

PHELAN-McDERMID SYNDROME FOUNDATION, INC.
FINANCIAL STATEMENTS
AND
INDEPENDENT AUDITOR'S REPORT
DECEMBER 31, 2018 AND 2017

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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, 2018 and 2017, and the related statements of activities, functional expenses 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, 2018 and 2017, and the changes in its net assets and cash flows for the years then ended in accordance with accounting principles generally accepted in the United States of America.



Whittaker & Associates, CPA's, PA
Certified Public Accountants
Venice, Florida

April 22, 2019

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.
STATEMENT OF FINANCIAL POSITION
December 31, 2018

(See Independent Auditor's Report)

ASSETS			
	Without Donor Restrictions	With Donor Restrictions	Total
Current Assets			
Cash and cash equivalents	\$ 1,126,708	\$ 55,822	\$ 1,182,530
Contract billings receivable	77,321	-	77,321
Unbilled contract revenue	81,141	-	81,141
Contributions receivable	40,000	-	40,000
Other receivables	4,600	-	4,600
Prepaid insurance	2,830	-	2,830
Deposits	200	-	200
Total Current Assets	<u>1,332,800</u>	<u>55,822</u>	<u>1,388,622</u>
Non Current Assets			
Investments	32,588	-	32,588
Equipment, net of \$11,110 accumulated depreciation	1,907	-	1,907
Total Non Current Assets	<u>34,495</u>	<u>-</u>	<u>34,495</u>
Total Assets	<u>\$ 1,367,295</u>	<u>\$ 55,822</u>	<u>\$ 1,423,117</u>
LIABILITIES AND NET ASSETS			
Current Liabilities			
Accounts payable	\$ 7,195	\$ -	\$ 7,195
Accrued liabilities	75,134	-	75,134
Accrued payroll and related taxes	6,950	-	6,950
Total Current Liabilities	<u>89,279</u>	<u>-</u>	<u>89,279</u>
Total Liabilities	<u>89,279</u>	<u>-</u>	<u>89,279</u>
Net Assets			
Without donor restrictions	1,278,016	-	1,278,016
With donor restrictions	-	55,822	55,822
Total Net Assets	<u>1,278,016</u>	<u>55,822</u>	<u>1,333,838</u>
Total Liabilities and Net Assets	<u>\$ 1,367,295</u>	<u>\$ 55,822</u>	<u>\$ 1,423,117</u>

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

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

(See Independent Auditor's Report)

ASSETS			
	Without Donor Restrictions	With Donor Restrictions	Total
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	1,148,481	8,877	1,157,358
Non Current Assets			
Investments	36,577	-	36,577
Equipment, net of \$9,710 accumulated depreciation	3,307	-	3,307
Total Non Current Assets	39,884	-	39,884
Total Assets	\$ 1,188,365	\$ 8,877	\$ 1,197,242

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	3,643	-	3,643
Total Current Liabilities	163,062	-	163,062
Total Liabilities	163,062	-	163,062
Net Assets			
Without donor restrictions	1,025,303	-	1,025,303
With donor restrictions	-	8,877	8,877
Total Net Assets	1,025,303	8,877	1,034,180
Total Liabilities and Net Assets	\$ 1,188,365	\$ 8,877	\$ 1,197,242

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, 2018

(See Independent Auditor's Report)

	<u>Without Donor Restrictions</u>	<u>With Donor Restrictions</u>	<u>Total</u>
Support and Revenue:			
General Contributions:			
Individuals	\$ 177,939	35,660	\$ 213,599
Businesses and organizations	312,853	95,292	408,145
In-kind	4,431	-	4,431
Total General Contributions	<u>495,223</u>	<u>130,952</u>	<u>626,175</u>
Special Events:			
Contributions	34,158	-	34,158
Other event revenue	70,766	-	70,766
Less: direct expenses	<u>(2,098)</u>	<u>-</u>	<u>(2,098)</u>
Total Special Events	<u>102,826</u>	<u>-</u>	<u>102,826</u>
Other Revenue:			
Family conference registration fees	56,901	-	56,901
Contractual income	397,240	-	397,240
Interest income	273	-	273
Investment income	<u>(2,640)</u>	<u>-</u>	<u>(2,640)</u>
Store sales	19,034	-	19,034
Total Other Revenue	<u>470,808</u>	<u>-</u>	<u>470,808</u>
Net assets released from restriction:			
Satisfaction of program restrictions	<u>84,007</u>	<u>(84,007)</u>	<u>-</u>
Total Support and Revenue	<u>1,152,864</u>	<u>46,945</u>	<u>1,199,809</u>
Expenses:			
Program services	670,907	-	670,907
Management and general	179,906	-	179,906
Fund raising	49,338	-	49,338
Total Expenses	<u>900,151</u>	<u>-</u>	<u>900,151</u>
Increase (decrease) in net assets	252,713	46,945	299,658
Net assets at beginning of year	<u>1,025,303</u>	<u>8,877</u>	<u>1,034,180</u>
Net assets at end of year	<u>\$ 1,278,016</u>	<u>\$ 55,822</u>	<u>\$ 1,333,838</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)

	Without Donor Restrictions	With Donor Restrictions	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
Net assets released from restriction:			
Satisfaction of program restrictions	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 FUNCTIONAL EXPENSES
For the year ended December 31, 2018

(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	\$ 160,956	\$ 116,228	\$ 37,114	\$ 314,298
Advertising and promotion	21,002	100	-	21,102
Depreciation	-	1,400	-	1,400
Insurance	-	5,798	-	5,798
Conventions / conferences / meetings	98,978	535	-	99,513
Miscellaneous	885	596	-	1,481
Occupancy	-	13,619	-	13,619
Office expenses	6,398	18,736	883	26,017
Fees to institutions	225,597	-	-	225,597
Professional services	72,458	6,346	6,093	84,897
Lobbying	30,076	-	-	30,076
Grants	11,394	-	-	11,394
IT support and website including PMSIR registry	26,420	9,700	4,816	40,936
Travel - lodging	6,548	3,232	-	9,780
Travel - meals	790	2,134	105	3,029
Travel - transportation	9,405	1,482	327	11,214
Total Expenses	<u>\$ 670,907</u>	<u>\$ 179,906</u>	<u>\$ 49,338</u>	<u>\$ 900,151</u>

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.
STATEMENT 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
Total Expenses	<u>\$ 899,918</u>	<u>\$ 172,543</u>	<u>\$ 47,906</u>	<u>\$ 1,120,367</u>

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.
STATEMENT OF CASH FLOWS
For the Years Ended December 31, 2018 and 2017

(See Independent Auditor's Report)

	2018	2017
Cash flows from operating activities:		
Increase (decrease) in net assets	\$ 299,658	\$ 43,734
Adjustments to reconcile increase in net assets to net cash provided by operating activities:		
Depreciation	1,400	2,211
Change in contract billings receivable	73,875	60,715
Change in unbilled contract revenue	(73,341)	6,900
Change in contributions receivable	(40,000)	34,999
Change in other receivables	(4,600)	-
Change in prepaid insurance	(6)	863
Change in deposits	7,360	(7,360)
Change in fixed asset additions	-	-
Change in accounts payable	(123,425)	(41,248)
Change in grants payable	(21,000)	7,000
Change in accrued liabilities	67,334	7,800
Change in accrued payroll and related taxes	3,307	(11,057)
Total Adjustments	(109,096)	60,823
Net cash provided (used) by operating activities	190,562	104,557
Cash flows from investing activities:		
Change in investments	3,989	(3,923)
Cash payments for purchase of equipment	-	(1,803)
Net cash provided (used) by investing activities	3,989	(5,726)
Cash flows from financing activities:		
Payment of Capital lease	-	(2,800)
Net cash provided (used) by financing activities	-	(2,800)
Net increase (decrease) in cash and equivalents	194,551	96,031
Cash and equivalents, beginning of year	987,978	891,947
Cash and equivalents, end of year	\$ 1,182,529	\$ 987,978
Supplemental Disclosure:		
Interest paid	\$ -	\$ -

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

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2018 and 2017

(See Independent Auditor's Report)

NOTE 1 – DESCRIPTION OF THE 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 conferences, 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.

NOTE 2 – SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

New Accounting Pronouncement – On August 18, 2016, FASB issued ASU 2016-14, Not-for-Profit Entities (Topic 958) – *Presentation of Financial Statements of Not-for-Profit Entities*. The update addresses the complexity and understandability of net asset classification, deficiencies in information about liquidity and availability of resources, and the lack of consistency in the type of information provided about expenses and investment return. The ASU is effective for the Organization's year ending December 31, 2018 and thereafter and is applied on a retroactive basis. The Organization has adjusted the presentation of these statements accordingly.

Basis of presentation – ASU 2016-14 requires significant changes to the financial reporting model of organizations that follow the not-for-profit reporting model. Under ASU 2016-14, classes of net assets are reduced from three (unrestricted, temporarily restricted, and permanently restricted) to two. In accordance with U.S. generally accepted accounting principles ("US GAAP") the Organization now reports information regarding its financial position and activities according to the following net asset classifications:

Net assets without donor restrictions: Net assets that are not subject to donor-imposed restrictions and may be expended for any purpose in performing the primary objectives of the organization. These net assets may be used at the discretion of the Organization's management and board of directors.

Net assets with donor restrictions: Net assets subject to stipulations imposed by donors, and grantors. Some donor restrictions are temporary in nature; those restrictions will be met by actions of the Organization or by the passage of time. Other donor restrictions are perpetual in nature, where by the donor has stipulated the funds be maintained in perpetuity.

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2018 and 2017

(See Independent Auditor's Report)

NOTE 2 – SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

Donor restricted contributions are reported as increases in net assets with donor restrictions. When a restriction expires, net assets are reclassified from net assets with donor restrictions to net assets without donor restrictions in the statements of activities.

Cash and cash equivalents – The Organization's cash consists of cash on deposit with banks. Cash equivalents represent money market funds or short-term investments with original maturities of three months or less from the date of purchase, except for those amounts that are held in the investment portfolio which are invested for long-term purposes.

Concentrations of credit risk – Financial instruments that potentially subject the Organization to concentrations of credit risk consist principally of cash and cash equivalents and investments. The Organization maintains its cash and cash equivalents in various bank accounts that, at times, may exceed federally insured limits of \$250,000. The Organization's cash and cash equivalent accounts have been placed with high credit quality financial institutions. The Organization has not experienced, nor does it anticipate, any losses with respect to such accounts. At December 31, 2018 and 2017, there were \$929,537 and \$718,377 in deposits that were uninsured, respectively.

Contributions receivable – Unconditional promises to give that are expected to be collected within one year are recorded at net realizable value. Unconditional promises to give that are expected to be collected in future years are recorded at the present value of their estimated future cash flows. The discounts on those amounts are computed using risk-adjusted interest rates applicable to the years in which the promises are received. Discount amortization is included in contribution revenue. Conditional promises to give are not included as support until the conditions are met.

As of December 31, 2018, The Organization's contributions receivable consisted of unconditional promises to give in the amount of \$40,000, all of which are expected to be collected within one year. As of December 31, 2017, there were no contributions receivable.

Property and equipment, net – Property and equipment are stated at cost at the date of purchase or, for donated assets, at fair value at the date of donation, less accumulated depreciation. Depreciation is calculated using the straight-line method over the lesser of the estimated useful lives of the assets or the lease term. The useful lives range from three to seven years. The Organization's policy is to capitalize renewals and betterments acquired for greater than \$1,000 and expense normal repairs and maintenance as incurred. The Organization's management periodically evaluates whether events or circumstances have occurred indicating that the carrying amount of long-lived assets may not be recovered.

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2018 and 2017

(See Independent Auditor's Report)

NOTE 2 – SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

Investments – Investments are reported at cost, if purchased, or at fair value, if donated. Thereafter, investments are reported at their fair values in the statements of financial position, and changes in fair value are reported as investment return in the statements of activities.

Purchases and sales of securities are reflected on a trade-date basis. Gains and losses on sales of securities are based on average cost and are recorded in the statements of activities in the period in which the securities are sold. Interest is recorded when earned. Dividends are accrued as of the ex-dividend date.

Fair value measurements – Fair value is defined as the price that would be received to sell an asset in the principal or most advantageous market for the asset in an orderly transaction between market participants on the measurement date. Fair value should be based on the assumptions market participants would use when pricing an asset. US GAAP establishes a fair value hierarchy that prioritizes investments based on those assumptions. The fair value hierarchy gives the highest priority to quoted prices in active markets (observable inputs) and the lowest priority to an entity's assumptions (unobservable inputs). The Organization groups assets at fair value in three levels, based on the markets in which the assets and liabilities are traded and the reliability of the assumptions used to determine fair value. These levels are:

- Level 1 Unadjusted quoted market prices for identical assets or liabilities in active markets as of the measurement date.

- Level 2 Other observable inputs, either directly or indirectly, including:
 - Quoted prices for similar assets/liabilities in active markets;
 - Quoted prices for identical or similar assets in non-active markets;
 - Inputs other than quoted prices that are observable for the asset/liability; and
 - Inputs that are derived principally from or corroborated by other observable market data.

- Level 3 Unobservable inputs that cannot be corroborated by observable market data.

Contributions – Contributions received are recorded as net assets without donor restrictions or net assets with donor restrictions, depending on the existence and/or nature of any donor-imposed restrictions. When a restriction expires (that is, when a stipulated time restriction ends or purpose restriction is accomplished), net assets with donor restrictions are reclassified to net assets without donor restrictions and reported in the statements of activities as net assets released from restrictions.

Contributed property and equipment are recorded at fair value at the date of donation. Contributions with donor-imposed stipulations regarding how long the contributed assets must be used are recorded as net assets with donor restrictions; otherwise, the contributions are recorded as net assets without donor restrictions.

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2018 and 2017

(See Independent Auditor's Report)

NOTE 2 – SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

In-kind donations – The Organization received donated professional services and other advertising services of \$4,431 and \$2,754 for the year ended December 31, 2018 and 2017, respectively. Such amounts, which are based upon information provided by third-party service providers, are recorded at their estimated fair value determined on the date of contribution and are reported as contributions in-kind and supporting services on the accompanying statements of activities and statements of functional expenses.

Several volunteers have made significant contributions of their time in furtherance of the Organization's mission. These services were not reflected in the accompanying statements of activities because they do not meet the necessary criteria for recognition under US GAAP.

Functional expenses – The financial statements report certain categories or expenses that are attributable to both program and supporting functions of the Organization. Those expenses include salaries, wages, payroll taxes, depreciation, insurance, occupancy, and IT support and website costs. Salaries, wages, payroll taxes, insurance, and IT support and website costs are allocated based upon estimates of time and effort. Depreciation and occupancy are allocated based upon square footage. Such allocations are determined by management on an equitable basis.

These allocated costs, along with other expenses that clearly only benefit program functions or only benefit supporting activities, have been summarized on a functional basis in the statements of activities.

Use of estimates – The preparation of financial statements in conformity with US GAAP requires management to make estimates and assumptions that affect certain reported amounts and disclosures. Actual results could differ from those estimates.

Income taxes –The Organization is exempt from income tax under IRC section 501(c)(3), though it is subject to tax on income unrelated to its exempt purpose, unless that income is otherwise excluded by the Code. The Organization has processes presently in place to ensure the maintenance of its tax-exempt status; to identify and report unrelated income; to determine its filing and tax obligations in jurisdictions for which it has nexus; and to identify and evaluate other matters that may be considered tax positions. The Organization has determined that there are no material uncertain tax positions that require recognition or disclosure in the financial statements.

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, 2018 the Organization's federal information returns (Forms 990) filed for 2015, 2016 and 2017 remain open for examination by the Internal Revenue Service.

Reclassifications – Certain prior year amounts have been reclassified to conform to the current year presentation.

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2018 and 2017

(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 market value.

An analysis of the composition, cost and market values of investments at December 31, 2018 and 2017 are as follows:

<u>December 31, 2018</u>			Net
	<u>Fair Value</u>	<u>Cost</u>	<u>Gain/(Loss)</u>
Endowment fund	<u>\$ 32,588</u>	<u>\$ 25,000</u>	<u>\$ 7,588</u>
<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>

During the years ended December 31, 2018 and 2017, the Organization had net investment income (loss) comprised as follows:

	<u>2018</u>	<u>2017</u>
Interest and dividends	\$ 772	\$ 837
Realized investment gain (loss)	849	546
Unrealized investment gain (loss)	(4,004)	4,048
Administrative expenses	<u>(257)</u>	<u>(174)</u>
Total net investment income	<u>\$ (2,640)</u>	<u>\$ 5,257</u>

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2018 and 2017

(See Independent Auditor's Report)

NOTE 4 – LIQUIDITY AND AVAILABILITY

The following table represents the Organization's financial assets at December 31, 2018 and 2017 reduced by amounts that are not available to meet general expenditures within one year of the statement of financial position date because of contractual or donor restrictions or internal board designations:

	<u>2018</u>	<u>2017</u>
Cash and cash equivalents	\$ 1,182,530	\$ 987,978
Contract billings and contributions receivable	121,922	151,196
Investments	32,588	36,577
Total financial assets	<u>1,337,040</u>	<u>1,175,751</u>
Investments with liquidity horizons greater than one year	(32,588)	(36,577)
Board-designated operating reserve fund	<u>(247,800)</u>	<u>(189,550)</u>
Financial assets available to meet cash needs for general expenditures within one year	<u>\$ 1,056,652</u>	<u>\$ 949,624</u>

The Organization receives contributions and promises to give restricted by donors, and considers contributions restricted for programs which are ongoing, major, and central to its annual operations to be available to meet cash needs for general expenditures. The organization manages its liquidity and reserves following three guiding principles: operating within a prudent range of financial soundness and stability, maintaining adequate liquid assets to fund near-term operating needs, and maintaining sufficient reserves to provide reasonable assurance that any long-term obligations will be discharged. To achieve these targets, the entity forecasts its future cash flows and monitors its liquidity quarterly, and monitors its reserves annually. During the years ended December 31, 2018 and 2017, the level of liquidity and reserves was managed within the policy requirements.

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2018 and 2017

(See Independent Auditor's Report)

NOTE 5 - FAIR VALUE MEASUREMENTS

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, 2018 and 2017:

	<u>Assets at fair value as of December 31, 2018</u>			
	<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>	<u>Total</u>
Cash and cash equivalents				
Checking accounts	\$ 1,179,736	\$ -	\$ -	\$1,179,736
PayPal account	2,794	-	-	2,794
	<u>1,182,530</u>	<u>-</u>	<u>-</u>	<u>1,182,530</u>
Available-for-sale securities:				
Endowment fund (1)	29,525	2,802	261	32,588
	<u>\$ 1,212,055</u>	<u>\$ 2,802</u>	<u>\$ 261</u>	<u>\$1,215,118</u>

	<u>Assets at fair value as of December 31, 2017</u>			
	<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>	<u>Total</u>
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>

(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, 2018 and 2017, the Foundation considers 90.6% and 90.6% to be invested in Level 1, 8.6% and 8.3% to be invested in Level 2 and 0.8% and 1.1% to be invested in Level 3, respectively.

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS (Continued)

December 31, 2018 and 2017

(See Independent Auditor's Report)

NOTE 6 - CLASSIFICATION AND RESTRICTIONS OF NET ASSETS

Net assets of the Organization are classified based on the presence or absence of donor-imposed requirements. Net assets are grouped as either Net Assets With Donor Restrictions or Net Assets Without Donor Restrictions.

Net Assets With Donor Restrictions as of December 31, 2018 and 2017 consisted of the following:

Purpose Restricted :	<u>2018</u>	<u>2017</u>
PMSF Australia Support	\$ 232	\$ 1,020
2019 Conference Lodging	3,994	1,790
2019 Research	11,596	6,067
Total Purpose Restricted	<u>15,822</u>	<u>8,877</u>
Time Restricted	<u>40,000</u>	<u>-</u>
Total Net Assets with Donor Restrictions	<u>\$ 55,822</u>	<u>\$ 8,877</u>

Net Assets Without Donor Restrictions as of December 31, 2018 and 2017 consisted of the following:

	<u>2018</u>	<u>2017</u>
Board Designated Operating Reserve	\$ 247,800	\$ 189,550
Undesignated	<u>1,030,215</u>	<u>835,753</u>
Total Net Assets without Donor Restrictions	<u>\$ 1,278,015</u>	<u>\$ 1,025,303</u>

NOTE 7 - LEASES

In March 2015, the Organization signed a lease agreement for office space in Venice, Florida. The lease agreement ended in February 2016. Since the time of the lease expiration date the Organization has been renting on a month-to-month basis. Rent expense totaled \$12,028 and \$11,450 for the years ended 2018 and 2017 respectively.

NOTE 8 - 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.

PHELAN-MCDERMID SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS (Continued)

December 31, 2018 and 2017

(See Independent Auditor's Report)

NOTE 8 – GRANT AWARDS PAYABLE (CONTINUED)

In 2018 and 2017, the Organization committed \$359 and \$108,000 in grant assistance, respectively, to support the DSC study. The Organization also awarded \$5,000 in 2018 to a researcher studying the microbiome of individuals with PMS. Grants payable were \$21,000 at December 31, 2017 and funds were disbursed in that amount during 2018. There were no grants payable at December 31, 2018.

NOTE 9 - PCORI CONTRACTS REVENUE AND RELATED ACCRUED LIABILITY

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. 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.

In October 2015, the Organization was awarded an additional \$1,640,791 in funding for this project ("Phase II"), extending the contract to September 30, 2018. In late 2018, Phase II was amended to reflect a contract end date of March 31, 2019 and to add an additional \$84,000 in funding to the budget. During 2018 and 2017, total program revenue earned from this contract totaled \$379,697 and \$617,031 respectively. The \$379,697 of 2018 revenue included \$81,141 that was unbilled but accrued at December 31, 2018. An amount of \$75,134, pertaining to research work performed at Harvard University in support of the PCORI endeavor, was accrued as a liability at December 31, 2018.

NOTE 10 - CONCENTRATIONS

The Organization received approximately 33% and 53% of its revenue from PCORI during the years ended December 31, 2018 and 2017 respectively.

NOTE 11 - SUBSEQUENT EVENTS

The Organization has evaluated subsequent events through April 22, 2019, which is the date the financial statements were available for issue. The Organization is not aware of any material subsequent events.