FORM 990

Return of Organization Exempt From Income Tax

OMB No. 1545-0047 2016

Open to Public

Department of the Treasury Internal Revenue Service

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

Information about Form 990 and its instructions is at www.irs.gov/form990. Inspection For the 2016 calendar year, or tax year beginning and ending Check if applicable: C Name of organization PRADER-WILLI SYNDROME ASSOCIATION (USA) D Employer Identification number Address change Doing business as Number and street (or P.O. box if mail is not delivered to street address) Name change 41-1306908 8588 POTTER PARK DRIVE, SUITE 500 E Telephone number Initial return ZtP code SARASOTA (941) 312-0400 FL 34238 Final return/terminated Foreign country name Foreign province/state/county Foreign postal code Amended return G Gross receipts \$ 2,137,283 Application pending F Name and address of principal officer: H(a) Is this a group return for subordinates? Yes X No KEN SMITH 8588 POTTER PARK DRIVE, SUITE 500, SARASOTA, FL H(b) Are all subordinates included? X 501(c)(3) Tax-exempt status: 501(c) (If "No," attach a list. (see instructions)) < (insert no.) 4947(a)(1) or J Website: ► WWW.PWSAUSA.ORG H(c) Group exemption number K Form of organization: X Corporation Other -L Year of formation: M State of legal domicite: Part I Summary Briefly describe the organization's mission or most significant activities: ADVOCATE, EDUCATE AND SUPPORT INDIVIDUAL Activities & Governance AFFECTED BY PRADER-WILLI SYNDROME AND THEIR CAREGIVERS. Check this box ▶ if the organization discontinued its operations or disposed of more than 25% of its net assets. 15 Number of independent voting members of the governing body (Part VI, line 1b) 4 15 Total number of individuals employed in calendar year 2016 (Part V, line 2a) 5 21 Total number of volunteers (estimate if necessary) . 6 Total unrelated business revenue from Part VIII, column (C), line 12. 7a 0 Net unrelated business taxable income from Form 990-T, line 34 . . . 0 **Current Year** Contributions and grants (Part VIII, line 1h) 916,256 1,565,184 9 451,123 87,567 Investment income (Part VIII, column (A), lines 3, 4, and 7d) 10 54,561 79,680 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) . . . 11 422,122 Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12) 336,673 12 1,844,062 2,069,104 13 Grants and similar amounts paid (Part IX, column (A), lines 1-3) 140,428 284,405 14 Benefits paid to or for members (Part IX, column (A), line 4) 0 15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5–10). 698,430 772,498 Professional fundraising fees (Part IX, column (A), line 11e) 16a 0 Total fundraising expenses (Part IX, column (D), line 25) b Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e) 17 615,651 386,711 18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25) . . . 1,454,509 1,443,614 19 Revenue less expenses. Subtract line 18 from line 12 389,553 625,490 Beginning of Current Year 20 Total assets (Part X, line 16) 1,980,049 2,434,992 21 Total liabilities (Part X, line 26) 240,473 71,811 22 Net assets or fund balances. Subtract line 21 from line 20 . 2,363,181 Signature Block Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete. Declaration of preparer (other than officer) is based on all information of which preparer has any knowledge Sign Signature of office Неге KEN SMITH EXECUTIVE DIRECTOR Type or print name and title Print/Type preparer's name Preparer's signature Paid Check X if LAWRENCE A. KRAUJALIS -aurmee A Krau Preparer 7/25/2017 self-employed Firm's name LAWRENCE A. KRAUJALIS, CPA, P.A. **Use Only** Firm's EIN ► 20-1577831 Firm's address ► 4016 CORTEZ ROAD WEST, SUITE 1205, BRADENTON, FL 34210 Phone no. May the IRS discuss this return with the preparer shown above? (see instructions) X Yes

	90 (2016)			DROME ASSOC				41-1306908	Page Z
Pa	rt III				complishmen ponse or note t		Part III	· <u>· · · · · · · · · · · · · · · · · · </u>	x
1	Briefly d ADVOC CAREG		E AND SUPF	ORT INDIVIDU			I SYNDROME AND		
	_				<u>-</u> -				
2	the prior	Form 990 or 9 describe these	990-EZ? . , new service	 s on Schedule (D.			Yes	X No
3	services					in how it conducts,	any program	Yes	X No
4	Describe expense	e the organizat es. Section 501	ion's program (c)(3) and 50	service accom 1(c)(4) organiza	plishments for ea itions are require ogram service rep	d to report the amo	est program services, unt of grants and allo	as measured by cations to others,	
4a	PRADE	RENCE FOR F R-WILLI SYND	PROFESSION PROME.	IALS AND PAR	ENTS DESIGNE	D TO SHARE NEW) (Revenue JAPPROACHES IN D	DEALING WITH	
4b	CRISIS	AND INTERVE	NTION TRAI	NING TO ASSI	ST IN TREATME	NT AND SUPPORT) (Revenue		
4c	(Code: DISTRIE	BUTION OF EC) (Expenses DUCATIONAL	\$ 331 MATERIALS A	,993 including g ND PARENT INT	rants of \$ ERVENTION REG) (Revenue ARDING PRADER-W	\$ MILLI SYNDROME)
4d		ogram services				0.1/2			
	(Expens			including grants		0) (Reve	nue \$	0)	
4e	Total pro	ogram servic <u>e e</u>	expenses	P	1,104,166				

Part IV	Checklist of F	Required Schedules

			Yes	s No
1	Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? If "Yes," complete Schedule A.	1	X	1
2	Is the organization required to complete Schedule B, Schedule of Contributors (see instructions)?	2	X	
3	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I.		<u> </u>	
4	Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h)	3	-	X
	election in effect during the tax year? If "Yes," complete Schedule C, Part II	4		x
5	Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues,		1	
	assessments, or similar amounts as defined in Revenue Procedure 98-19? If "Yes," complete Schedule C,	1_		
6	Did the organization maintain any donor advised funds or any similar funds or accounts for which donors	5	+	<u> </u>
Ī	have the right to provide advice on the distribution or investment of amounts in such funds or accounts? If "Yes," complete Schedule D, Part I			
7	Did the organization receive or hold a conservation easement, including easements to preserve open space,	6	+	<u>X</u>
	the environment, historic land areas, or historic structures? If "Yes," complete Schedule D. Part II	7		X
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III	8	 	×
9	Did the organization report an amount in Part X, line 21, for escrow or custodial account liability, serve as a	<u>ا</u>	╁╾	+^
	custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt	1	1	
	negotiation services? If "Yes," complete Schedule D, Part IV	9		X
10	Dld the organization, directly or through a related organization, hold assets in temporarily restricted			
	endowments, permanent endowments, or quasi-endowments? If "Yes," complete Schedule D, Part V	10	X	1
11	If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI,		\Box	
_	VII, VIII, IX, or X as applicable.			
а	Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D, Part VI.			
h	Did the organization report an amount for investments—other securities in Part X, line 12 that is 5% or more	11a	X	Ļ
	of its total assets reported in Part X, line 16? If "Yes," complete Schedule D. Part VII	11b		х
	Did the organization report an amount for investments—program related in Part X, line 13 that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VIII.	11c		x
	Did the organization report an amount for other assets in Part X, line 15 that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part IX.	11d		х
6	Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X.	11e		X
f	Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses			
12a	the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? If "Yes," complete Schedule D, Part X. Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete	11f		Χ.
h	Schedule D, Parts XI and XII.	12a	Х	
D	Was the organization included in consolidated, independent audited financial statements for the tax year? If "Yes,"			
13	and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional. Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E.	12b		<u>X</u>
	Did the organization maintain an office, employees, or agents outside of the United States?	13		X
b	Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking,	14a		X
	fundraising, business, investment, and program service activities outside the United States, or aggregate]	
	foreign investments valued at \$100,000 or more? If "Yes," complete Schedule F, Parts I and IV.	14b	Ì	Х
5	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or	· · · · ·		<u>~</u>
_	for any foreign organization? If "Yes," complete Schedule F, Parts II and IV	15		Χ
6	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? If "Yes," complete Schedule F, Parts III and IV	16		x
7	Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? If "Yes," complete Schedule G, Part I (see instructions).			
8	Did the organization report more than \$15,000 total of fundraising event gross income and contributions on	17	$\cdot +$	_X_
	Part VIII, lines 1c and 8a? If "Yes," complete Schedule G, Part II	18	x	
9	Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII line 9a?			
	If "Yes," complete Schedule G, Part III	19]	<u>X</u>
		Form (יי מפנ	20401

Par	TIV Checklist of Required Schedules (continued)			r
		60	Yes	No
	Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H	20a	_	X
	If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?	20b		
21	Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? If "Yes," complete Schedule I, Parts I and II	24	х	Ì
00		21		-
22	Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? If "Yes," complete Schedule I, Parts I and III.	22	х	
22	Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the	122	^	
23	organization's current and former officers, directors, trustees, key employees, and highest compensated	1		
	employees? If "Yes," complete Schedule J	23		Х
2/12	Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than			
24 a	\$100,000 as of the last day of the year, that was issued after December 31, 2002? If "Yes," answer lines	i l		
	24b through 24d and complete Schedule K. If "No," go to line 25a	24a		х
h	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		
	Did the organization maintain an escrow account other than a refunding escrow at any time during the year			
·	to defease any tax-exempt bonds?	24c		
ч	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d		
	Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit	- · · ·		
200	transaction with a disqualified person during the year? If "Yes," complete Schedule L, Part I	25a		Х
b	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a			
_	prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or			
	990-EZ? If "Yes," complete Schedule L, Part I	25b		Х
26	Did the organization report any amount on Part X, line 5, 6, or 22 for receivables from or payables to any		İ	
	current or former officers, directors, trustees, key employees, highest compensated employees, or			
	disqualified persons? If "Yes," complete Schedule L, Part II	26	ļ	Χ
27	Did the organization provide a grant or other assistance to an officer, director, trustee, key employee,			
	substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled		1	
	entity or family member of any of these persons? If "Yes," complete Schedule L, Part III	27		Χ
28	Was the organization a party to a business transaction with one of the following parties (see Schedule L,	- 11		
	Part IV instructions for applicable filing thresholds, conditions, and exceptions):			÷
а	A current or former officer, director, trustee, or key employee? If "Yes," complete Schedule L, Part IV	28a		Χ
b	A family member of a current or former officer, director, trustee, or key employee? If "Yes," complete			
	Schedule L, Part IV	28b		Χ
C	An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof)			
	was an officer, director, trustee, or direct or indirect owner? If "Yes," complete Schedule L, Part IV	28c		Χ
29	Did the organization receive more than \$25,000 in non-cash contributions? If "Yes," complete Schedule M	29		Χ
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified		i	
	conservation contributions? If "Yes," complete Schedule M	30	\Box	<u>X</u>
31	Did the organization liquidate, terminate, or dissolve and cease operations? If "Yes," complete Schedule N,			
	Part I	31		X
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets?		İ	
	If "Yes," complete Schedule N, Part II	32		<u>X</u>
33	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations			
	sections 301.7701-2 and 301.7701-37 If "Yes," complete Schedule R, Part I	33		Х
34	Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Part II,		J	
	III, or IV, and Part V, line 1	34		X
	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a		Χ
b	If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled			
	entity within the meaning of section 512(b)(13)? If "Yes," complete Schedule R, Part V, line 2	35b		
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related		i	.,
	organization? If "Yes," complete Schedule R, Part V, line 2	36		_X
37	Did the organization conduct more than 5% of its activities through an entity that is not a related organization			
	and that is treated as a partnership for federal income tax purposes? If "Yes," complete Schedule R, Part			v
	VI	37	\dashv	Х
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and			
	19? Note. All Form 990 filers are required to complete Schedule O	38	X	
		Form S	7岁リ (2	2016)

Pa	It V Statements Regarding Other IRS Filings and Tax Compliance Check if Schedule O contains a response or note to any line in this Part V			П
			Yes	No
1a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable		1,7	
b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable			
C	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable			
_	gaming (gambling) winnings to prize winners?	1c	<u> </u>	X
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax	ř: i		
	Statements, filed for the calendar year ending with or within the year covered by this return 21			
þ	If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	2b	X	<u> </u>
_	Note. If the sum of lines 1a and 2a is greater than 250, you may be required to e-file. (see instructions)	j.,		1.
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?	За	$ldsymbol{f eta}$	X
b	If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation in Schedule O.	3b	╙	<u> </u>
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other authority			
	over, a financial account in a foreign country (such as a bank account, securities account, or other financial			l
	account)?	<u>4a</u>	<u> </u>	X
b	If "Yes," enter the name of the foreign country:	Sail.		1
	See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts			[
	(FBAR).	112.1	•	
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5a	<u> </u>	X
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction? [5b	<u></u>	Х
C	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?	5c	l	
6a	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the			
	organization solicit any contributions that were not tax deductible as charitable contributions?	6a		X
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or			
	gifts were not tax deductible?	6b		l
7	Organizations that may receive deductible contributions under section 170(c).	111		
а	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods	- 1		
	and services provided to the payor?	7a	х	1
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?	7b	Х	
C	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was			
	required to file Form 8282?	7c		Х
d	If "Yes," indicate the number of Forms 8282 filed during the year	-		
е	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	7e		X
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7f		X
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	7g		
h		7h		
8	Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the	7.		
	sponsoring organization have excess business holdings at any time during the year?	8		
9	Sponsoring organizations maintaining donor advised funds.			
а	POLICE TO THE POLICE OF THE PO	9a		
b		9b		
10	Section 501(c)(7) organizations. Enter:	-		. T.
а	Initiation fees and capital contributions included on Part VIII, line 12			
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities 10b			÷.
11	Section 501(c)(12) organizations. Enter:		- {	
а	Gross income from members or shareholders			
b	Gross income from other sources (Do not net amounts due or paid to other sources	. **		100
	against amounts due or received from them.)			
12a		12a		
b	If "Yes," enter the amount of tax-exempt interest received or accrued during the year	120		
13	Section 501(c)(29) qualified nonprofit health insurance issuers.		; - 1) i
a		13a		<u> </u>
u	Note. See the instructions for additional information the organization must report on Schedule O.	Ja		
b	Enter the amount of reserves the organization is required to maintain by the states in which		1	
	the organization is licensed to issue qualified health plans			
С	Enter the amount of reserves on hand	;		- 21
14a		45		
		14a	\dashv	<u>X</u>
b	<u>in res, has it lieu a nomi rzy ty report mese payments? Il riyo, provide an explanation in Schedule U </u>	14b	- 1	

Part VI

Sec	tion A. Governing Body and Management			1	T			
4-	Catastha average of voting members of the appearing hady at the and of the toy year	40 15		Yes	No			
та	Enter the number of voting members of the governing body at the end of the tax year If there are material differences in voting rights among members of the governing body, or	<u>1a 15</u>	4	1	ĺ			
	if the governing body delegated broad authority to an executive committee or similar				ĺ			
	committee, explain in Schedule O.			. :				
b	Enter the number of voting members included in line 1a, above, who are independent	1b 15						
2	Did any officer, director, trustee, or key employee have a family relationship or a business relationsh		1					
2	any other officer, director, trustee, or key employee?							
3	Did the organization delegate control over management duties customarily performed by or under t		2	 	<u>X</u>			
J	supervision of officers, directors, or trustees, or key employees to a management company or other		3		х			
4	Did the organization make any significant changes to its governing documents since the prior Form 990 wa		4	\vdash	x			
4	Did the organization make any significant changes to as governing documents since the prior Form 330 was Did the organization become aware during the year of a significant diversion of the organization's a		5	1	X			
5	Did the organization become aware during the year of a significant diversion of the organization have members or stockholders?	550151	6		x			
6	Did the organization have members of stockholders, or other persons who had the power to elect or a	nnnoint	۳	 	 ^			
7a	one or more members of the governing body?		7a	x				
h	Are any governance decisions of the organization reserved to (or subject to approval by) members,		<u> </u>	 ^ -				
b			7b	x				
	stockholders, or persons other than the governing body?	durina	"	 ^	-			
8	the year by the following:	during						
_	The governing body?		8a	Х	- 1.			
a b	Each committee with authority to act on behalf of the governing body?		8b	x	-			
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be re		- 05	├^-				
9	at the organization's mailing address? If "Yes," provide the names and addresses in Schedule O		9		х			
Sect	ion B. Policies (This Section B requests information about policies not required by the I			1	L <u>^`</u>			
Jeci	ton b. I oncles (Time occuen b requests anothingtion about policies not regulated by the I	ntomar i tovomao t	<u>/040</u>	Yes	No			
10a	Did the organization have local chapters, branches, or affiliates?		10a	Х				
b	If "Yes," did the organization have written policies and procedures governing the activities of such control of the control of							
_	affiliates, and branches to ensure their operations are consistent with the organization's exempt pur		10b	x				
11a	Has the organization provided a complete copy of this Form 990 to all members of its governing body befor		11a		Х			
b	Describe in Schedule O the process, if any, used by the organization to review this Form 990.	v						
12a	Did the organization have a written conflict of interest policy? If "No," go to line 13		12a	x				
b	Were officers, directors, or trustees, and key employees required to disclose annually interests that could gi		12b	Х				
C	Did the organization regularly and consistently monitor and enforce compliance with the policy? If "							
	describe in Schedule O how this was done		12c	L <u>x</u>				
13	Did the organization have a written whistleblower policy?		13	Х				
14	Did the organization have a written document retention and destruction policy?		14	X				
15	Did the process for determining compensation of the following persons include a review and approv	al by						
	independent persons, comparability data, and contemporaneous substantiation of the deliberation a	nd decision?						
a	The organization's CEO, Executive Director, or top management official.		15a	Х				
b	Other officers or key employees of the organization		15b		<u> </u>			
	If "Yes" to line 15a or 15b, describe the process in Schedule O (see instructions).			:				
16a	Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrange	ment	- P		T			
	with a taxable entity during the year?		16a		_X_			
b	If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate							
	participation in joint venture arrangements under applicable federal tax law, and take steps to safego		100					
	the organization's exempt status with respect to such arrangements?		16b					
Sect	ion C. Disclosure							
17	List the states with which a copy of this Form 990 is required to be filed	T 10						
18	Section 6104 requires an organization to make its Forms 1023 (or 1024 if applicable), 990, and 990	· F(Section 501(c)(3)	s only	()				
	available for public inspection. Indicate how you made these available. Check all that apply.							
		lain in Schedule O)		_				
19 Describe in Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy,								
financial statements available to the public during the tax year.								
20	State the name, address, and telephone number of the person who possesses the organization's bo		•					
	EXECUTIVE DIRECTOR 8588 POTTER PARK DRIVE, SUITE 500, SARASOTA, FL 34238	(941) 312-0400						
	0000 FO FILIX FARK DIVINE, OUT E 000, OAKAOO IA, FE 04200							

Form 990 (2016)	PRADER-WILLI SYNDROME ASSOCIATION (USA) 41-1306908	D '
Part VII	Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated	Page
	Employees, and Independent Contractors	
	Check if Schedule O contains a response or note to any line in this Part VII	
Section A.	Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees	<u> </u>

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

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

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

(A) Name and Title	(B) Average hours per week (list any hours for related	Average box, unless person is both an Reportable hours per officer and a director/fursiee) compensation							(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the
	organizations below dotted líne)	Individual trustee or director	institutional trustee		nployee	Highest compensated employee	7	(W-2/1099-MISC)	(**************************************	organization and related organizations
(1) MICHELLE TOLBERT	2.00									
CHAIR	0.00	X	<u> </u>	X				0	0	0
(2) JIM KOERBER	2.00	İ								
VICE-CHAIR	0.00	X	_	X				0	0	0
(3) JULIE DOHERTY	2.00	l i								
SECRETARY	0.00	Х		Х				0	0	0
(4) DENISE WESTENFIELD TREASURER	2.00						J		ļ	
(5) DAN BEAVER	0.00	Χ.		Х			\dashv	0	0	0
DIRECTOR	1.00	١.,		- 1		- 1			ľ	
(6) DAN DRISCOLL	0.00	<u> </u>		_				<u>o</u> l	0	0
DIRECTOR	1.00	ا را			ŀ	ſ	ı			
(7) PETE GIRARD	0.00	<u> </u>	-1	-	-			0	0	0
DIRECTOR	1.00 0.00	, l			ļ	1		_1		
(8) ROB LUTZ	1.00	<u> </u>	-	\dashv	-+		\dashv	0	0	0
DIRECTOR	0.00	x			i	1	-			
(9) ROB SEELY	1.00	^	+	+	-		\dashv	0	0	0
DIRECTOR	0.00	х		- [i				_[
(10) TAMMIE PENTA	1.00	^	\dashv		\dashv			<u></u>	0	0
DIRECTOR	0.00	х		-		ľ				
(11) JAMES KANE	1.00	^	\dashv	╅	\dashv		+	0	0	0
DIRECTOR	0.00	x		1	- 1	- {	-		ا	_
(12) LEON CALDWELL, PHD	1.00	^	-+	+	-	\dashv	+	0	약	0
DIRECTOR	0.00	\times		- [1	o		
(13) TOM CONWAY	1.00	~~		\forall	┪	_	╁	<u>v</u>	0	0
DIRECTOR	0.00	\times]				0	o	5
(14) TOM NOONAN	1.00	~	+	\top		\dashv	┰┼	<u></u>		0
DIRECTOR	0.00	\times						o	0	0

P	art VII Section A. Officers, Directors, 7	Trustees, Key Em	ploye	es,	an	d Hi	ighes	st C	ompensated En	nployees (contir	nued)
	(A)	(B)	(do i	not ci	Pos	C) sition more	e than	one	(D)	(F)	
	Name and title	Average hours per week (list any hours for related organizations below dotted line)	box	unle: er an	ss pe	rson lirect	is bot or/trus	h an lee)	Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	Estimated amount of other compensation from the organization and related organizations
	MARGUERITE RUPNOW ECTOR	1.00	l						0	0	
		- 								Ů	
(17)					-	-		-		 	
(18)											
(19)			ļ -		-						
(20)			-		_	-					<u>l</u>
(21)											
(22)											1
(23)											
(24)											
(25)							-				
1b c	Sub-total	Section A						>	0	0	0
d 	Total (add lines 1b and 1c)	limited to those lis		bove					0 more than \$100	0) ,000 of	0
3	Did the organization list any former officer, di employee on line 1a? If "Yes," complete Sche	rector, or trustee, I	-	mple		e, o	r higł	nest	compensated		Yes No
4	For any individual listed on line 1a, is the sum the organization and related organizations gro	of reportable com	pens	atio					•	1	
5	individual. Did any person listed on line 1a receive or act for services rendered to the organization? If "	•			•			-			4 X 5 X
Sec	tion B. Independent Contractors	res, complete sc	reuu	8 3	101	Suci	i per	3011			<u> </u>
1	Complete this table for your five highest comp compensation from the organization. Report of year.										ax
	(A) Name and business ad	idress							(B) Description of serv	rices C	(C) ompensation
						_	\Box				0
		-									0
				_	_	_					0
											0
2	Total number of independent contractors (incl	-	ed to	thos	e li:	sted	abo	ve) י	wno received		3.据于1.5.5。

ra	L VIII	Check if Schedule O contains a re	sponse of I	note to any line i	n this Part VIII			\square
					(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512-514
Contributions, Gifts, Grants and Other Similar Amounts	1a b c d e f	Federated campaigns Membership dues Fundraising events Related organizations Government grants (contributions) All other contributions, gifts, grants, ar	1b 1c 1d 1e	0 0				
Contribu	g h	similar amounts not included above. Noncash contributions included in lines 1 Total. Add lines 1a-1f	•	0	1,565,184			
се Revenue	2a b	MEMBERSHIP DUES CONFERENCE INCOME		Business Code	55,875 31,692			31,692
Ргодгат Service Revenue	d e f	All other program service revenue			0 0			
<u> </u>	3 4	Total. Add lines 2a–2f Investment income (including dividend other similar amounts) Income from investment of tax-exempt	s, interest,	and ▶	79,680 0	t	2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2	79,680
}	5 6a b	Royalties		(ii) Personal	0			
	d 7a b	assets other than inventory Less: cost or other basis and sales expenses	Securities 0 0	(ii) Other 0	0			
enue	d 8a	Gain or (loss) Net gain or (loss) Gross income from fundraising events (not including \$	<u>-</u> -	•	0			
Other Reven	b c 9a	of contributions reported on line 1c). See Part IV, line 18. Less: direct expenses. Net income or (loss) from fundraising e Gross income from gaming activities. See Part IV, line 19. Less: direct expenses.	a bevents	386,356 52,808 • • • • • • • • • • • • • • • •	333,548			
	С	Net income or (loss) from gaming active Gross sales of inventory, less returns and allowances. Less: cost of goods sold	ities a .	18,496 15,371	3,125			
	11a b	Miscellaneous Revenue		Business Code	0 0			
	d e 12	All other revenue		, >	0 0 2 069 104	55 875	0	111 372

Part IX Statement of Functional Expenses Section 501(c)(3) and 501(c)(4) organizations must complete all columns. All other organizations must complete column (A)

260	tion 50 (c)(3) and 50 (c)(4) organizations must complete all c			complete column (A	<i>).</i>
	Check if Schedule O contains a response or note t		· · · · ·		
	not include amounts reported on lines 6b, 7b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1	Grants and other assistance to domestic organizations				
	domestic governments. See Part IV, line 21	238,802	238,802		
2	Grants and other assistance to domestic				}
	individuals. See Part IV, line 22	45,603	45,603		
3	Grants and other assistance to foreign				
	organizations, foreign governments, and foreign			图44111 11 11 11 11 11 11 11 11 11 11 11 1	
	individuals. See Part IV, lines 15 and 16	0			
4	Benefits paid to or for members	0			
5	Compensation of current officers, directors,			ĺ	
	trustees, and key employees	0		0	
6	Compensation not included above, to disqualified	:			
	persons (as defined under section 4958(f)(1)) and				
	persons described in section 4958(c)(3)(B)	0	<u> </u>		
7	Other salaries and wages	651,018	475,310	123,930	51,778
8	Pension plan accruals and contributions (include				
	section 401(k) and 403(b) employer contributions)	0			
9	Other employee benefits	69,375	50,651	13,207	5,517
10	Payroll taxes	52,105	38,042	9,919	4,144
11	Fees for services (non-employees):				
а	Management	0			
b	Legal , , . , ,	0			-
С	Accounting	12,355	8,860	1,978	1,517
d	Lobbying	0			
e	Professional fundraising services. See Part IV, line 17	0			<u> </u>
f	Investment management fees [60,000		60,000	(
g	Other. (If line 11g amount exceeds 10% of line 25, column				
	(A) amount, list line 11g expenses on Schedule O.)	lo	i		
12	Advertising and promotion	0			
13	Office expenses	28,618	20,522	4,582	3,514
14	Information technology	14,734	10,568	2,357	1,809
15	Royallies	0			<u> </u>
16	Occupancy	84,561	60,639	13,538	10,384
17	Travel	17,185	12,324	2,751	2,110
18	Payments of travel or entertainment expenses			,	· · · · · · · · · · · · · · · · · · ·
	for any federal, state, or local public officials	0			
19	Conferences, conventions, and meetings	5,854	5,854	0	0
20	Interest	0			
21	Payments to affiliates	0			
22	Depreciation, depletion, and amortization	3,493	0	3,493	0
23	Insurance	13,993	10,035	2,240	1,718
24	Other expenses. Itemize expenses not covered			# 1 P P P P P P P P P P P P P P P P P P	
	above (List miscellaneous expenses in line 24e. If	0.			
	line 24e amount exceeds 10% of line 25, column		•		
	(A) amount, list line 24e expenses on Schedule O.)				
а	NEWSLETTER	24,349	24,349	0	0
b	FAMILY SUPPORT	28,057	28,057	0	0
c	OFFICE SUPPLIES	20,461	14,673	3,275	2,513
đ	BANK CHARGES	16,317	11,700	2,613	2,004
e	All other expenses OTHER	56,734	48,177	4,842	3,715
25	Total functional expenses. Add lines 1 through 24e .	1,443,614	1,104,166	248,725	90,723
26	Joint costs. Complete this line only if the		, ,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,		
	organization reported in column (B) joint costs			;	
	from a combined educational campaign and		ļ	j	
	fundraising solicitation. Check here ► if		1		
	following SOP 98-2 (ASC 958-720)			j	
		<u>-</u> <u>-</u>			

41-1306908 Page **11** PRADER-WILLI SYNDROME ASSOCIATION (USA) Form 990 (2016) Part X **Balance Sheet**

		Check is Scriedule O Contains a response of			(A) Beginning of year	ļ	(B) End of year
	1	Cash—non-interest-bearing			771,513	1	1,001,865
	2	Savings and temporary cash investments				2	
	3	Pledges and grants receivable, net	22,575		23,449		
	4	Accounts receivable, net	5,472		780		
	5	Loans and other receivables from current and for trustees, key employees, and highest compens Complete Part II of Schedule L.		5			
र	6	Loans and other receivables from other disqualified persises 4958(f)(1)), persons described in section 4958(c)(3)(B), a sponsoring organizations of section 501(c)(9) voluntary e organizations (see instructions). Complete Part II of Sche		6			
Assets	7	Notes and loans receivable, net			0	7	0
Ž	8	Inventories for sale or use			22,349	8	10,275
	9	Prepaid expenses and deferred charges			16,800	9	9,735
	10a	Land, buildings, and equipment: cost or					
		other basis. Complete Part VI of Schedule D	10a	78,874			
	b	Less: accumulated depreciation	10b	75,765		10c	3,109
	11	Investments—publicly traded securities			1,056,943	11	1,275,696
	12	Investments-other securities. See Part IV, line		0	12	0	
	13	Investments-program-related. See Part IV, line	0	13	0		
	14	Intangible assets		0	14	0	
	15	Other assets. See Part IV, line 11		77,795	15	110,083	
	16	Total assets. Add lines 1 through 15 (must equ	al line 3	34)	1,980,049	16	2,434,992
	17	Accounts payable and accrued expenses			240,473	17	71,811
	18	Grants payable			18		
	19	Deferred revenue		19			
	20	Tax-exempt bond liabilities			20		
	21	Escrow or custodial account liability. Complete	Part IV	of Schedule D		21	
S	22	Loans and other payables to current and former					
Liabilities		trustees, key employees, highest compensated				W.	
ap:		disqualified persons. Complete Part II of Sched				22	<u> </u>
Ï	23	Secured mortgages and notes payable to unrela			0		0
	24	Unsecured notes and loans payable to unrelate			0	24	0
	25	Other liabilities (including federal income tax, pa					
		parties, and other liabilities not included on lines					
		Part X of Schedule D			0		74.044
	26	Total liabilities. Add lines 17 through 25			240,473	26	71,811
S		Organizations that follow SFAS 117 (ASC 956 complete lines 27 through 29, and lines 33 at		k here ► X and		: ?	
ĕ	27	Unrestricted net assets			535,395	27	864,952
<u> </u>	28	Temporarily restricted net assets			1,070,297	28	1,338,295
m	29	Permanently restricted net assets			133,884		159,934
or Fund Balances	20	Organizations that do not follow SFAS 117 (ASC958), complete lines 30 through 34.					
	20	Capital stock or trust principal, or current funds				30	
Set	30	Paid-in or capital surplus, or land, building, or e			31		
As	31 32	Retained earnings, endowment, accumulated in				32	
Net Assets	33	Total net assets or fund balances			1,739,576		2,363,181
~	34	Total liabilities and net assets/fund balances			1,980,049		2,434,992
	JH	Total nabilities and not assets fully balances.		 	1,000,010		Form 990 (2016)

Form	990 (2016) PRADER-WILLI SYNDROME ASSOCIATION (USA)	41-	-1306908	Par	ge 12
Par	t XI Reconciliation of Net Assets				
	Check if Schedule O contains a response or note to any line in this Part XI				
1	Total revenue (must equal Part VIII, column (A), line 12)	1		2,069	9,104
2	Total expenses (must equal Part IX, column (A), line 25)	2		1,443	3,614
3	Revenue less expenses. Subtract line 2 from line 1	3		625	5,490
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4		1,739	9,576
5	Net unrealized gains (losses) on investments	5			1,885
6	Donated services and use of facilities	6			
7	Investment expenses	7			
8	Prior period adjustments	8			
9	Other changes in net assets or fund balances (explain in Schedule O)	9	•		
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 33,				
	<u>column (B)) </u>	10		2,36 3	3,181
Par	X(Financial Statements and Reporting				_
	Check if Schedule O contains a response or note to any line in this Part XII			.	\sqcup
				Yes	No
1	Accounting method used to prepare the Form 990: Cash X Accrual Other		_	1. 25	
	If the organization changed its method of accounting from a prior year or checked "Other," explain in				
	Schedule O.				
2a	Were the organization's financial statements compiled or reviewed by an independent accountant?		2a		Х
	If "Yes," check a box below to indicate whether the financial statements for the year were compiled or				si
	reviewed on a separate basis, consolidated basis, or both:				
	X Separate basis Consolidated basis Both consolidated and separate basis				
ь	Were the organization's financial statements audited by an independent accountant?		2b	X	
	If "Yes," check a box below to indicate whether the financial statements for the year were audited on a				٠.
	separate basis, consolidated basis, or both:				
	X Separate basis Consolidated basis Both consolidated and separate basis				
С	If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of			. : .	
·	the audit, review, or compilation of its financial statements and selection of an independent accountant?		2c	x	
	If the organization changed either its oversight process or selection process during the tax year, explain in				
	Schedule O.				
За	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in				
U	the Single Audit Act and OMB Circular A-133?		3a	J	Х
b	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the		"		
	required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits.		3b		
				990 (2016)

8868

(Rev. January 2017)

Department of the Treasury Internal Revenue Service

Application for Automatic Extension of Time To File an Exempt Organization Return

OMB No. 1545-1709

► File a separate application for each return.

Information about Form 8868 and its instructions is at www.irs.gov/form8868.

Electronic filing (e-file). You can electronically file Form 8868 to request a 6-month automatic extension of time to file any of the forms listed below with the exception of Form 8870, Information Return for Transfers Associated With Certain Personal Benefit Contracts, for which an extension request must be sent to the IRS in paper format (see instructions). For more details on the

electronic filing of this form, visit www.irs.gov/efile, click on Charities & Non-Profits, and click on e-file for Charities and Non-Profits. Automatic 6-Month Extension of Time. Only submit original (no copies needed) All corporations required to file an income tax return other than Form 990-T (including 1120-C filers), partnerships, REMICs, and trusts must use Form 7004 to request an extension of time to file income tax returns. Enter filer's identifying number, see instructions Type or Name of exempt organization or other filer, see instructions. Employer identification number (EIN) or print PRADER-WILLI SYNDROME ASSOCIATION (USA) 41-1306908 Number, street, and room or suite no. If a P.O. box, see instructions. File by the Social security number (SSN) due date for 8588 POTTER PARK DRIVE, SUITE 500 filing your City, town or post office, state, and ZIP code. For a foreign address, see instructions. return. See instructions SARASOTA, FL 34238 01 Application Return Application Return Is For Code Is For Code Form 990 or Form 990-EZ 01 Form 990-T (corporation) 07 Form 990-BL 02 Form 1041-A 08 Form 4720 (individual) 03 Form 4720 (other than individual) 09 Form 990-PF 04 Form 5227 10 Form 990-T (sec. 401(a) or 408(a) trust) 05 Form 6069 11 Form 990-T (trust other than above) 06 Form 8870 12 The books are in the care of ► EXECUTIVE DIRECTOR Telephone No. ► (941) 312-0400 Fax No. ▶ If the organization does not have an office or place of business in the United States, check this box. If this is for a Group Return, enter the organization's four digit Group Exemption Number (GEN) If this is for the whole group, check this box..... and attach a list with the names and EINs of all members the extension is for. I request an automatic 6-month extension of time until 11/15 , 20 17 , to file the exempt organization return for the organization named above. The extension is for the organization's return for: ► X calendar year 20 tax year beginning , 20 , and ending , 20 . . If the tax year entered in line 1 is for less than 12 months, check reason: Initial return Change in accounting period 3a If this application is for Forms 990-BL, 990-PF, 990-T, 4720, or 6069, enter the tentative tax, less any nonrefundable credits. See instructions. За If this application is for Forms 990-PF, 990-T, 4720, or 6069, enter any refundable credits and estimated tax payments made. Include any prior year overpayment allowed as a credit. 3b Balance due. Subtract line 3b from line 3a. Include your payment with this form, if required, by using EFTPS (Electronic Federal Tax Payment System). See instructions. Caution: If you are going to make an electronic funds withdrawal (direct debit) with this Form 8868, see Form 8453-EO and Form 8879-EO for payment instructions.

SCHEDULE A (Form 990 or 990-EZ)

Public Charity Status and Public Support

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

2016

Department of the Treasury Internal Revenue Service ► Attach to Form 990 or Form 990-EZ.
Information about Schedule A (Form 990 or 990-EZ) and its instructions is at www.frs.gov/form990.

Open to Public Inspection

Name of the organization Employer identification number PRADER-WILLI SYNDROME ASSOCIATION (USA) 41-1306908 Reason for Public Charity Status (All organizations must complete this part.) See instructions. The organization is not a private foundation because it is: (For lines 1 through 12, check only one box.) A church, convention of churches, or association of churches described in section 170(b)(1)(A)(i), 2 A school described in section 170(b)(1)(A)(ii). (Attach Schedule E (Form 990 or 990-EZ).) A hospital or a cooperative hospital service organization described in section 170(b)(1)(A)(iii). 3 A medical research organization operated in conjunction with a hospital described in section 170(b)(1)(A)(iii). Enter the hospital's name, city, and state: An organization operated for the benefit of a college or university owned or operated by a governmental unit described in section 170(b)(1)(A)(iv). (Complete Part II.) A federal, state, or local government or governmental unit described in section 170(b)(1)(A)(v). An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in section 170(b)(1)(A)(vI). (Complete Part II.) A community trust described in section 170(b)(1)(A)(vi). (Complete Part II.) 8 An agricultural research organization described in section 170(b)(1)(A)(lx) operated in conjunction with a land-grant college or university or a non-land-grant college of agriculture (see instructions). Enter the name, city, and state of the college or X An organization that normally receives: (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions—subject to certain exceptions, and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See section 509(a)(2). (Complete Part III.) An organization organized and operated exclusively to test for public safety. See section 509(a)(4). 11 An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes 12 of one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2). See section 509(a)(3). Check the box in lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g. Type I. A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization. You must complete Part IV, Sections A and B. Type II. A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s). You must complete Part IV, Sections A and C. Type III functionally integrated. A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions). You must complete Part IV, Sections A. D. and E. Type III non-functionally integrated. A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions). You must complete Part IV, Sections A and D, and Part V. Check this box if the organization received a written determination from the IRS that it is a Type II, Type III, functionally integrated, or Type III non-functionally integrated supporting organization. Enter the number of supported organizations 0 Provide the following information about the supported organization(s). (i) Name of supported organization (II) EIN (III) Type of organization (iv) is the organization (v) Amount of monetary (vi) Amount of (described on lines 1-10 listed in your governing support (see other support (see above (see instructions)) document? instructions) instructions) Yes No (A) (B)

Total

(C)

(D)

(E)

Schedule A (Form 990 or 990-EZ) 2016 PRADER-WILLI SYNDROME ASSOCIATION (USA) 41-1306908 Page 2 Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi) (Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.) Section A. Public Support Calendar year (or fiscal year beginning in) (a) 2012 (b) 2013 (c) 2014 (d) 2015 (e) 2016 (f) Total Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") 0 Tax revenues levied for the organization's benefit and either paid to or expended on 0 The value of services or facilities furnished by a governmental unit to the organization without charge Total. Add lines 1 through 3 0 0 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, 6 Public support. Subtract line 5 from line 4. Section B. Total Support Calendar year (or fiscal year beginning in) (a) 2012 (f) Total (b) 2013 (c) 2014 (d) 2015 (e) 2016 0 0 7 0 0 Gross income from interest, dividends. payments received on securities loans. rents, royalties and income from similar 0 Net income from unrelated business activities, whether or not the business is regularly carried on 0 10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) 11 Total support. Add lines 7 through 10. 0 13 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) Section C. Computation of Public Support Percentage 14 0.00% 15 0.00% 16a 33 1/3% support test—2016. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, b 33 1/3% support test—2015. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this 17a 10%-facts-and-circumstances test—2016. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported b 10%-facts-and-circumstances test—2015. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in

Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly

Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see

instructions.

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

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

Se	ction A. Public Support						
Cale	endar year (or fiscal year beginning in)	(a) 2012	(b) 2013	(c) 2014	(d) 2015	(e) 2016	(f) Total
1	Gifts, grants, contributions, and membership fees						
	received. (Do not include any "unusual grants.")	496,832	450,130	838,581	989,771	1,621,059	4,396,373
2	Gross receipts from admissions, merchandise						
	sold or services performed, or facilities furnished in any activity that is related to the						
	organization's lax-exempt purpose	364,120	403,601	380,667	422,122	336,673	1,907,183
3	Gross receipts from activities that are not an	<u>'-</u>	•	· -			.,,
	unrelated trade or business under section 513	68,058	291,881	74,070	377,608	31,692	843,309
4	Tax revenues levied for the organization's						; · · · · · · · · · · · · · · · · · · ·
	benefit and either paid to or expended on						
	its behalf						0
5	The value of services or facilities						
	furnished by a governmental unit to the						
	organization without charge	ı					0
6	Total. Add lines 1 through 5	929,010	1,145,612	1,293,318	1,789,501	1,989,424	7,146,865
7a	Amounts included on lines 1, 2, and 3			}			
	received from disqualified persons						0
b	Amounts included on lines 2 and 3 received						
	from other than disqualified persons that		•				
	exceed the greater of \$5,000 or 1% of the						
	amount on line 13 for the year	216,065	302,365	670,777	315,523	597,673	2,102,403
¢	Add lines 7a and 7b	216,065	302,365	670,777	315,523	597,673	2,102,403
8	Public support (Subtract line 7c from	경우 수 있다.					
	line 6.)				<u> </u>		5,044,462
Sec	ction B. Total Support						
Cale	ndar year (or fiscal year beginning in) 💎 🕨	(a) 2012	(b) 2013	(c) 2014	(d) 2015	(e) 2016	(f) Total
9	Amounts from line 6	929,010	1,145,612	1,293,318	1,789,501	1,989,424	7,146,865
10a	Gross income from interest, dividends,]			
	payments received on securities loans,						
	rents, royalties and income from similar sources	61,803	63,898	65,635	54,561	79,680	325,577
b	Unrelated business taxable income (less					i	
	section 511 taxes) from businesses						
	acquired after June 30, 1975		· · · · · ·				0
C	Add lines 10a and 10b	61,803	63,898	65,635	54,561	79,680	325,577
11	Net income from unrelated business						
	activities not included in line 10b, whether			Į.		I	
	or not the business is regularly carried on .						0
12	Other income. Do not include gain or		i				
	loss from the sale of capital assets		İ				
	(Explain in Part VI.)						0
13	Total support. (Add lines 9, 10c, 11,				ļ		
	and 12.)	990,813	1,209,510	1,358,953	1,844,062	2,069,104	7,472,442
14	First five years. If the Form 990 is for the or	-		•	, , ,	,	
	organization, check this box and stop here.						<u></u> .▶ <u> </u>
	tion C. Computation of Public Sup	•					
	Public support percentage for 2016 (line 8, co	,,,		•	-	15	67.51%
	Public support percentage from 2015 Schedu			<u></u>		16	67.57%
Sec	tion D. Computation of Investmen						<u>_</u>
17	Investment income percentage for 2016 (line	10c, column (f) div	ided by line 13, co	lumn (f)) . , , .		17	4.36%
18	Investment income percentage from 2015 Sc	•			٠.	18	4.48%
19a	33 1/3% support tests—2016. If the organiz				•		_
	not more than 33 1/3%, check this box and st				_		▶ 🔀
þ	33 1/3% support tests—2015. If the organiz						. —
	line 18 is not more than 33 1/3%, check this b						==
20	Private foundation. If the organization did no	ot check a box on I	ine 14, 19a, or 19b	, check this box an	id see instructions		🕨 🛄

Part IV Supporting Organizations

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

Section A. All Supporting Organizations

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

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	ule A (Form 980 or 990-EZ) 2016 PRADER-WILLI SYNDROME ASSOCIATION (USA) 41-1300900			age 0
Par	Supporting Organizations (continued)		Yes	No
	the the second of a sift or contribution from any of the following persons?		168	140
11	Has the organization accepted a gift or contribution from any of the following persons?			
а	A person who directly or indirectly controls, either alone or together with persons described in (b) and (c)	11a	1	
	below, the governing body of a supported organization?	11b	╁	
þ	A family member of a person described in (a) above?	11c	 	-
Sect	A 35% controlled entity of a person described in (a) or (b) above? If "Yes" to a, b, or c, provide detail in Part VI.	1116	J	J
000	301 B. Type I oupporting Organizations		Yes	No
1	Did the directors, trustees, or membership of one or more supported organizations have the power to			.
•	regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the			1
	tax year? If "No," describe in Part VI how the supported organization(s) effectively operated, supervised, or	1		
	controlled the organization's activities. If the organization had more than one supported organization,	1		İ
	describe how the powers to appoint and/or remove directors or trustees were allocated among the supported	1		
	organizations and what conditions or restrictions, if any, applied to such powers during the tax year.	1		
2	Did the organization operate for the benefit of any supported organization other than the supported			
	organization(s) that operated, supervised, or controlled the supporting organization? If "Yes," explain in Part			ļ
	VI how providing such benefit carried out the purposes of the supported organization(s) that operated,			
	supervised, or controlled the supporting organization.	2		
Sect	lion C. Type II Supporting Organizations			
			Yes	No
1	Were a majority of the organization's directors or trustees during the tax year also a majority of the directors			1100
	or trustees of each of the organization's supported organization(s)? If "No," describe in Part VI how control			1.7
	or management of the supporting organization was vested in the same persons that controlled or managed			
	the supported organization(s).	1		
Sect	ion D. All Type III Supporting Organizations		,	
			Yes	No
1	Did the organization provide to each of its supported organizations, by the last day of the fifth month of the			
	organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax			
	year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the	V Y		
	organization's governing documents in effect on the date of notification, to the extent not previously provided?	1		
2	Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported		1 1	
	organization(s) or (ii) serving on the governing body of a supported organization? If "No," explain in Part VI how			
	the organization maintained a close and continuous working relationship with the supported organization(s).	2		<u> </u>
3	By reason of the relationship described in (2), did the organization's supported organizations have a			
	significant voice in the organization's investment policies and in directing the use of the organization's			
	income or assets at all times during the tax year? If "Yes," describe in Part VI the role the organization's		1111	
	supported organizations played in this regard.	3		l
Sect	lon E. Type III Functionally Integrated Supporting Organizations			
1	Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instru	ction	s).	
a	The organization satisfied the Activities Test. Complete line 2 below.			
b	The organization is the parent of each of its supported organizations. Complete line 3 below.			
С	The organization supported a governmental entity. Describe in Part VI how you supported a government entity (see	instruc	ctions).
2	Activities Test. Answer (a) and (b) below.		Yes	No
a	Did substantially all of the organization's activities during the tax year directly further the exempt purposes of			-110
•	the supported organization(s) to which the organization was responsive? If "Yes," then in Part VI identify			:
	those supported organizations and explain how these activities directly furthered their exempt purposes,			
	how the organization was responsive to those supported organizations, and how the organization determined			
	that these activities constituted substantially all of its activities.	2a		
b	Did the activities described in (a) constitute activities that, but for the organization's involvement, one or more		-	
~	of the organization's supported organization(s) would have been engaged in? If "Yes," explain in Part VI the			
	reasons for the organization's position that its supported organization(s) would have engaged in these		13	
	activities but for the organization's involvement.	2b		
3	Parent of Supported Organizations. Answer (a) and (b) below.			
а	Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or			
-	trustees of each of the supported organizations? Provide details in Part VI.	3a		
b	Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each			-
	of its supported organizations? If "Yes," describe in Part VI the role played by the organization in this regard.	3b		

emergency temporary reduction (see instructions).

instructions).

Page 6 Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations 1 Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970 (explain in Part VI). See Instructions, All other Type III non-functionally integrated supporting organizations must complete Sections A through E. (B) Current Year Section A - Adjusted Net Income (A) Prior Year (optional) 1 Net short-term capital gain 1 2 Recoveries of prior-year distributions 2 3 3 Other gross income (see instructions) 4 Add lines 1 through 3. 4 5 5 Depreciation and depletion 6 Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions) 6 7 Other expenses (see instructions) 7 8 Adjusted Net Income (subtract lines 5, 6, and 7 from line 4). 8 (B) Current Year Section B - Minimum Asset Amount (A) Prior Year (optional) 1 Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year): a Average monthly value of securities 1a 1b b Average monthly cash balances c Fair market value of other non-exempt-use assets 1c 1d d Total (add lines 1a, 1b, and 1c) 0 0 e Discount claimed for blockage or other factors (explain in detail in Part VI): 2 Acquisition indebtedness applicable to non-exempt-use assets 2 3 3 Subtract line 2 from line 1d. 0 4 Cash deemed held for exempt use. Enter 1-1/2% of line 3 (for greater amount, 4 0 5 Net value of non-exempt-use assets (subtract line 4 from line 3) 5 0 6 Multiply line 5 by .035. 6 0 0 7 Recoveries of prior-year distributions 7 0 0 8 8 Minimum Asset Amount (add line 7 to line 6) 0 Section C - Distributable Amount Current Year 1 Adjusted net income for prior year (from Section A, line 8, Column A) 1 0 2 2 Enter 85% of line 1 0 3 3 Minimum asset amount for prior year (from Section B, line 8, Column A) 0 4 Enter greater of line 2 or line 3. 4 0 5 Income tax imposed in prior year 5 6 Distributable Amount. Subtract line 5 from line 4, unless subject to

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

0

0

0

Breakdown of line 7:

b Excess from 2013

c Excess from 2014. . .

Excess from 2015

Excess from 2016.

8 a

Schedule B

(Form 990, 990-EZ, or 990-PF)

Department of the Treasury Internal Revenue Service

Name of the organization

Schedule of Contributors

Attach to Form 990, Form 990-EZ, or Form 990-PF.

Information about Schedule B (Form 990, 990-EZ, or 990-PF) and its instructions is at www.irs.gov/torm990.

OMB No. 1545-0047

2016

Employer identification number

PRADER-WILLI SYNDROM	ME ASSOCIATION (USA) 41-1306908					
Organization type (check	ne):					
Filers of:	Section:					
Form 990 or 990-EZ	X 501(c)(3) (enter number) organization					
	4947(a)(1) nonexempt charitable trust not treated as a private foundation					
	527 political organization					
Form 990-PF	501(c)(3) exempt private foundation					
	4947(a)(1) nonexempt charitable trust treated as a private foundation					
	501(c)(3) taxable private foundation					
	covered by the General Rule or a Special Rule. (7), (8), or (10) organization can check boxes for both the General Rule and a Special Rule. See					
General Rule						
	filing Form 990, 990-EZ, or 990-PF that received, during the year, contributions totaling \$5,000 or property) from any one contributor. Complete Parts I and II. See instructions for determining a intributions.					
Special Rules						
regulations under se 13, 16a, or 16b, and	described in section 501(c)(3) filing Form 990 or 990-EZ that met the 33 1/3 % support test of the actions 509(a)(1) and 170(b)(1)(A)(vi), that checked Schedule A (Form 990 or 990-EZ), Part II, line that received from any one contributor, during the year, total contributions of the greater of (1) the amount on (i) Form 990, Part VIII, line 1h, or (ii) Form 990-EZ, line 1. Complete Parts I and II.					
contributor, during the	described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one ne year, total contributions of more than \$1,000 exclusively for religious, charitable, scientific, all purposes, or for the prevention of cruelty to children or animals. Complete Parts I, II, and III.					
contributor, during the contributions totaled during the year for a General Rule applic	For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions exclusively for religious, charitable, etc., purposes, but no such contributions totaled more than \$1,000. If this box is checked, enter here the total contributions that were received during the year for an exclusively religious, charitable, etc., purpose. Don't complete any of the parts unless the General Rule applies to this organization because it received nonexclusively religious, charitable, etc., contributions totaling \$5,000 or more during the year.					
990-EZ, or 990-PF), but it m	at isn't covered by the General Rule and/or the Special Rules doesn't file Schedule B (Form 990, ust answer "No" on Part IV, tine 2, of its Form 990; or check the box on line H of its Form 990-EZ or on its ocertify that it doesn't meet the filing requirements of Schedule B (Form 990, 990-EZ, or 990-PF).					

SCHEDULE D (Form 990)

Supplemental Financial Statements

Complete if the organization answered "Yes" on Form 990, Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b. OMB No. 1545-0047

Open to Public Inspection

Department of the Treasury

► Attach to Form 990.

► Information about Schedule D (Form 990) and its instructions is at www.irs.gov/form990. Internal Revenue Service Name of the organization Employer Identification number PRADER-WILLI SYNDROME ASSOCIATION (USA) 41-1306908 Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts. Complete if the organization answered "Yes" on Form 990, Part IV, line 6. (a) Donor advised funds 1 Total number at end of year Aggregate value of contributions to (during year). 2 3 Aggregate value of grants from (during year) . Aggregate value at end of year Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control? Yes Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other Part II Conservation Easements. Complete if the organization answered "Yes" on Form 990, Part IV, line 7. Purpose(s) of conservation easements held by the organization (check all that apply). Preservation of land for public use (e.g., recreation or education) Preservation of a historically important land area Protection of natural habitat Preservation of a certified historic structure Preservation of open space Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form of a conservation 2 easement on the last day of the tax year. Held at the End of the Tax Year 2b Number of conservation easements on a certified historic structure included in (a) Number of conservation easements included in (c) acquired after 8/17/06, and not on a 3 Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during Number of states where property subject to conservation easement is located Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds?..... 6 Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing conservation easements during the year Amount of expenses incurred in monitoring, inspecting, handling of violations, and enforcing conservation easements during the year Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) In Part XIII, describe how the organization reports conservation easements in its revenue and expense statement, and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements. Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets. Complete if the organization answered "Yes" on Form 990, Part IV, line 8. 1a If the organization elected, as permitted under SFAS 116 (ASC 958), not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIII, the text of the footnote to its financial statements that describes these items. If the organization elected, as permitted under SFAS 116 (ASC 958), to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items: If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under SFAS 116 (ASC 958) relating to these items:

Assets included in Form 990, Part X.

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sets	(continue	ed)	

Sched		SYNDROME ASSOC			41-13069	
Par						
3	Using the organization's acquisition,		records, check any	of the following that	at are a significant u	se of its
	collection items (check all that apply)	1:				
а	Public exhibition		=	or exchange progra	ims	
b	Scholarly research		e Other			
c	Preservation for future general					
4	Provide a description of the organiza XIII.	tion's collections and	explain how they for	urther the organizati	ion's exempt purpos	se in Part
5	During the year, did the organization assets to be sold to raise funds rathe					Yes No
Par	Complete if the organization 990, Part X, line 21.	on answered "Yes"	•			t on Form
1a b	Is the organization an agent, trustee, included on Form 990, Part X? If "Yes," explain the arrangement in F					Yes No
•	ii Tes, explain iile anangement iii	are complete	tive removing table	·	Ar	mount
c	Beginning balance			🔟	С	
d	Additions during the year			<u>1</u>	d	
e	Distributions during the year			 	e	
f	Ending balance			· · · · · · · · · · · · · · · · · · ·	<u> f </u>	
2a	Did the organization include an amou	ınt on Form 990, Part	X, line 21, for escr	ow or custodial acc	ount liability?	Yes X No
b	If "Yes," explain the arrangement in P	Part XIII. Check here i	f the explanation ha	as been provided or	n Part XIII	. ,
Part						
	Complete if the organizatio	n answered "Yes"	on Form 990, Pa			
		(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1a	Beginning of year balance	133,884	111,150		97,821	89,079
b	Contributions	26,050	22,734	7,702	5,627	8,74
C	Net investment earnings, gains,				,	
A	and losses					
ď		ī				i

		(a) Outlett year	(D) I HOLYCOL	(c) Inc) cars pace	(a) Thice years back	(b) I call Jeals back
1a	Beginning of year balance	133,884	111,150	103,448	97,821	89,079
b	Contributions	26,050	22,734	7,702	5,627	8,742
C	Net investment earnings, gains,		-			
	and losses				,	
ď	Grants or scholarships					
e	Other expenditures for facilities					
	and programs					
f	Administrative expenses					
9	End of year balance	159,934	133,884	111,150	103,448	97,821
2	Provide the estimated percentage of the	ne current year end ba	alance (line 1g, co	lumn (a)) held as:		

2	Provide the estimated percentage of	of the current	year end balance (line	e 1g, column (a)) held as:
---	-------------------------------------	----------------	------------------------	----------------------------

	Provide the estimated percentage of the	current year	end balanc
а	Board designated or quasi-endowment	•	6%
b	Permanent endowment	94%	
C	Temporarily restricted endowment		%

The percentages on lines 2a, 2b, and 2c should equal 100%. Are there endowment funds not in the possession of the organization that are held and administered for the 3a

organ	ization by:		Yes	No
(i)	unrelated organizations	3a(i)		Х
(ii)	related organizations	3a(li)		X
If "Yes	s" on line 3a(ii), are the related organizations listed as required on Schedule R?	3b		

Describe in Part XIII the intended uses of the organization's endowment funds.

Part VI	Land,	Buildings,	and	Equipmen	t
---------	-------	------------	-----	----------	---

b

Complete if the organization answered "Yes" on Form 990, Part IV, line 11a. See Form 990, Part X, line 10. Description of property (a) Cost or other basis (b) Cost or other (c) Accumulated (d) Book value depreciation basis (other) (investment) 0 0 Land Buildings 0 0 0 11,706 11,706 0 Leasehold improvements. C 0 67,168 64,059 3,109 d Equipment . . . 0 0 Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10c.) ▶ 3,109

Part VII	Investments—Other Securit Complete if the organization a		rm 990	Part IV line 11b See For	m 990 Part X line 12
(a)	Description of security or category (including name of security)	(b) Book value		(c) Method of ve Cost or end-of-year	aluation:
(1) Financial o	lerivatives		0		
	ld equity interests		0		
(3) Other					
					
(B)				 	
(C)					
(D)	· 	 			
		<u> </u>			
					· · · · · · · · · · · · · · · · · · ·
(G) (H)					
	oust equal Form 990, Part X, col. (B) line 12.)	 	0		
Part VIII	Investments-Program Rela	ted.	<u> </u>	<u> </u>	
	Complete if the organization a		m 990,	Part IV, line 11c. See Form	n 990, Part X, line 13
	(a) Description of investment	(b) Book value		(c) Method of va Cost or end-of-year r	
(1)					
(2)					
(3)		 			
<u>(4)</u> <u>(5)</u>		<u> </u>			
(6)					
(7)		† · · · · · · · · · · · · · · · · · · ·			
(8)					· · ·
(9)					
	ust equal Form 990, Part X, col. (8) lina 13.)		0		
Part IX	Other Assets. Complete if the organization a	nswered "Yes" on For	m 990, l	Part IV, line 11d. See For	n 990, Part X, fine 15.
(1)		(a) Description			(b) Book value
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					
(8)					
(9)					
	n (b) must equal Form 990, Part X, co	ol. (B) line 15.)		<u> </u>	(
Part X	Other Liabilities. Complete if the organization ar	nswered "Yes" on Fori	m 990, l	Part IV, line 11e or 11f. Se	e Form 990, Part X.
	line 25	Г			
1.	(a) Description of liability	(b) Book value			
(1) Federal in	icome taxes		_0 :		
(2)					
<u>(3)</u> (4)					
(5)					
(6)					
(7)					
(8)					
(9)					
Total. (Column (b) mus	st equal Form 990, Part X, col. (B) line 25.)		0		
2. Liability for ur	ncertain tax positions. In Part XIII, provid	ie the lext of the footnote t	o the orga	anization's financial statements	that reports the

organization's liability for uncertain tax positions under FIN 48 (ASC 740). Check here if the text of the footnote has been provided in Part XIII

Schedule D (Form	990) 2016	PRADER-WILLI SYNDROME ASSOCIATION (USA)	41-1306908 Page	5
Part XIII	Supple	PRADER-WILLI SYNDROME ASSOCIATION (USA) mental Information (continued)		
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SCHEDULE G (Form 990 or 990-EZ)

Supplemental Information Regarding Fundraising or Gaming Activities

Complete if the organization answered "Yes" on Form 990, Part IV, line 17, 18, or 19, or If the organization entered more than \$15,000 on Form 990-EZ, line 6a.

OMB No. 1545-0047

Inspection

Department of the Treasury Internal Revenue Service

2a

► Attach to Form 990 or Form 990-EZ.

Information about Schedule G (Form 990 or 990-EZ) and its instructions is at www.irs.gov/torm990. Employer Identification number Name of the organization PRADER-WILLI SYNDROME ASSOCIATION (USA) 41-1306908 Fundraising Activities. Complete if the organization answered "Yes" on Form 990, Part IV, line 17. Form 990-EZ filers are not required to complete this part. Indicate whether the organization raised funds through any of the following activities. Check all that apply. 1 Solicitation of non-government grants а Mail solicitations e i f Solicitation of government grants Internet and email solicitations b Special fundraising events Phone solicitations C In-person solicitations d Did the organization have a written or oral agreement with any individual (including officers, directors, trustees, or

key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services?

If "Yes," list the 10 highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization. (v) Amount paid to (III) Did fundralser have (vI) Amount paid to (or retained by) (I) Name and address of individual (Iv) Gross receipts (II) Activity custody or control of (or retained by) from activity fundraiser listed in or entity (fundraiser) organization contributions? col. (I) Yes No 1 0 0 0 2 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 Я 0 0 0 9 0 0 0 10 0 0 0

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3	List all states in which the organization is registered or licensed to solicit registration or licensing.			
-	· · · · · · · · · · · · · · · · · · ·			
		· · · · · · · · · · · · · · · · · · ·		

F	art II				s" on Form 990, Part IV	
			nundraising event cont eipts greater than \$5,00		ncome on Form 990-EZ	L, lines 1 and ob. List
		Greine with gross root	(a) Event #1 JNDRAISING EVENT	(b) Event #2	(c) Other events	(d) Total events (add col. (a) through
a)	ļ		(event type)	(event type)	(total number)	col. (c))
Revenue	1	Gross receipts	386,356		0	386,356
ш	2 3	Less: Contributions			0	<u>o</u>
		minus line 2)	386,356		0	386,356
	4	Cash prizes			0	0
w	5	Noncash prizes			0	0
ense	6	Rent/facility costs			0	0
Direct Expenses	7	Food and beverages			0	0
Dire	8	Entertainment			0	0
	9	Other direct expenses	52,808		0	52,808
	10 11	Direct expense summary. Add Net income summary. Subtract	l lines 4 through 9 in colur ct line 10 from line 3, colur	nn (d)	· · · · · · ·	(52,808) 333,548
Pa	ırt III	Gaming. Complete if t	he organization answe	red "Yes" on Form 99	90, Part IV, line 19, or r	
	Ι	than \$15,000 on Form	990-EZ, line 6a.			
Revenue			(a) Bingo	(b) Pull tabs/instant bingo/progressive bingo	(c) Other garning	(d) Total gaming (add col. (a) Through col. (c))
8	1	Gross revenue				0
ses	2	Cash prizes				0
Expe	3	Noncash prizes				0
Direct Expenses	4	Rent/facility costs				0
_	5	Other direct expenses				0
	6	Volunteer labor	☐ Yes <u>%</u> ☐ No	Yes %	Yes %	
	7	Direct expense summary. Add	lines 2 through 5 in colun	nn (d)		(0)
	8	Net gaming income summary.	Subtract line 7 from line 1	, column (d)	<u> </u>	0
9		nter the state(s) in which the org	-			
				.		
		ere any of the organization's ga	ming licenses revoked, su	spended, or terminated		Yes No

Sched	ule G (Form 990 or 990-EZ) 2016 PRADER-WILLI SYNDROME ASSOCIATION (USA)	41-1306908 Page 3
11	Does the organization conduct gaming activities with nonmembers?	Yes No
12	Is the organization a grantor, beneficiary or trustee of a trust, or a member of a partnership or other entity formed to administer charitable gaming?	Tyes No
13	Indicate the percentage of gaming activity conducted in:	
а	The organization's facility	13a %
b	An outside facility	13b %
14	Enter the name and address of the person who prepares the organization's gaming/special events books and records:	
	Name ►	
	Address ►	
15a	Does the organization have a contract with a third party from whom the organization receives gaming revenue?	Yes No
b	If "Yes," enter the amount of gaming revenue received by the organization \$\infty\$ and the amount of gaming revenue retained by the third party \$\infty\$ \$\\$.	
С	If "Yes," enter name and address of the third party:	
	Name ▶	
	Address ►	
16	Gaming manager information:	
	Name ▶	
	Gaming manager compensation > \$ 0	
	Description of services provided	·
	Director/officer Employee Independent contractor	
17 a b	Mandatory distributions: Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license? Enter the amount of distributions required under state law to be distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year	. Yes No
Part		(iii) and (v); and
		-
	***************************************	- -

SCHEDULEI (Form 990)

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

Complete if the organization answered "Yes" on Form 990, Part IV, line 21

■ Attach to Form 990.

Information about Schedule I (Form 990) and its instructions is at www.irs.gov/form990.

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OMB No. 1545-0047	2016	Open to Public
	- '	

Employer identification number

41-1306908

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|X| Yes |

. Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States. the selection criteria used to award the grants or assistance?.

General Information on Grants and Assistance

RADER-WILLI SYNDROME ASSOCIATION (USA)

Part

Department of the Treasury Internal Revenue Service Name of the organization

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

		,				ביורים: ייי כמוי כם מקיים וו מממווסומו פרמה וו וומפתפת	בנים וא וומפתעת.	
7	1 (a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non- cash assistance	(f) Method of valuation (book, FMV, appraisal,	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
£	(1) UNIV OF SOUTH FLORIDA			טטט אני				DATA MANAGEMENT
ଥି	(2) KANSAS UNIV MEDICAL CENTER			10 000				PWS MORTALITY & THROMBOTIC
2	(3) CASE WESTERN RESERVE UNIN			990 00				TELEHEALTH INTERVENTION
a	(4) INTL CONSORTIUM TO ADV CLIN			10.000				CLINICAL TRIALS
9	(6) ST LOUIS UNIVERSITY			7,867				ABNORMAL PROTEINS DRIVE
(9)	(6) CHILDREN'S HOSPITAL OF PITT			138,750				PIG MODEL RESEARCH
ε								
8								
ව								
<u>6</u>								
Ê								
<u>[2</u>					5 5 5			
64 W	Enter total number of section 501(c)(3) and government organizations listed in the line 1 table.	501(c)(3) and g	overnment organiza	tions listed in the line 1	table		A	
	l						A	ထ

For Paperwork Reduction Act Notice, see the Instructions for Form 990. $_{
m HTA}$

Schedule I (Form 990) (2016)

PRADER-WILLI SYNDROME ASSOCIATION (USA)

Grants and Other Assistance to Domestic Individuals. Complete if the organization answered "Yes" on Form 990, Part IV, line 22. Part III can be dublicated if additional charge is needed Schedule I (Form 990) (2016)
Part III Grants an

(f) Description of noncash assistance						3		tional information.		4 4 7 7 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1							
(e) Method of valuation (book. FMV. appraisal, other)								(b); and any other addit						1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1			
(d) Amount of noncash assistance								2; Part III, column						1		1	
(c) Amount of cash grant	45,603							equired in Part I, line									
(b) Number of recipients								le the information re			, , , , , , , , , , , , , , , , , , ,	1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1				1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1	
(a) Type of grant or assistance (b) Number of recipients	CRISIS INTERVENTION - VARIOUS	2	3	4	5	9	4	Part W Supplemental Information. Provide the information required in Part I, line 2; Part III, column (b); and any other additional information.									

SCHEDULE O (Form 990 or 990-EZ)

Supplemental Information to Form 990 or 990-EZ

Complete to provide information for responses to specific questions on Form 990 or 990-EZ or to provide any additional information.

Attach to Form 990 or 990-EZ.

OMB No. 1645-0047

2016

Open to Public Inspection

Department of the Treasury Internal Revenue Service Name of the organization

Information about Schedule O (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.

Employer Identification number

PRADER-WILLI SYNDROME ASSOCIATION (USA)

41-1306908

Form 990, Part III, Line 4d: Program Service Expenses: 372,857, Grants and allocations: 0,
Revenue: 0 RESEARCH DIRECTED AT IMPROVING CURRENT TREATMENT METHODS AND TO DEVELOP A CURE.
Form 990, Part VI, Section A, Line 7A: ELECTION OF BOARD MEMBERS AND THEIR RIGHTS - THE
ORGANIZATION HAS MEMBERS THAT MAY BE MEMBERS OF THE BOARD OF DIRECTORS.
Form 990, Part VI, Section A, Line 7B: DECISIONS SUBJECT TO APPROVAL OF MEMBERS - SOME
DECISIONS OF THE GOVERNING BODY ARE SUBJECT TO APPROVAL OF THE MEMBERS OF THE ORGANIZATION.
Form 990, Part VI, Section B, Line 10B: POLICIES AND PROCEDURES GOVERNING CHAPTERS - THE
ORGANIZATION HAS WRITTEN POLICIES AND PROCEDURES GOVERNING THE ACTIVITIES OF CHAPTERS,
AFFILIATES, AND BRANCHES TO ENSURE THAT THEIR OPERATIONS ARE CONSISTENT WITH THOSE OF THE
ORGANIZATION.
Form 990, Part VI, Section B, Line 11B: ORGANIZATION'S PROCESS TO REVIEW FORM 990 - THE
EXECUTIVE COMMITTEE AND TREASURER REVIEWED AND APPROVED THE IRS FORM 990.
Form 990, Part VI, Section B, Line 12C: ENFORCEMENT OF CONFLICTS OF INTEREST POLICY -
OFFICERS, DIRECTORS, AND KEY EMPLOYEES SIGN A CONFLICT OF INTEREST FORM EACH YEAR AT THE FALL
SEMI-ANNUAL BOARD MEETING
Form 990, Part VI, Section B, Line 15A: COMPENSATION PROCESS FOR TOP OFFICIALS - THE POLICY
FOR DETERMINING COMPENSATION OF THE PWSA EXECUTIVE DIRECTOR INCLUDES THE ELEMENTS OF 1) REVIEW
AND APPROVAL BY THE EXECUTIVE COMMITTEE OF BOARD OF DIRECTORS, 2) USE OF DATA OF COMPARABLE
COMPENSATION, AND 3) CONTEMPORANEOUS DOCUMENTATION AND RECORDICEPING.
Form 990, Part VI, Section C, Line 19: GOVERNING DOCUMENTS DISCLOSURE EXPLANATION - THE
ASSOCIATION WHEN REQUESTED WILL PROVIDE ITS GOVERNING DOCUMENTS, CONFLICT OF INTEREST POLICY,
AND FINANCIAL STATEMENTS AVAILABLE TO THE REQUESTING PUBLIC.

Schedule O (Form 990 or 990-EZ) (2016)	Page 2
Name of the organization	Employer Identification number
	41-1306908
TRADER-WILL OT INDROWLE ADOODIATION (DDA)	41-1300300
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## Form 4562

Department of the Treasury

Internal Revenue Service

#### **Depreciation and Amortization**

#### (Including Information on Listed Property)

Attach to your tax return.

Information about Form 4562 and its separate instructions is at www.irs.gov/form4562.

20**16** 

Attachment Sequence No. 179

Name(s) shown on return Business or activity to which this form relates Identifying number PRADER-WILLI SYNDROME ASSOCIATION (U 990) 41-1306908 Election To Expense Certain Property Under Section 179 Note: If you have any listed property, complete Part V before you complete Part I. Threshold cost of section 179 properly before reduction in limitation (see instructions) . . . . . . . . . . . . 3 Reduction in limitation. Subtract line 3 from line 2. If zero or less, enter -0-Dollar limitation for tax year. Subtract line 4 from line 1, If zero or less, enter -0-, If married filing separately, see instructions (a) Description of property Listed property. Enter the amount from line 29 . . . . . . . . . Total elected cost of section 179 property. Add amounts in column (c), lines 6 and 7 . . . . . 8 9 0 10 Carryover of disallowed deduction from line 13 of your 2015 Form 4562. 10 11 Business income limitation. Enter the smaller of business income (not less than zero) or line 5 (see instructions) 11 12 Section 179 expense deduction. Add lines 9 and 10, but don't enter more than line 11 o 13 Carryover of disallowed deduction to 2017. Add lines 9 and 10, less line 12 ▶ 13 Note: Don't use Part II or Part III below for listed property. Instead, use Part V. Special Depreciation Allowance and Other Depreciation (Don't include listed property.) (See instructions.) 14 Special depreciation allowance for qualified property (other than listed property) placed in service 14 15 16 Other depreciation (including ACRS). MACRS Depreciation (Don't include listed property.) (See instructions.) Part II Section A 17 MACRS deductions for assets placed in service in tax years beginning before 2016 . . . . . . . . 3.493 18 If you are electing to group any assets placed in service during the tax year into one or more general Section B - Assets Placed in Service During 2016 Tax Year Using the General Depreciation System (b) Month and (c) Basis for depreciation (d) Recovery (a) Classification of property year placed (business/investment use (e) Convention (f) Method (g) Depreciation deduction in service only-see instructions) 19 a 3-year property b 5-year property 7-year property d 10-year property e 15-year property f 20-year property g 25-year property 25 yrs. h Residential rental 27.5 yrs. MM S/L property 27.5 yrs. MM S/L I Nonresidential real 39 yrs. MM S/L property MM S/L Section C - Assets Placed in Service During 2016 Tax Year Using the Alternative Depreciation System 20 a Class life S/L b 12-year 12 yrs. S/L c 40-year 40 yrs. S/L Summary (See instructions.) 21 22 Total. Add amounts from line 12, lines 14 through 17, lines 19 and 20 in column (g), and line 21. Enter here and on the appropriate lines of your return. Partnerships and S corporations—see instructions 3,493 23 For assets shown above and placed in service during the current year, enter the portion of the basis attributable to section 263A costs

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