|------------------|
| Research Support | \$ 7,000 |
| 2018 Conference Scholarships | 1,790 |
| 2018 Conference Lodging | 2,752 |
| | <u>\$ 11,542</u> |

NOTE 5 - LEASES

In March 2015, the Organization signed a lease agreement for office space in Venice, Florida. Terms of the agreement include monthly payments in the amount of \$950 beginning in March 2015 and ending in February 2016. Either party may terminate the lease for any reason on 30 days prior written notice at any time after March 1, 2015. The lease expired in February 2016, since then the Organization is on a month to month lease for this space. Rent expense totaled \$11,450 and \$11,368 for the years ended 2017 and 2016 respectively.

NOTE 6 – GRANT AWARDS PAYABLE

In October of 2014, the Developmental Synaptopathies Consortium (DSC) was awarded a \$6,000,000 federal grant for clinical research of three rare genetic syndromes, to include Phelan-McDermid Syndrome. Since then, the Organization has supported this study in the form of various grants to the associated DSC clinical research sites as well as grants to another 501(c)(3) organization that administers a program to help families with travel costs to the DSC sites.

In 2017 and 2016, the Organization committed \$108,000 and \$71,500 in grant assistance, respectively, to support the DSC study. Grants payable of \$21,000 and \$14,000 at December 31, 2017 and 2016, respectively, represent the unpaid balance of these commitments. All grants payable at December 31 were disbursed in the following year.

NOTE 7 - CAPITAL LEASE PAYABLE

In September 2012, the Organization signed a four year capital lease agreement to purchase office equipment at monthly payments of \$158. This lease included a fair market value purchase option for the equipment and has been appropriately capitalized. There were no future lease payments due as the equipment was rented on a month to month basis from October 2016 through September 2017. The Organization exercised the purchase option at a cost of \$1,298 in October 2017.

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS (Continued)

DECEMBER 31, 2017 and 2016

(See Independent Auditor's Report)

NOTE 8 - PCORI CONTRACTS REVENUE

In March 2014, the Organization was awarded an eighteen month cost-reimbursement contract from the Patient-Centered Outcomes Research Institute ("PCORI") for an amount not to exceed \$957,328. During 2015 and 2014, total reimbursed costs (program revenue earned) from this contract totaled \$573,685 and \$375,328 respectively. The purpose of this contract is to collect and integrate all available patient data from patients with Phelan-McDermid Syndrome and make it available to researchers in a meaningful way. The contract will also help to develop and expand the Foundation's international health data registry that will become part of PCORnet: The National Patient-Centered Clinical Research Network.

In October 2015, the Organization was awarded an additional \$1,640,791 in funding for this project, extending the contract to September 30, 2018. Total program revenue earned in 2016 under this extension/amendment ("Phase II") was \$574,278. During 2017 total revenue earned from the contract extension was \$617,031.

The organization also recognized \$48,184 in fees on a separate limited scope contract with PCORI to fund a research workshop during the 2016 biennial international conference focused on 7 topics of high priority to individuals with PMS and their caregivers.

NOTE 9 - CONCENTRATIONS

The Organization received approximately 53% and 49% of its revenue from PCORI during the years ended December 31, 2017 and 2016 respectively.

NOTE 10 - TAX RETURN STATUS

Phelan-McDermid Syndrome Foundation, Inc. is exempt from federal income taxes under Section 501 (c) (3) of the Internal Revenue Code and therefore has no provision for income taxes.

Under federal and state income tax laws, an entity's income tax returns are subject to examination by the applicable taxing authorities. The time period during which a return may be selected for examination generally ends at the later of three years after the initial due date of the return or three years after the return is filed. At December 31, 2017 the Organization's federal information returns (forms 990) filed for 2014, 2015 and 2016 remain open for examination by the Internal Revenue Service.

NOTE 11 - SUBSEQUENT EVENTS

In accordance with FASB Accounting Standards Codification 855, Subsequent Events, the Organization has evaluated subsequent events to the Statement of Financial Position date of December 31, 2017 through April 20, 2018 (the date of financial statement issuance) for potential recognition and disclosure. Management has determined that there are no subsequent events that require disclosure.

SUPPLEMENTARY INFORMATION

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.
SCHEDULE OF FUNCTIONAL EXPENSES
For the year ended December 31, 2017

(See Independent Auditor's Report)

| | <u>Program Services</u> | <u>Management and General</u> | <u>Fund Raising</u> | <u>Total</u> |
|--------------------------------------|-----------------------------|-----------------------------------|-------------------------|----------------------------|
| Salaries, wages and payroll taxes | \$ 79,417 | \$ 93,965 | \$ 30,315 | \$ 203,697 |
| Advertising and promotion | 6,479 | 550 | - | 7,029 |
| Depreciation | - | 2,211 | - | 2,211 |
| Insurance | 264 | 6,540 | - | 6,804 |
| Conventions / conferences / meetings | 16,489 | - | - | 16,489 |
| Miscellaneous | 580 | 533 | 421 | 1,534 |
| Occupancy | - | 12,859 | - | 12,859 |
| Office expenses | 868 | 18,839 | 6,118 | 25,825 |
| Fees to institutions | 488,577 | - | - | 488,577 |
| Professional services | 129,315 | 13,073 | 1,592 | 143,980 |
| Lobbying | 30,056 | - | - | 30,056 |
| Grants | 108,750 | - | - | 108,750 |
| IT support and website | - | - | - | - |
| including PMSIR registry | 18,222 | 11,519 | 5,988 | 35,729 |
| Travel - lodging | 6,358 | 5,116 | 674 | 12,148 |
| Travel - meals | 878 | 1,711 | 2,798 | 5,387 |
| Travel - transportation | 13,665 | 5,627 | - | 19,292 |
| | <u>13,665</u> | <u>5,627</u> | <u>-</u> | <u>19,292</u> |
| Total Expenses | <u>\$ 899,918</u> | <u>\$ 172,543</u> | <u>\$ 47,906</u> | <u>\$ 1,120,367</u> |

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.
SCHEDULE OF FUNCTIONAL EXPENSES
For the year ended December 31, 2016

(See Independent Auditor's Report)

| | <u>Program Services</u> | <u>Management and General</u> | <u>Fund Raising</u> | <u>Total</u> |
|--|-----------------------------|-----------------------------------|-------------------------|---------------------|
| Salaries, wages and payroll taxes | \$ 39,095 | \$ 77,132 | \$ 12,441 | 128,668 |
| Advertising and promotion | 10,794 | - | 13,501 | 24,295 |
| Depreciation | - | 1,942 | - | 1,942 |
| Insurance | - | 6,495 | - | 6,495 |
| Interest | - | 69 | - | 69 |
| Conventions / conferences / meetings | 114,037 | - | - | 114,037 |
| Miscellaneous | 153 | 218 | 102 | 473 |
| Occupancy | - | 12,651 | - | 12,651 |
| Office expenses | 1,895 | 12,032 | 2,927 | 16,854 |
| Fees to institutions | 400,840 | - | - | 400,840 |
| Professional fees | 114,470 | 26,751 | - | 141,221 |
| Lobbying | 30,756 | - | - | 30,756 |
| Grants | 80,623 | - | - | 80,623 |
| Accounting | - | 5,636 | - | 5,636 |
| IT support and website including PMSIR registry | 43,514 | 11,089 | 5,389 | 59,992 |
| Travel - lodging | 14,023 | - | 498 | 14,521 |
| Travel - meals | 1,045 | 309 | - | 1,354 |
| Travel - transportation | 11,493 | - | - | 11,493 |
| Total Expenses | \$ 862,738 | \$ 154,324 | \$ 34,858 | \$ 1,051,920 |