Financial Statements
December 31, 2016

# PRADER-WILLI SYNDROME ASSOCIATION (USA) FINANCIAL STATEMENTS December 31, 2016

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#### INDEPENDENT AUDITOR'S REPORT

To the Board of Directors
Prader-Willi Syndrome Association (USA)

I have audited the accompanying financial statements of Prader-Willi Syndrome Association (USA) (a nonprofit organization), which comprise the statement of financial position as of December 31, 2016, and the related statements of activities, functional expenses, and cash flows for the year 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

My responsibility is to express an opinion on these financial statements based on my audit. I conducted my audit in accordance with auditing standards generally accepted in the United States of America. Those standards require that I 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, I 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.

I believe that the audit evidence I have obtained is sufficient and appropriate to provide a basis for my audit opinion.

#### Opinion

In my opinion, the financial statements referred to above present fairly, in all material respects, the financial position of Prader-Willi Syndrome Association (USA) as of December 31, 2016, and the changes in its net assets and its cash flows for the year then ended in accordance with accounting principles generally accepted in the United States of America.

CERTIFIED PUBLIC ACCOUNTANT

June 21, 2017

ASSOCIATION (USA)
STATEMENT OF FINANCIAL POSITION
December 31, 2016

## ASSETS

CURRENT ASSETS		
Cash	\$	1,001,865
Investments		1,275,696
Membership dues receivable		780
Unconditional promises to give		23,449
Inventory		10,275
Prepaid expenses		9,735
ricpard expenses	***	
TOTAL CURRENT ASSETS		2,321,800
FURNITURE AND EQUIPMENT		10.170
Office furniture		18,179
Computer equipment		36,877
Telephone system		12,112
Leasehold improvements	-	11,706
		78,874
Less accumulated depreciation	-	75,765
TOTAL FURNITURE AND EQUIPMENT		3,109
OTHER ASSETS		5,549
Security deposits		104,534
Investments held at The Community Foundation of Sarasota County	-	104,334
TOTAL OTHER ASSETS	-	110,083
TOTAL ASSETS	\$_	2,434,992
LIABILITIES AND NET ASSETS		
CURRENT LIABILITIES		
Accounts payable	\$	20,036
Accrued liabilities	Ţ	52,223
Due to related parties		(448)
TOTAL CURRENT LIABILITIES		71,811
NET ASSETS		
Unrestricted		854,952
Undesignated Designated by Board of Directors		10,000
	-	864,952
Total unrestricted		1,338,295
Temporarily restricted		159,934
Permanently restricted		
TOTAL NET ASSETS	-	2,363,181
TOTAL LIABILITIES AND NET ASSETS	\$	2,434,992

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

# PRADER-WILLI SYNDROME

ASSOCIATION (USA) STATEMENT OF ACTIVITIES For The Year Ended December 31, 2016

	Y	Inrestricted	7	Cemporarily Restricted		ermanently Restricted	Total
SUPPORT AND REVENUES	***	*********	n.k.		10000		
Support						2000	1 5/5 104
Contributions	\$	945,065	S	594,069	\$	26,050 \$	1,565,184
Fundraising contributions		386,356					386,356
Conference income		1,692		30,000			31,692
Donated services		710,406					710,406
Revenues		10121 10212					10 406
Educational material sales		18,496				~~	18,496
Membership dues		55,875		***		***	55,875
Investment income/(loss)		77,795					77,795
Net assets released from restrictions				and the second second			
Satisfaction of program restrictions	•••	356,071	-	(356,071)			***
TOTAL SUPPORT AND REVENUES		2,551,756		267,998		26,050	2,845,804
EXPENSES							
Program services							
Crisis intervention and support		355,715		***		***	355,715
Education		36,139				**	36,139
Medical intervention and support		385,958		***		~~	385,958
New diagnosis support		79,206		wa		**	79,206
Chapter, affiliate and local support		52,265		~~		***	52,265
National conference		106,211		***		***	106,211
Advocacy, awareness, external							
collaborative relationships		188,720		-		***	188,720
Research		557,129					557,129
Total program services	**	1,761,343		,A 1-2	0 0700	And also	1,761,343
Supporting services							
Administration		332,035		****		*.*	332,035
Fund development		128,821		***			128,821
Total supporting services	~	460,856		~-		***	460.856
TOTAL EXPENSES	_	2,222,199					2,222,199
CHANGE IN NET ASSETS		329,557		267,998		26,050	623,605
NET ASSETS AT BEGINNING OF YEAR		535,395		1,070,297		133,884	1,739,576
NET ASSETS AT END OF YEAR	\$	864,952		1,338,295		159,934 \$	2,363,181

# PRADER-WILLI SYNDROME

ASSOCIATION (USA)
STATEMENT OF FUNCTIONAL EXPENSES
For The Year Ended December 31, 2016

				PROC	PROGRAM SERVICES	CES				SCPP	SUPPORTING SERVICES	KCES	
	Crisis Intervention and Support	Eduration	Medical Intervention and Support	New Duggrous Support	Chapter, Affiliste and Local Support	National	Advocacy, Awareness, Extrassi Collaborative Relationships	Research	Totai Program Services	Administration Development	Fund	Total Supporning Services	Total
Salacies Payroli faces Errolovne benefits	\$ 151,195 \$		1	50,167	2,447	\$ 56,534 4,524 6,025	\$ 78,858 \$ 6,311 8,404	35,017 \$ 2,803 3,731	475,310 38,042 50,651	\$ 123,930 9,919 13,207	\$ 51,778 \$ 4,144 5,517	175,708 \$ 14,063	52,103 52,103 69,375
Awareness and education International activities Crisis assisbance	45,603	111	: 1 1	: 1 1	.111	113	5,000	111	30,743 5,000 45,603	1 1 1	113	111	30,743 5,000 45,603
Newsletter Family support	28,057	1:	1 1	1 1	1 1	1 1	696,949	1 1	28,057	1	1	1 1	28,057
Direct fundraising costs Direct conference costs Research grants	.1111	: 111	: [ ] [	1 1 1 1	11.19	28.8.2	1111	238,802	5,854 238,802 6,116	1 1 1 1	36,039	360,036	36,039 5,854 238,862 6,116
Office operating expenses Office supplies Equipment rental	6,934 4,958 2,077	890 637 267 382	2,355 1,684 705 1,013	1,577	1,108	1,863 1,332 558 799	3,929 2,810 1,177 1,686	1,237 883 371 530	20,522 14,673 6,148 8,805	3,275	3,514	8,096 5,788 2,425 3,473	28,618 20,461 8,573 12,278
Database Websin Insurance Rent Utilities	2,849 1,390 15,997 4,492	366 92 435 2,054 576	967 245 1,152 5,433 1,526	907 230 1,079 5,030 1,429	2355	766 194 912 4,298 1,207	1,613 409 1,921 9,066	2,852 801 801	8,431 2,137 10,035 47,345 13,294	1,881 476 476 10,571 2,967	1,443 366 1,718 8,107 7,22,2	3,324 842 3,958 18,678 5,244	13,993 66,023 18,538
Professional fees State registrations and taxes Travel and board expenses Bank charges	2,993	385 195 534 508	1,016	953 485 1,325 1,258	478 242 665 653	805 411 1,119 1,062	1,696 867 2,359 2,240	234 272 743	8,860 4,520 12,324 11,700	61,978 1,010 2,751 2,613	7,517	1,784	72,355 6,304 17,185 16,317
Dues and subscriptions Logo wens Depreciation Donated services	40,799	96 522 522 420	1,380	1,293	646	1,091	2,302	134 724 265,750	2,216 12,025 629,781	493 2,685 3,493 80,525	3,059	875 4,744 3,493 80,625	3,091 16,759 3,493 710,436
Total acpenses	\$ 355,715	\$ 36,139	\$ 385,958	\$ 79,206	\$ 52,265	\$ 106,211	188,720	\$ 557,129	\$ 1,761,343	S 332,035	\$ 128,821	\$ 460,856	\$ 2,222,199

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

#### PRADER-WILLI SYNDROME ASSOCIATION (USA) STATEMENT OF CASH FLOWS

#### STATEMENT OF CASH FLOWS For The Year Ended December 31, 2016

CASH FLOWS FROM OPERATING ACTIVITIES  Change in net assets  Adjustments to reconcile change in net assets	S	623,605
to net cash provided by operating activities:  Depreciation  Realized and unrealized losses on investments		3,493 (55,852)
(Increase) decrease in operating assets:  Membership dues receivable Unconditional promises to give Inventory Prepaid expenses		4,692 (874) 12,074 7,065
Increase (decrease) in operating liabilities:  Accounts payable  Accrued liabilities  Due to related parties		(155,731) (2,398) (10,533)
NET CASH PROVIDED BY OPERATING ACTIVITIES		425,541
CASH FLOWS FROM INVESTING ACTIVITIES  Change in investments  Change in investments held at The Community Foundation of Sarasota County		(162,901) (32,288)
NET CASH USED BY INVESTING ACTIVITIES		(195,189)
NET INCREASE IN CASH		230,352
CASH - BEGINNING OF YEAR		771,513
CASH - END OF YEAR	\$ =	1,001,865

NOTES TO FINANCIAL STATEMENTS
December 31, 2016

# NOTE 1 - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

#### Nature of Activities

Prader-Willi Syndrome Association (USA) ("PWSA (USA)" or "The Association") is a not-for-profit organization which has as its mission statement: PWSA (USA) is an organization of families and professionals working together to raise awareness, offer support, provide education and advocacy, and promote and fund research to enhance the quality of life of those affected by Prader-Willi syndrome.

The Association has further defined its business activities into the Focus Areas outlined below:

Family Support

Crisis Intervention and Support – The Association maintains a crisis counseling system that provides support and assistance for families experiencing urgent problems and preventive needs and experiencing difficulties obtaining services.

Education – Strive to be a world leader in the development of materials and instruction in the knowledge of PWS and make such information accessible to families, educators, medical and law enforcement personnel, residential providers, and the community at large, on a timely basis.

Medical Intervention and Support - Provide a response system to provide families and the medical community with accurate and timely assistance in dealing with the various medical issues confronting people with PWS. Such system will be the leading international source for materials and assistance on medical issues.

New Diagnoses Support - Provide mentoring to parents of newly diagnosed persons with PWS.

Chapter, Affiliate and Local Support

Develop, strengthen and nurture state chapters and affiliates to (i) ensure that families have personal support from their local community, (ii) increase the diagnosis rates and (iii) increase the funding for The Association.

National Conference

Provide forums on a biennial basis for PWS families and/or professionals to collaborate through the exchange of information and education and provide support to families.

Advocacy - Awareness - External Collaborative Relationships

Advocacy - Increase the general knowledge of PWS and The Association.

Awareness - Provide support for ideas and causes relevant to PWS.

External Collaborative Relationships -- Work to expand the relationships between PWSA (USA) and organizations throughout the world.

NOTES TO FINANCIAL STATEMENTS December 31, 2016

## NOTE 1 - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES - CONTINUED

#### Research

Increase research into the various aspects of PWS, throughout the world, particularly those areas identified by PWSA (USA) as priorities. Actively solicit funding for such projects, collaboration. Maintain an active scientific advisory board with world leaders from the various medical disciplines that impact PWS.

#### Fund Development

Develop and maintain programs to ensure long-term sustainable financial support for PWSA (USA) and its activities and short-term funding for specific projects. Such support will be developed through various programs of charitable giving and community programs.

#### Administration

Provide effective management of the PWSA (USA) by developing a well-balanced, team oriented, well trained workforce that is diverse, agile, committed to the organization's mission, and continuously expanding their capabilities to shape the organization's future and build effective, efficient, strategically aligned business process that integrate and capitalize on the organization's human capital and technology resources to provide accurate and timely information for the optimum management of PWSA (USA).

#### Basis of Accounting

The Association's policy is to prepare its financial statements on the accrual basis of accounting and accordingly reflect all significant receivables, payables and other liabilities.

#### Financial Statement Presentation

PWSA (USA) has adopted Financial Accounting Standards Board (FASB) Accounting Standards Codification (ASC) 958-205, Not-for-Profit Entities – Presentation of Financial Statements. Under ASC 958-205, the Association is required to report information regarding its financial position and activities according to three classes of net assets: unrestricted net assets, temporarily restricted net assets, and permanently restricted net assets. In addition, the Association is required to present a statement of cash flows.

#### Contributions

PWSA (USA) has also adopted FASB ASC 958-605, Not-for-Profit Entities — Revenue Recognition. All contributions are considered to be available for unrestricted use unless specifically restricted by the donor. Amounts received that are designated for future periods or restricted by the donor for specific purposes are reported as temporarily restricted or permanently restricted support that increases those net asset classes. When a temporary restriction expires, temporarily restricted net assets are reclassified to unrestricted net assets and reported in the statement of activities as net assets released from restrictions. Temporarily restricted contributions whose restrictions are met in the same reporting period are reported as unrestricted contributions.

# NOTES TO FINANCIAL STATEMENTS

December 31, 2016

# NOTE 1 - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES - CONTINUED

#### Donated Services and Materials

Contributions of donated professional and volunteer services that create or enhance nonfinancial assets or that require specialized skills, are provided by individuals possessing those skills, and would typically need to be purchased if not provided by donation, are recorded at their fair values in the period received. Donated materials, when received, are reflected in the accompanying statements at their estimated fair market values at date of receipt.

#### Fair Value Measurements

The Association follows generally accepted accounting principles with regards to fair value measurements and disclosures, which establishes a hierarchy framework for measuring fair value of instruments. The hierarchy is described below and listed in order of priority:

- Level 1 inputs are quoted prices in active markets for identical assets or liabilities that the Association has the ability to access at the measurement dates.
- Level 2 inputs are inputs other than quoted prices included in Level 1 that are observable for the asset or liability, either directly or indirectly.
- Level 3 inputs are unobservable inputs for the asset or liability.

Generally accepted accounting principles require disclosure of an estimate of fair value of certain financial instruments. The Association's significant financial instruments are cash, investments, receivables, accounts payable and other short-term assets and liabilities. For these financial instruments (Level 1), carrying values approximate fair value because of the short maturity of these investments, except investments – See Note 2.

#### Income Tax Status

The Association is exempt from federal income tax under Section 501(c)(3) of the Internal Revenue Code. It is also exempt from state income taxes. Accordingly, no provision has been made for income taxes in the accompanying statements. FASB ASC 740, Accounting for Income Taxes, prescribes a recognition threshold and measurement attribute of the financial statement recognition and measurement of a tax position taken or expected to be taken in a tax return. As of December 31, 2016, management has determined that all past and current tax positions were likely to be realized and sustainable upon examination and that the calculation of a tax liability was not necessary.

#### Cash and Cash Equivalents

For purposes of the statement of cash flows, the Association considers all highly liquid investments available for current use with an initial maturity of three months or less to be cash equivalents.

NOTES TO FINANCIAL STATEMENTS December 31, 2016

# NOTE 1 - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES - CONTINUED

#### Investments

Investments as of December 31, 2016 are carried at the quoted market value of the securities. Realized and unrealized gains and losses are included in the change in net assets in the accompanying statement of activities.

#### Promises to Give

Unconditional promises to give are recognized as revenue in the period received and as assets, decreases of liabilities, or expenses depending on the form of the benefits received. Promises to give are recorded at net realizable value if they are expected to be collected in one year and at fair value if they are expected to be collected in more than one year. Conditional promises to give are recognized when the conditions on which they depend are substantially met.

#### Inventory

Inventories are stated at the lower of cost or market determined by the first-in, first-out method. Inventory consists of educational materials and promotional items.

#### Furniture and Equipment

Furniture and equipment is carried at cost, except for donated assets, which are recorded at the fair market value at the time of the gift. Equipment acquisitions in excess of \$500 are capitalized. Depreciation is provided for and is computed using the straight-line method based on the estimated useful lives of the assets. The estimated useful lives of the office furniture and computer equipment is five years, the telephone system is seven years, and leasehold improvements is seven years. Maintenance and repair costs are expensed as incurred. Depreciation expense for the year ended December 31, 2016 was \$3,493.

#### Compensated Absences

Employees of the Association are entitled to paid vacation, paid sick days and personal days off, depending on job classification, length of service, and other factors. The Association has accrued \$23,533 for earned time off, but not taken, by its employees as of December 31, 2016.

#### Use of 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.

NOTES TO FINANCIAL STATEMENTS

December 31, 2016

#### NOTE 1 - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES - CONTINUED

#### Functional Allocation of Expenses

The costs of providing PWSA's various programs and supporting services have been detailed in the statement of functional expenses and summarized on a functional basis in the statement of activities. Accordingly, certain costs have been allocated among the programs and supporting services benefited.

#### Allocation of Joint Costs

Joint costs have been incurred in the production of the Gathered View bimonthly newsletter. The newsletter is primarily educational in nature, but it does contain a small fundraising appeal. Accordingly, the costs of producing the newsletter have been allocated to the various program and fundraising expense categories, as reported in the Statement of Functional Expenses.

#### NOTE 2 - INVESTMENTS

Investments cost, fair value, and unrealized appreciation (depreciation) at December 31, 2016, consisted of the following:

Tlansalizad

		Cost		Fair Value	App	reciation reciation)
Cash and money market funds	\$	14,150	\$	14,150	\$	
Certificates of deposit		212,150		213,591		1,441
Corporate bonds		330,541		323,902		(6,639)
Municipal bonds		145,670		142,000		(3,670)
Mutual funds		465,727		582,053		116.326
Total investments	S	.168.238	\$1,	275,696	\$	107,458

The following schedule summarizes the investment income and its classifications in the statement of activities for the year ended December 31, 2016:

	Unrestricted
Interest and dividends	\$ 21,943
Net realized and unrealized gains on investments	55,852
Total investment income	\$ 77,795

#### NOTE 3 - PROMISES TO GIVE

Unconditional promises to give at December 31, 2016, consists of contributions in the amount of \$23,449, and is receivable within one year.

NOTES TO FINANCIAL STATEMENTS December 31, 2016

## NOTE 4 - TEMPORARILY RESTRICTED NET ASSETS

Temporarily restricted net assets are available for the following purposes at December 31, 2016:

Research	\$ 1,078,243
Crisis and family support	107,798
Legal counsel and education	61,483
Kentucky group home	60,771
Conference	30.000
Total temporarily restricted net assets	<u>\$ 1,338,295</u>

Net assets were released from donor restrictions by satisfying the program restrictions specified by donors during 2016 as follows:

Research	\$ 266,802
Crisis and family support	28,057
Legal counsel and education	61,212
Total restrictions released	<u> 5.356.071</u>

# NOTE 5 - DESIGNATED UNRESTRICTED NET ASSETS

The Board of Directors has designated \$10,000 of unrestricted net assets for the purpose of additional funding of the endowment.

# NOTE 6 - PERMANENTLY RESTRICTED NET ASSETS

Permanently restricted net assets consist of endowment fund investments to be held indefinitely, the income from which is expendable for providing assistance to families dealing with Prader-Willi Syndrome.

## NOTE 7 - LEASE COMMITMENTS

PWSA (USA) has entered into various non-cancellable operating lease agreements for the rental of office facilities and office equipment that expire at various dates through August 2021. Rental expenses for those leases amounted to \$74,596 for the year ended December 31, 2016.

Future minimum lease payments under operating leases that have remaining terms in excess of one year as of December 31, 2016, were:

Year	ending December 31,		
	2017	\$	65,749
	2018		5,556
	2019		5,556
	2020		5,305
	2021		1,696
		<u>\$</u>	83,862

NOTES TO FINANCIAL STATEMENTS December 31, 2016

### NOTE 8 - CONCENTRATION OF CREDIT RISK

The Association maintains cash demand deposits with a financial institution which is insured by the Federal Deposit Insurance Corporation (FDIC) up to \$250,000. Cash at the financial institution exceeded Federally insured limits. The amount in excess of the FDIC insurance limit totaled \$717,662 as of December 31, 2016.

#### NOTE 9 - DONATED SERVICES

The value of donated services included as contributions in the financial statements and the corresponding donated services expense for the year ended December 31, 2016, are as follows:

Crisis intervention and support	\$ 40,799
Education	4,200
Medical intervention and support	302,376
National conference	16,656
Research	265,750
Administration	80.625
Total in-kind contributions	\$ 710,406

These donated services are recognized since they require specialized skills that would otherwise be purchased by the Association. There is a significant amount of donated services that were not recognized in these financial statements because they could not be estimated. In addition, many individuals volunteer their time and perform a variety of tasks that assist the Association, but these services do not meet the criteria for recognition as donated services.

#### NOTE 10 - SUBSEQUENT EVENTS

The Association has evaluated subsequent events through June 21, 2017, the date which the financial statements were available to be issued, and is unaware of any subsequent events requiring disclosure.