

*National Tuberous Sclerosis Association & Affiliate*

*Consolidated Financial Statements*

*For the Years Ended December 31, 2017 and 2016*

---

**NATIONAL TUBEROUS SCLEROSIS ASSOCIATION & AFFILIATE  
TABLE OF CONTENTS  
FOR THE YEARS ENDED DECEMBER 31, 2017 AND 2016**

---

REPORT OF INDEPENDENT AUDITORS	1 - 2
FINANCIAL STATEMENTS	
Consolidated Statements of Financial Position	3
Consolidated Statement of Activities	4
Consolidated Statement of Functional Expenses	5
Consolidated Statements of Cash Flows	6
Notes to Consolidated Financial Statements	7 - 21
REPORT OF INDEPENDENT AUDITORS ON SUPPLEMENTAL INFORMATION	22
SUPPLEMENTAL INFORMATION	
Consolidating Statement of Financial Position	23
Consolidating Statement of Activities	24

---

## REPORT OF INDEPENDENT AUDITORS

---

To the Board of Directors  
National Tuberous Sclerosis Association &  
Affiliate

### **Report on the Financial Statements**

We have audited the accompanying consolidated financial statements of National Tuberous Sclerosis Association & Affiliate, which comprise the consolidated statement of financial position as of December 31, 2017 and the related consolidated statements of activities and cash flows for the year then ended, and the related notes to the consolidated financial statements.

#### ***Management's Responsibility for the Financial Statements***

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

#### ***Auditor's Responsibility***

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

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

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

**REPORT OF INDEPENDENT AUDITORS**

---

***Opinion***

In our opinion, the 2017 consolidated financial statements referred to above present fairly, in all material respects, the financial position of National Tuberous Sclerosis Association & Affiliate as of December 31, 2017, and the changes in their net assets and their cash flows for the year then ended in accordance with accounting principles generally accepted in the United States of America.

***Other Matter - December 31, 2016 Financial Statements***

The financial statements of National Tuberous Sclerosis Association & Affiliate for the year ended December 31, 2016 were audited by Bond Beebe, PC, who joined WithumSmith+Brown, PC effective September 1, 2017, and they expressed an unmodified opinion on the statements in their report dated April 6, 2017. No auditing procedures have been performed with respect to the December 31, 2016 financial statements since that date.



Bethesda, MD  
April 2, 2018

**NATIONAL TUBEROUS SCLEROSIS ASSOCIATION & AFFILIATE  
CONSOLIDATED STATEMENTS OF FINANCIAL POSITION  
DECEMBER 31, 2017 AND 2016**

<u>ASSETS</u>	<u>2017</u>	<u>2016</u>
<b>CURRENT ASSETS</b>		
Cash and cash equivalents	\$ 1,537,343	\$ 1,975,799
Short-term investments	807,688	779,808
Accounts receivable	278,373	262,025
Promises to give - current portion	746,536	683,294
Prepaid expenses and other assets	346,526	182,942
<b>TOTAL CURRENT ASSETS</b>	<u>3,716,466</u>	<u>3,883,868</u>
<b>PROPERTY AND EQUIPMENT</b>		
Property and equipment	372,051	360,151
Accumulated depreciation and amortization	(186,050)	(169,819)
<b>PROPERTY AND EQUIPMENT - NET</b>	<u>186,001</u>	<u>190,332</u>
<b>OTHER ASSETS</b>		
Long-term investments	5,689,777	5,214,829
Promises to give - non-current portion	242,763	797,694
<b>TOTAL OTHER ASSETS</b>	<u>5,932,540</u>	<u>6,012,523</u>
<b>TOTAL ASSETS</b>	<u>\$ 9,835,007</u>	<u>\$ 10,086,723</u>
<b><u>LIABILITIES AND NET ASSETS</u></b>		
<b>CURRENT LIABILITIES</b>		
Accounts payable and accrued expenses	\$ 258,028	\$ 320,774
Accrued compensation	214,661	203,109
Deferred rent and lease incentive - current portion	25,206	22,318
Gift annuity obligations - current portion	12,530	12,530
Deferred revenue - current portion	167,293	39,476
<b>TOTAL CURRENT LIABILITIES</b>	<u>677,718</u>	<u>598,207</u>
<b>LONG-TERM LIABILITIES</b>		
Deferred rent and lease incentive - non-current portion	35,378	60,584
Gift annuity obligations - non-current portion	65,131	69,228
Deferred revenue - non-current portion	-	92,500
<b>TOTAL LONG-TERM LIABILITIES</b>	<u>100,509</u>	<u>222,312</u>
<b>TOTAL LIABILITIES</b>	<u>778,227</u>	<u>820,519</u>
<b>NET ASSETS</b>		
Unrestricted		
Undesignated	623,862	520,953
Designated	5,352,087	4,782,158
Total unrestricted	5,975,949	5,303,111
Temporarily restricted	2,201,387	3,083,649
Permanently restricted	879,444	879,444
<b>TOTAL NET ASSETS</b>	<u>9,056,780</u>	<u>9,266,204</u>
<b>TOTAL LIABILITIES AND NET ASSETS</b>	<u>\$ 9,835,007</u>	<u>\$ 10,086,723</u>

**NATIONAL TUBEROUS SCLEROSIS ASSOCIATION & AFFILIATE**  
**CONSOLIDATED STATEMENT OF ACTIVITIES**  
**FOR THE YEAR ENDED DECEMBER 31, 2017 WITH COMPARATIVE TOTALS FOR 2016**

	2017			2016 Total
	Unrestricted	Temporarily Restricted	Permanently Restricted	
<b>REVENUE AND SUPPORT</b>				
Special events				
Special events	\$ 1,418,146	\$ 81,429	\$ -	\$ 1,499,575
Costs of direct benefits to donors	(175,616)	-	-	(175,616)
Special events - net	1,242,530	81,429	-	1,323,959
Contributions	885,192	1,163,950	-	2,049,142
Contracts	824,241	-	-	824,241
Interest and dividend income	152,166	27,177	-	179,343
Memorials and honorariums	103,914	1,815	-	105,729
Sponsorships	86,865	-	-	86,865
Federated funding	45,150	-	-	45,150
Other income	885	-	-	885
Loss on disposal of property and equipment	-	-	-	-
Net assets released from restrictions	2,248,172	(2,248,172)	-	-
<b>TOTAL REVENUE AND SUPPORT</b>	<b>5,589,115</b>	<b>(973,801)</b>	<b>-</b>	<b>4,615,314</b>
<b>EXPENSES</b>				
Program activities				
Research	2,745,515	-	-	2,745,515
Family Services	801,081	-	-	801,081
Public health education	322,284	-	-	322,284
Government relations	147,996	-	-	147,996
Professional education	82,183	-	-	82,183
Total program activities	4,099,059	-	-	4,099,059
Supporting services				
Fundraising	761,427	-	-	761,427
Management and general	534,994	-	-	534,994
Total supporting services	1,296,421	-	-	1,296,421
<b>TOTAL EXPENSES</b>	<b>5,395,480</b>	<b>-</b>	<b>-</b>	<b>5,395,480</b>
<b>CHANGE IN NET ASSETS FROM OPERATIONS</b>	<b>193,635</b>	<b>(973,801)</b>	<b>-</b>	<b>(780,166)</b>
<b>NET GAIN ON INVESTMENTS</b>	<b>479,203</b>	<b>91,539</b>	<b>-</b>	<b>570,742</b>
<b>CHANGE IN NET ASSETS</b>	<b>672,838</b>	<b>(882,262)</b>	<b>-</b>	<b>(209,424)</b>
<b>NET ASSETS AT THE BEGINNING OF YEAR</b>	<b>5,303,111</b>	<b>3,083,649</b>	<b>879,444</b>	<b>9,266,204</b>
<b>NET ASSETS AT END OF YEAR</b>	<b>\$ 5,975,949</b>	<b>\$ 2,201,387</b>	<b>\$ 879,444</b>	<b>\$ 9,056,780</b>

See Notes to Consolidated Financial Statements

**NATIONAL TUBEROUS SCLEROSIS ASSOCIATION & AFFILIATE  
CONSOLIDATED STATEMENT OF FUNCTIONAL EXPENSES  
FOR THE YEAR ENDED DECEMBER 31, 2017 WITH COMPARATIVE TOTALS FOR 2016**

EXPENSES	2017										2017 Total	2016 Total
	Program Activities					Supporting Services						
	Research	Family Services	Public Health Education	Government Relations	Professional Education	Total Program Activities	Fundraising	Management and General	Total Supporting Services			
Salaries	\$ 369,768	\$ 320,062	\$ 109,346	\$ 26,355	\$ 27,904	\$ 853,435	\$ 332,392	\$ 287,847	\$ 620,239	\$ 1,473,674	\$ 1,351,771	
Employee benefits and payroll taxes	68,251	92,062	20,785	6,497	4,253	191,848	79,315	64,210	143,525	335,373	298,289	
Grants	528,743	-	-	-	-	528,743	-	-	-	528,743	940,040	
Biosample Repository	120,771	-	-	-	-	120,771	-	-	-	120,771	82,925	
Preclinical consortium	1,042,919	-	-	-	-	1,042,919	-	-	-	1,042,919	492,760	
Natural History Database	222,524	-	-	-	-	222,524	-	-	-	222,524	431,054	
Clinic expenses	25,568	-	-	-	-	25,568	-	-	-	25,568	25,568	
Professional fees	58,290	56,984	69,045	105,960	402	290,681	72,604	86,553	159,157	449,838	343,726	
Travel	59,219	140,496	12,630	622	14,926	227,893	41,145	3,047	44,192	272,085	218,467	
Training, conferences, and exhibits	102,389	61,133	3,974	20	30,851	198,367	8,202	7,860	16,062	214,429	115,506	
Equipment rental and maintenance	45,062	11	392	-	-	45,465	1,409	95,397	96,806	142,271	136,261	
Printing and promotion	21,230	15,355	46,912	1,611	30	85,138	57,236	1,710	58,946	144,084	144,762	
Rent	-	285	-	-	-	285	284	93,712	93,996	94,281	81,757	
Postage and shipping	529	9,348	11,762	588	38	22,265	24,250	16,246	40,496	62,761	63,128	
Bank and credit card fees	183	214	-	-	-	397	42,419	15,096	57,515	57,912	52,994	
Depreciation and amortization	7,736	3,614	24,166	-	-	35,516	3,614	29,965	33,579	69,095	50,471	
Telephone	2,352	4,740	1,095	-	-	8,187	3,814	21,299	25,113	33,300	32,291	
Dues, fees and subscriptions	5,520	8,024	2,900	-	-	16,444	14,586	18,377	32,963	49,407	40,756	
Board and committee meetings	-	-	-	-	-	-	1,084	26,848	27,932	27,932	19,902	
Supplies	538	1,660	278	-	45	2,521	2,420	3,385	5,805	8,326	10,936	
Insurance	-	150	-	-	-	150	159	10,183	10,342	10,492	9,814	
Other expense	1,060	2,903	-	-	265	4,228	4,192	1,275	5,467	9,695	5,590	
	2,682,652	717,041	303,285	141,653	78,714	3,923,345	689,125	783,010	1,472,135	5,395,480	4,948,768	
Overhead allocation	62,863	84,040	18,999	6,343	3,469	175,714	72,302	(248,016)	(175,714)	-	-	
<b>TOTAL EXPENSES</b>	<b>\$ 2,745,515</b>	<b>\$ 801,081</b>	<b>\$ 322,284</b>	<b>\$ 147,996</b>	<b>\$ 82,183</b>	<b>\$ 4,099,059</b>	<b>\$ 761,427</b>	<b>\$ 534,994</b>	<b>\$ 1,296,421</b>	<b>\$ 5,395,480</b>	<b>\$ 4,948,768</b>	

**NATIONAL TUBEROUS SCLEROSIS ASSOCIATION & AFFILIATE  
CONSOLIDATED STATEMENTS OF CASH FLOWS  
FOR THE YEARS ENDED DECEMBER 31, 2017 AND 2016**

	<b>2017</b>	<b>2016</b>
<b>CASH FLOWS FROM OPERATING ACTIVITIES</b>		
Change in net assets	\$ (209,424)	\$ 845,593
Adjustments to reconcile change in net assets to net cash provided (used) by operating activities		
Net gain on investments	(570,742)	(423,558)
Discount on promises to give	(20,069)	26,003
Depreciation and amortization	69,095	50,471
Change in value of gift annuity obligation	8,433	8,710
Loss on disposal of property and equipment	-	1,900
(Increase) decrease in		
Accounts receivable	(16,348)	(259,477)
Promises to give	511,758	(1,190,794)
Prepaid expenses and other assets	(163,584)	(72,673)
Increase (decrease) in		
Accounts payable and accrued expenses	(62,746)	283,074
Accrued compensation	11,552	54,808
Deferred rent and lease incentive	(22,318)	(19,525)
Deferred revenue	35,317	131,976
	<u>(429,076)</u>	<u>(563,492)</u>
<b>CASH FLOWS FROM INVESTING ACTIVITIES</b>		
Purchases of short-term investments	(27,880)	(16,999)
Proceeds from sales and maturities of long-term investments	95,793	4,942,538
Purchases of long-term investments	-	(5,044,558)
Purchases of property and equipment	(64,763)	(96,266)
	<u>3,150</u>	<u>(215,285)</u>
<b>CASH FLOWS FROM FINANCING ACTIVITIES</b>		
Payments on gift annuity obligations	(12,530)	(12,530)
	<u>(438,456)</u>	<u>(791,307)</u>
<b>DECREASE IN CASH AND CASH EQUIVALENTS</b>		
<b>CASH AND CASH EQUIVALENTS AT BEGINNING OF YEAR</b>	<u>1,975,799</u>	<u>2,767,106</u>
<b>CASH AND CASH EQUIVALENTS AT END OF YEAR</b>	<u>\$ 1,537,343</u>	<u>\$ 1,975,799</u>
<b>NONCASH TRANSACTIONS</b>		
Donated goods and services for use in special events	\$ 37,193	\$ 17,410
Donated securities	\$ 115,040	\$ 19,494
Donated investment management services	\$ 27,262	\$ 24,761



## **NOTE 1: ORGANIZATION**

National Tuberous Sclerosis Association, Inc. (TS Alliance), d/b/a Tuberous Sclerosis Alliance, is a not-for-profit organization incorporated in the State of California on March 15, 1975. TS Alliance is dedicated to finding a cure for tuberous sclerosis complex (TSC) while improving the lives of those affected through:

- The stimulation and sponsorship of research into the diagnosis, cause, management, and cure of tuberous sclerosis complex;
- The development of programs providing individuals with tuberous sclerosis complex and their families access to support services, resource information, and health care professionals engaged in the diagnosis, treatment, and management of tuberous sclerosis complex; and
- The development and implementation of public and professional education programs designed to heighten awareness of tuberous sclerosis complex, thereby prompting early, accurate diagnosis and effective treatment of tuberous sclerosis complex.

National Tuberous Sclerosis Association Endowment Fund, Inc. (the Endowment Fund) is a not-for-profit organization incorporated in the State of Maryland on April 3, 1995. The Endowment Fund is a separate organization specifically chartered to receive gifts that are invested to generate an income stream to support the fulfillment of the mission of TS Alliance.

## **NOTE 2: SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES**

### **Consolidation**

The consolidated financial statements include the accounts of TS Alliance and the Endowment Fund. Significant intra-entity transactions and balances have been eliminated in consolidation. For purposes of this report, the entities are collectively referred to as the Alliance.

### **Basis of Accounting**

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

### **Accounting Estimates**

The preparation of consolidated financial statements in conformity with accounting principles generally accepted in the United States of America requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities and the disclosure of contingencies, if any, at the date of the consolidated financial statements and the reported amounts of revenue and expenses during the reporting period. Actual results could differ from those estimates.

### **Cash Equivalents**

For financial statement purposes, the Alliance classifies certain money market accounts as cash equivalents, which are reported at fair market value. However, money market funds and certificates of deposit held within the short-term investment portfolio are classified as short-term investments.

**NOTE 2: SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES - continued**

**Net Assets**

Net assets are reported as temporarily restricted or permanently restricted if they arise from contributions received with donor stipulations on their use. Temporarily restricted net assets are the portion of net assets resulting from contributions or other inflows of assets whose use is limited by donor-imposed stipulations that can be removed by the passage of time or action of the organization pursuant to those stipulations. Permanently restricted net assets are the portion of net assets whose use is limited by donor-imposed stipulation that cannot be removed by the passage of time or action of the organization.

Unrestricted net assets are the portion of net assets that are not subject to limitations imposed by donors, but which may be subject to limitations and allocations imposed by the board of directors.

**Short-term Investments**

To minimize market risk on the principal balance, the investment of operating funds is limited to U.S. government protected (i.e., FDIC insured) bank deposit accounts, FDIC insured certificates of deposit, short-term U.S. Treasuries with a maximum duration of three years, and money market funds with the highest possible principal stability rating. Uninsured money markets are limited to 20% of gross operating funds. Balances held in bank accounts may exceed the FDIC insurance limit by an aggregate total of no more than \$1,000,000, but every effort is made to keep the balances within the FDIC insured limits.

**Long-term Investments**

Investments shall be made solely in the interest of and for the benefit of the Endowment Fund. The Endowment Fund's assets shall be invested with the care, skill, prudence, and diligence under the circumstances then prevailing that a prudent expert acting in like capacity and familiar with such matters would use in the investment of a fund of like character and with like aims. Investment of the Endowment Fund's assets shall be diversified in order to minimize the risk of large losses, unless under the circumstances it is clearly prudent not to do so. The Endowment Fund's Board of Directors will employ one or more investment managers of varying styles and philosophies to attain these objectives. Cash is to be employed productively at all times, by investment in short-term cash equivalents to provide safety, liquidity, and return. The investment manager(s) should, at all times, be guided by the principles of "best price and execution" and by the fact that the Endowment Fund's best interests are the primary consideration.

Investments are reported at fair value. Fair value is the price that would be received to sell an asset or paid to transfer a liability in an orderly transaction between market participants at the measurement date. In accordance with the policy of presenting investments at fair value, net appreciation or depreciation (realized and unrealized gains and losses) in value is reported for investments bought and sold, as well as held, in the statements of changes in net assets available for benefits for the period in which it occurs. Purchases and sales of securities are recorded on a trade-date basis. Interest income is recorded on the accrual basis. Dividend income is recorded on the ex-dividend date. See Note 4 for discussion of fair value measurements.

**Accounts Receivable**

Accounts receivable primarily consists of amounts due to the Alliance relating to various contracts. The Alliance's management periodically reviews the status of all accounts receivable balances for collectability. Each receivable balance is assessed based on management's knowledge of and relationship with the customer and the age of the receivable balance. As a result of these reviews, balances deemed to be uncollectible are charged directly to bad debt expense. Management believes that the use of the direct write-off method approximates the results that would be presented if an allowance for doubtful accounts had been recorded.

**Accrued Compensation**

Accrued compensation consists of salaries including related payroll tax withholding and paid time off earned but not yet paid or taken.

**NOTE 2: SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES - continued****Deferred Rent and Lease Incentive Obligation**

The Alliance recognizes rents required under its operating leases as rent expense on a straight line basis over the term of the lease, with the differences between amounts recognized and amounts actually paid reflected in deferred rent and lease incentive obligation in the accompanying consolidated statements of financial position. The Alliance also recorded a deferred tenant improvement liability based on the improvement allowance provision included in the office lease agreement. The deferred tenant improvement liability is included in deferred rent and lease incentive obligation on the accompanying consolidated statements of financial position and will be amortized ratably over the term of the lease.

**Costs of Direct Benefits to Donors**

Costs of direct benefits to donors include (1) the venue, entertainment, and refreshments in the case of a major event; (2) the refreshments, t-shirts, or other items provided to participants in a walk-a-thon; or (3) the items raffled in the case of a raffle.

**Contributions**

Contributions are recognized when unconditionally promised to, or received by, the Alliance. Contributions are recorded as unrestricted, temporarily restricted, or permanently restricted support depending upon the existence and/or nature of any donor restrictions. Within temporarily restricted net assets, amounts are reclassified to unrestricted net assets when the time restriction expires or when the purpose restriction is satisfied.

**Contracts**

Contracts consist of revenue earned by the Alliance under the terms of various contracts to provide services to the TSC community. Contracts for services include 1) a significant enhancement to the Natural History Database on TSC, 2) those related to the preclinical evaluation of candidate treatments using animal models and 3) a robust review of materials and programs of importance to the TSC community. Contract revenue is recognized when services have been provided under the terms of the contracts.

**Conferences**

The TS Alliance and The LAM Foundation jointly sponsored the 2017 International Research Conference on TSC and LAM: Innovating through Partnerships, held June 22-24, 2017, at the Hyatt Regency Capitol Hill in Washington, DC. More than 200 people, including 183 professional attendees from 27 countries, participated in scientific sessions featuring oral presentations, a poster session, and working groups of researchers tackling specific issues related to genetic, multidisciplinary clinical care, and translational research strategies. The conference concluded with a joint session including individuals and families affected by tuberous sclerosis complex (TSC) and lymphangioleiomyomatosis (LAM). This session highlighted how quickly the fields of TSC and LAM treatment are moving and emphasized the need for further collaboration between individuals with TSC or LAM and their families, clinicians and researchers to accelerate the development of greatly improved treatments for these disorders.

In 2017, the TS Alliance hosted two Regional TSC and LAM Conferences in Houston, TX and Washington, DC with 118 combined attendees. These conferences, co-hosted by The LAM Foundation, brought together individuals, parents, caregivers and members of the medical community to provide the most up-to-date information so parents and adults with TSC and LAM can make informed decisions when evaluating treatment options. These one-day symposiums offered educational outreach, information on the latest treatments in TSC and LAM, research updates, and support options. Regional TSC and LAM Conferences provide much-needed forums for the growing number of people facing the daily challenges of TSC.

**NOTE 2: SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES - continued**

The TS Alliance also held two Transition Workshops in New York, NY and San Diego, CA. The combined attendance at these workshops was 58. The goal of these all-day transition workshops was to give parents and caregivers tangible resources to empower them with resources, clear timelines and next steps to develop an effective transition plan for their children. The TS Alliance partnered with Arc USA, Child Neurology Foundation and Mass Mutual because these organizations have pre-existing tools and best practices to assist through different aspects of the transition plan, and their expertise was vital to families in attendance.

In 2016, the TS Alliance hosted three *Regional TSC and LAM Conferences* in partnership with The LAM Foundation held in Nashville, TN; Seattle, WA; and Cleveland, Ohio with 247 combined attendees. Tuberous sclerosis complex (TSC) and lymphangiomyomatosis (LAM) are rare, life-threatening disorders sharing a common genetic and biological pathology. TSC is caused by germline or sporadic mutations in TSC1 or TSC2 genes. Individuals with TSC may develop LAM, or sporadic LAM may occur in the absence of TSC due to somatic mutations in the TSC2 gene, affecting cells in lung, lymph nodes, and renal angiomyolipomas. These conferences brought together individuals, parents, caregivers and member of the medical community to provide the most up-to-date information so parents and adults with TSC and LAM can make informed decisions when evaluating treatment options. These one-day symposiums offered educational outreach, information on the latest treatments in TSC and LAM, research updates, and support options. They featured the region's top experts in a nurturing, supportive environment. *Regional TSC and LAM Conferences* provide much needed forums for the growing number of people facing the daily challenges of TSC and LAM.

**Functional Allocation of Expenses**

The costs of providing the Alliance's programs and services are summarized on a functional basis in the accompanying consolidated financial statements. Accordingly, certain costs have been allocated between the programs and services benefited based on either employee effort or direct cost.

**Program Services**

Program services include the following activities, the descriptions for each of which follow:

**Research**

Research program stimulates and supports basic, translational, and clinical research on the various manifestations of TSC to further the development of clinical therapies and ultimately a cure for TSC.

**Family Services**

Family services develops programs and services that provide individuals with TSC and their caregivers direct access to the information, resources and specialists experienced in the diagnosis, treatment and management of TSC.

To address unmet needs within the global TSC community, the TS Alliance Global Alliance program was launched in 2014 with the TS Alliance of Israel. The program provides the opportunity for the TS Alliance to share experiences and assist in the start-up of support of TSC-related organizations in other countries. A Global Alliance is a structured group of empowered and caring volunteers who work closely with the TS Alliance to facilitate local connections for individuals and families affected by TSC, and raise revenue and awareness while supporting the mission of the organization. In 2017, the TS Alliance signed a global agreement with the Hungarian Foundation for Tuberous Sclerosis. This was preceded by the 2016 signing of global agreements with TS Canada ST, TS Alliance of Mexico and the TS Alliance ASEAN Foundation.

**Public Health Education**

Public health education heightens awareness of TSC throughout the general public to broaden scope of support and understanding beyond the TSC individuals and their families.

**NOTE 2: SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES - continued**

**Government Relations**

Government relations focuses on educating members of Congress about TSC to further TSC research, awareness, and clinical care.

**Professional Education**

Professional education expands programs targeting those specialists who treat patients with TSC, medical students, genetic counselors and educators to minimize the consequences of ignorance and misinformation.

**Supporting Services**

Supporting services reflected in the accompanying consolidated statements of activities include both TS Alliance and the Endowment Fund. On a separate entity basis, supporting services compared to total expense for TS Alliance were 23% and 24% for the years ended December 31, 2017 and 2016, respectively. Supporting services include the following activities, the descriptions for each of which follow:

**Fundraising**

Fundraising includes activities that encourage and secure financial support for the Alliance.

**Management and General**

Management and general includes activities necessary for the administrative processes of the Alliance and managing the financial responsibilities of the Alliance.

**Prior-year Comparative Totals**

The accompanying consolidated financial statements include certain prior-year summarized comparative information in total, but not by net asset class or by functional area. Such information does not include sufficient detail to constitute a presentation in conformity with accounting principles generally accepted in the United States of America. Accordingly, such information should be read in conjunction with the Alliance's 2016 consolidated financial statements, from which the summarized information was derived.

**Measure of Operations**

The Alliance considers items which are unbudgeted or unusual in nature to be non-operating items. Thus, the net gain on investments is not included in the change in net assets from operations.

**Subsequent Events**

In preparing these consolidated financial statements, management has evaluated events and transactions that occurred after December 31, 2017 for potential recognition or disclosure in the consolidated financial statements. These events and transactions were evaluated through April 2, 2018, the date that the consolidated financial statements were available to be issued.

**NOTE 3: TAX STATUS**

TS Alliance is exempt from the payment of income taxes on its exempt activities under Section 501(c)(3) of the Internal Revenue Code and has been classified by the Internal Revenue Service as other than a private foundation within the meaning of Section 509(a)(1) of the Internal Revenue Code. The Endowment Fund is exempt from the payment of income taxes on its exempt activities under Section 501(c)(3) of the Internal Revenue Code and has been classified by the Internal Revenue Service as other than a private foundation within the meaning of Section 509(a)(3) of the Internal Revenue Code. The Endowment Fund is further classified as a Type II supporting organization.

**NOTE 3: TAX STATUS**

Accounting principles generally accepted in the United States of America require management to evaluate income tax positions taken and accrue an income tax liability if the organization has taken an uncertain position that more likely than not would not be sustained upon examination by the Internal Revenue Service. Management has evaluated the income tax positions taken and concluded that as of December 31, 2017 there are no uncertain positions taken or expected to be taken that would require accrual of a liability in the consolidated financial statements. The Alliance is subject to routine audits by taxing jurisdictions; however, there are currently no audits in progress for any tax periods. As of December 31, 2017 the statute of limitations for tax years 2014 through 2016 remains open with the U.S. federal jurisdiction or the various states and local jurisdictions in which the Alliance files tax returns.

**NOTE 4: FAIR VALUE**

The framework for measuring fair value provides a fair value hierarchy that prioritizes the inputs to valuation techniques used to measure fair value. The hierarchy gives the highest priority to unadjusted quoted prices in active markets for identical assets or liabilities (level 1) and the lowest priority to unobservable inputs (level 3). The three levels of the fair value hierarchy are described as follows:

**Level 1**

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

**Level 2**

Inputs to the valuation methodology include quoted prices for similar assets or liabilities in active markets, quoted prices for identical or similar assets or liabilities that are not active or inputs that are derived principally from or corroborated by observable market data by correlation or other means.

**Level 3**

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

A financial instrument's level within the fair value hierarchy is based on the lowest level of any input that is significant to the fair value measurement. Valuation techniques maximize the use of relevant observable inputs and minimize the use of unobservable inputs.

The availability of observable market data is monitored to assess the appropriate classification of financial instruments within the fair value hierarchy. Changes in economic conditions or model-based valuation techniques may require the transfer of financial instruments from one fair value level to another. In such instances, the transfer is reported at the end of the reporting period.

For the years ended December 31, 2017 and 2016, there were no transfers in or out of levels 1, 2 or 3.

Cash equivalents, short-term investments and money market funds are carried at cost, which approximates fair value. Mutual funds are valued based on quoted market prices. The methodology has not changed during the years ended December 31, 2017 and 2016.

**NOTES TO CONSOLIDATED FINANCIAL STATEMENTS**

**NOTE 4: FAIR VALUE - continued**

As of December 31, 2017 and 2016, assets measured at fair value on a recurring basis are summarized by level within the fair value hierarchy as follows:

	2017			Total Fair Value
	Level 1	Level 2	Level 3	
Money market funds	\$ -	\$ 924,976	\$ -	\$ 924,976
Mutual funds	5,572,489	-	-	5,572,489
Total investments at fair value	5,572,489	924,976	-	6,497,465
Cash equivalents	-	434,380	-	434,380
	<u>\$ 5,572,489</u>	<u>\$ 1,359,356</u>	<u>\$ -</u>	<u>\$ 6,931,845</u>

  

	2016			Total Fair Value
	Level 1	Level 2	Level 3	
Money market funds	\$ -	\$ 2,470,468	\$ -	\$ 2,470,468
Mutual funds	3,524,169	-	-	3,524,169
Total investments at fair value	3,524,169	2,470,468	-	5,994,637
Cash equivalents	-	1,701,164	-	1,701,164
	<u>\$ 3,524,169</u>	<u>\$ 4,171,632</u>	<u>\$ -</u>	<u>\$ 7,695,801</u>

The Alliance's consolidated investment income (loss) for the years ended December 31, 2017 and 2016 consisted of the following:

	2017	2016
Interest and dividend income	\$ 179,343	\$ 117,848
Net realized gains (losses)	21,130	(43,937)
Net unrealized gains	549,612	467,494
	<u>\$ 750,085</u>	<u>\$ 541,405</u>

**NOTE 5: PROPERTY AND EQUIPMENT**

Acquisitions of furniture and equipment greater than \$2,000 with a useful life of more than one year are recorded at cost and depreciated or amortized using the straight-line method over the following useful lives: software - three to ten years, office furniture and equipment - three to ten years and leasehold improvements over the lesser of the remaining life of the office lease or the estimated useful life of the improvements.

As of December 31, 2017 and 2016, the Alliance's property and equipment consists of the following:

	2017	2016
Software	\$ 105,249	\$ 147,093
Office furniture and equipment	110,257	56,513
Leasehold improvements	156,545	156,545
	372,051	360,151
Accumulated depreciation and amortization	(186,050)	(169,819)
Net property and equipment	<u>\$ 186,001</u>	<u>\$ 190,332</u>

---

**NOTES TO CONSOLIDATED FINANCIAL STATEMENTS**

---

**NOTE 5: PROPERTY AND EQUIPMENT - continued**

Depreciation and amortization expense for the years ended December 31, 2017 and 2016 was \$69,095 and \$50,471, respectively.

**NOTE 6: PROMISES TO GIVE**

Unconditional promises to give that are expected to be collected within one year are recorded at net realizable value. Promises to give that are expected to be collected in future years are recorded at the present value of their estimated future cash flows. The discount was determined using the interest rate in effect for three-year U.S. Treasury bills when the promises were received. Management periodically reviews the status of all promises to give for collectability. Each balance is assessed based on management's knowledge of and relationship with the donor and the age of the promise to give balance. As a result of these reviews, balances deemed to be uncollectible are written off and bad debt expense is recorded. Management believes that the use of the direct write-off method approximates the results that would be presented if an allowance for doubtful promises had been recorded.

As of December 31, 2017 and 2016, the Alliance's promises to give consists of the following:

	<u>2017</u>	<u>2016</u>
Amounts due in less than one year	\$ 746,536	\$ 683,294
Amounts due in one to two years	<u>250,000</u>	<u>825,000</u>
	996,536	1,508,294
Discount to net present value between 1.70% and 2.00%	<u>(7,237)</u>	<u>(27,306)</u>
	<u>\$ 989,299</u>	<u>\$ 1,480,988</u>

**NOTE 7: RETIREMENT PLAN**

TS Alliance maintains a defined contribution 401(k) retirement plan for all employees who have met certain eligibility requirements. The plan requires employer contributions equal to 3% of the participating employees' eligible compensation. TS Alliance's contributions to the plan totaled \$41,754 and \$39,488 for the years ended December 31, 2017 and 2016, respectively, and are included in employee benefits and payroll taxes on the Alliance's consolidated statements of functional expenses.

**NOTE 8: COMMITMENTS AND CONTINGENCIES****Grant Commitments**

The Alliance's Board of Directors authorized research grants totaling \$575,976 and \$473,429 as of December 31, 2017 and 2016, respectively. The research grants extend through 2019 and are contingent upon (1) a positive review by the Grant Review Committee and (2) sufficient funding availability in the year of the research grant. Due to their conditional nature, no liability has been recorded relating to the research grants. However, the commitments are reflected within Board-designated net assets.

As of December 31, 2017, the future research grants included within Board-designated net assets for the years ending December 31, are as follows:

2018	\$ 262,173
2019	<u>313,803</u>
Total minimum grant commitments	<u>\$ 575,976</u>



**NOTE 8: COMMITMENTS AND CONTINGENCIES - continued**

**Office Lease**

The Alliance's operating lease for office space was amended effective April 1, 2013. Under the terms of the amended office lease, the square footage occupied by the Alliance decreased and the lease expires March 2020. The lease required a security deposit of \$8,606, which is included in prepaid expenses and other assets in the consolidated statements of financial position at December 31, 2017 and 2016. The lease contains an escalation clause that adjusts annual base rentals. The lease also contains a pass through clause relating to real estate taxes and operating expenses, which are not included in base rentals. In addition, the Alliance was provided a tenant build-out allowance totaling \$143,333 as an incentive to lease the office space.

U.S. GAAP requires that the cost of the build-out be capitalized and depreciated or amortized as property and equipment. U.S. GAAP also requires that the lease incentive along with the scheduled rent increases, resulting from the escalation of base rentals be recorded as a liability and amortized ratably over the term of the lease. Accordingly, the Alliance has recorded leasehold improvements totaling \$143,333 and a deferred rent and lease incentive liability of \$60,584 and \$82,903 as of December 31, 2017 and 2016, respectively.

As of December 31, 2017, the minimum rental commitments for the lease for the years ending December 31, are as follows:

2018		\$	99,334
2019			102,330
2020			<u>25,708</u>
Total minimum rental commitments		<u>\$</u>	<u>227,372</u>

Total rent expense for the years ended December 31, 2017 and 2016, was \$94,281 and \$81,757, respectively.

**Hotel Contracts**

The Alliance has entered into agreements with hotels to provide conference facilities and room accommodations for future conferences. The agreements contain various attrition clauses whereby the Alliance may be liable for liquidated damages in the event of cancellation or lower than anticipated attendance. However, the Alliance's management does not believe that any material losses will be incurred under the hotel contracts.

**Employment Contract**

The Alliance has an employment contract with its President and CEO. Under the terms of the agreement, the Alliance may agree to pay severance upon termination of the employee. The amount of severance that may be agreed upon will take into account years of service and circumstances of separation.

**NOTE 9: CONCENTRATIONS**

Financial instruments that subject the Alliance to concentrations of credit risk include cash which is invested with financial institutions. While the Alliance attempts to limit their financial exposure, their deposit balances with financial institutions, at times, exceed the limits insured by agencies of the U.S. government. The Alliance has not experienced and management does not anticipate experiencing any credit losses on such deposits.

The Alliance also invests funds in a professionally managed portfolio of mutual funds. Such investments are exposed to various risks, such as fluctuations in market value and credit risk. Thus, it is at least reasonably possible that changes in these risks could materially affect investment balances and the amounts reported in the consolidated financial statements.

At December 31, 2017 and 2016, approximately 75% and 83%, respectively, of the outstanding promises to give balance is pledged from one donor.

**NOTE 10: GIFT ANNUITY OBLIGATIONS**

The Alliance has charitable gift annuity agreements with donors located in different states, each of which has specific regulations and requirements over such agreements. TS Alliance is aware of the regulations and requirements of each state, as applicable, and is in compliance with them.

Donated assets are included in long-term investments and are used to fund the annuity payments to donors as specified in the charitable gift annuity agreements. The Alliance has agreed to make annual payments totaling \$12,530 to the beneficiaries as long as they live, after which the remaining assets are available for the unrestricted use of the Alliance.

Unrestricted contribution revenue related to the charitable gift annuities was recognized at the date the agreements were established, net of the liability recorded for the present value of the estimated future payments to the respective donors and/or beneficiaries. The present value of annuity payments was calculated using 1) discount rates ranging from 3.20% to 6.80% which represent the risk-free long-term rates in existence at the date of each gift and 2) life expectancies based upon Table 2000CM from Internal Revenue Service Publication 1457: *Annuities, Life Estates, and Remainders*.

The net present value of the gift annuity obligations totaled \$77,661 and \$81,758 at December 31, 2017 and 2016, respectively.

**NOTE 11: NET ASSETS**

**Unrestricted Net Assets**

Unrestricted net assets include those net assets whose use is not restricted by donors, even though their use may be limited in other respects, such as by board designation. Undesignated net assets are used for the general operations of the Alliance. Designated net assets include those net assets whose use by the Alliance has been designated by resolution of the Board of Directors.

As of December 31, 2017 and 2016, designated net assets consisted of the following:

	2017	2016
Board-designated endowment funds	\$ 4,776,111	\$ 4,308,729
Grant commitments	575,976	473,429
	\$ 5,352,087	\$ 4,782,158

**Temporarily Restricted Net Assets**

Temporarily restricted net assets include those net assets whose use by the Alliance has been donor restricted by specified time or purpose limitations. Net assets are released from restrictions either as a result of the expiration of a time restriction or due to the satisfaction of a purpose restriction.

## NOTES TO CONSOLIDATED FINANCIAL STATEMENTS

### NOTE 11: NET ASSETS - continued

As of December 31, 2017 and 2016, temporarily restricted net assets consisted of the following:

	Balance December 31, 2016	Contributions and Net Gain	Releases	Transfers	Balance December 31, 2017
Unlock the Cure					
General	\$ 218,162	\$ 224,944	\$ (298,830)	\$ -	\$ 144,276
Biorepository	1,164,219	171,782	(134,548)	(351,254)	850,199
Preclinical consortium	969,597	361,479	(1,135,875)	351,254	546,455
Clinical research network	14,943	-	(14,943)	-	-
Indirect costs	152,468	66,808	(90,000)	-	129,276
Child epilepsy research	150,000	5,000	(5,000)	-	150,000
	<u>2,669,389</u>	<u>830,013</u>	<u>(1,679,196)</u>	<u>-</u>	<u>1,820,206</u>
Jordana Ariella Rothberg					
Courage Fund	110,020	-	(100,000)	-	10,020
Public education	97,637	47,000	(68,217)	-	76,420
TS International	50,787	60,000	(77,795)	-	32,992
Family services	50,000	38,000	(48,000)	-	40,000
Endowment funds	105,816	118,716	(224,532)	-	-
Research	-	50,432	(50,432)	-	-
Keith Hall Appeal	-	221,749	-	-	221,749
	<u>\$ 3,083,649</u>	<u>\$ 1,365,910</u>	<u>\$ (2,248,172)</u>	<u>\$ -</u>	<u>\$ 2,201,387</u>

Contributions and net gain for Endowment funds consisted of interest and dividends and net gain on investments.

### NOTE 12: ENDOWMENT FUNDS

The Alliance's endowments consist of two funds established for different purposes. The endowment funds include one traditional donor-restricted endowment fund and one board designated endowment fund.

The traditional donor-restricted endowment fund was established to support the continuing operations of the Endowment Fund. As a result, investment earnings are classified within temporarily restricted due to an implied time restriction and amounts are released from restriction when the board approves a resolution to release the funds.

The board-designated endowment fund solely consists of the unrestricted net asset balance of the Endowment Fund, the supporting organization which is included in the accompanying consolidated financial statements.

#### Interpretation of Relevant Law

The Board of Directors has interpreted the Maryland Uniform Prudent Management of Institutional Funds Act (MUPMIFA) as requiring the preservation of the fair value of the original gift as of the gift date of the donor-restricted endowment funds absent explicit donor stipulations to the contrary. As a result of this interpretation, the Alliance classifies as permanently restricted net assets (a) the original value of gifts donated to the permanent endowment, (b) the original value of subsequent gifts to the permanent endowment, and (c) accumulations to the permanent endowment made in accordance with the direction of the applicable donor gift instrument at the time the accumulation is added to the fund. The remaining portion of the donor-restricted endowment fund that is not classified in permanently restricted net assets is classified as temporarily restricted net assets until those amounts are appropriated for expenditure by the Alliance in a manner consistent with the standard of prudence prescribed by MUPMIFA.

**NOTE 12: ENDOWMENT FUNDS - continued**

**Return Objectives and Risk Parameters**

The Alliance has adopted investment and spending policies for endowment assets that attempt to provide a predictable stream of funding to programs supported by its endowment while seeking to maintain the purchasing power of the endowment assets. Endowment assets include those assets of donor-restricted funds that the organization must hold in perpetuity as well as board-designated funds. Under this policy, as approved by the Endowment Fund Board of Directors, the endowment assets are invested in a manner that is intended to produce results that achieves constant growth of the distribution amount and the corpus. Actual returns in any given year may vary from this amount.

**Strategies Employed for Achieving Objectives**

To satisfy its long-term rate-of-return objectives, the Alliance relies on a total return strategy in which investment returns are achieved through both capital appreciation (realized and unrealized) and current yield (interest and dividends). The Alliance targets a diversified asset allocation that places a greater emphasis on equity-based investments such as mutual funds to achieve its long-term return objectives within prudent risk constraints.

**Spending Policy and How Investment Objectives Relate to Spending Policy**

The Alliance has a policy of appropriating for distribution each year up to 5% of the average fair value of the assets underlying the endowment funds over the previous 5 years in which the distribution is planned. In establishing this policy, the Alliance considered the long-term expected return on its endowment. In addition, the Board of Directors may periodically authorize additional amounts to be spent from the endowment. Accordingly, over the long term, the Alliance expects the current spending policy to allow its endowment to grow at a constant rate annually. This is consistent with the Alliance's objective to maintain the purchasing power of the endowment assets as well as to provide additional real growth through new gifts and investment return. The spending authorization is the amount authorized to be contributed to TS Alliance from the Endowment Fund.

The budgeted spending amount for the board-designated endowment fund totaled \$328,000 and \$206,000 during the years ended December 31, 2017 and 2016, respectively. In 2017, the Endowment Board of Directors elected to increase the 2017 spend by \$75,000 to allow the TS Alliance to pursue an additional research opportunity. The actual contributions to TS Alliance totaled \$403,000 and \$0 during the years ended December 31, 2017 and 2016, respectively.

**Funds with Deficiencies**

From time to time, the fair value of assets associated with individual donor-restricted endowment funds may fall below the level that the donor or MUPMIFA requires the Alliance to retain as a fund of perpetual duration. However, there were no such deficiencies as of December 31, 2017 and 2016.

Endowment funds consisted of the following at December 31, 2017, with comparative totals at December 31, 2016:

	2017			Total	2016 Total
	Unrestricted	Temporarily Restricted	Permanently Restricted		
Donor-restricted - general operations	\$ -	\$ -	\$ 879,444	\$ 879,444	\$ 985,260
Board-designated	4,776,111	-	-	4,776,111	4,308,729
	<u>\$ 4,776,111</u>	<u>\$ -</u>	<u>\$ 879,444</u>	<u>\$ 5,655,555</u>	<u>\$ 5,293,989</u>

**NOTES TO CONSOLIDATED FINANCIAL STATEMENTS**

**NOTE 12: ENDOWMENT FUNDS - continued**

Changes in the endowment funds consisted of the following for the year ended December 31, 2017, with comparative totals for the year ended December 31, 2016:

	2017			Total	2016 Total
	Unrestricted	Temporarily Restricted	Permanently Restricted		
Endowments at beginning of year	\$ 4,308,729	\$ 105,816	\$ 879,444	\$ 5,293,989	\$ 4,763,518
Investment return					
Interest and dividends	142,016	27,177	-	169,193	103,085
Net gain on investments	478,340	91,539	-	569,879	422,783
Investment fees	(22,883)	(4,379)	-	(27,262)	(24,761)
	597,473	114,337	-	711,810	501,107
Appropriations and transfers					
Appropriation per spending policy	(403,000)	-	-	(403,000)	-
Transfers in	92,635	-	-	92,635	58,746
Transfers out	180,274	(220,153)	-	(39,879)	(29,382)
	467,382	(105,816)	-	361,566	530,471
Endowments at end of year	\$ 4,776,111	\$ -	\$ 879,444	\$ 5,655,555	\$ 5,293,989

The Endowment Fund's unrestricted revenue and support, other than investment income, is automatically transferred into the board-designated endowment fund. Similarly, the Endowment Fund's supporting services, other than in-kind investment fees, are paid from the board-designated endowment fund.

**NOTE 13: DONATED SERVICES AND GOODS**

**Recorded Amounts**

Donated goods used for special events are included in the costs of direct benefit to donors and donated services are included in professional fees within supporting services in the accompanying consolidated financial statements. Donated services are recognized at fair value if the services (a) create or enhance non-financial assets or (b) require specialized skills, are performed by people with those skills, and would otherwise have been purchased by the Alliance.

Donated goods and services used for operations or special events are recognized as in-kind contributions in accordance with accounting principles generally accepted in the United States of America. Donated auction items are recorded at the amount of cash received from the auction. Donated auction items of value that have not been auctioned at the end of the year are accrued at their estimated fair value at year end as inventory. These items are adjusted for the cash received when auctioned. Donated goods are valued at their estimated fair value relating to the particular items received.

Donated services and goods for the years ended December 31, 2017 and 2016 consisted of the following:

	2017	2016
Services donated for use in special events	\$ 32,186	\$ 12,186
Goods donated for use in special events	5,007	5,224
Investment management services	27,262	24,761
	\$ 64,455	\$ 42,171

**NOTES TO CONSOLIDATED FINANCIAL STATEMENTS**

---

**NOTE 13: DONATED SERVICES AND GOODS - continued**

**Unrecorded Amounts**

Many individuals volunteer their time and perform a variety of tasks that assist the Alliance with the administration of its programs. Without these volunteers, the Alliance would struggle to maintain the same level of program services. Although greatly appreciated by the Alliance, accounting principles generally accepted in the United States of America does not allow such services to be recorded in the consolidated financial statements because the criteria for recording donated services have not been met.

**NOTE 14: ALLOCATION OF JOINT COSTS**

The Alliance incurred joint costs relating to the Family services program. This program service activity included both program content and appeals for contributions. Therefore, joint costs allocated between program and supporting services amounted to \$78,961 and \$109,355 during the years ended December 31, 2017 and 2016, respectively.

Joint cost for the years ended December 31, 2017 and 2016 were allocated to activities as follows:

	2017	2016
Family services	\$ 39,480	\$ 54,677
Fundraising	39,481	54,678
	\$ 78,961	\$ 109,355

**NOTE 15: PROFESSIONAL FEES**

Professional fees for the years ended December 31, 2017 and 2016 consisted of the following:

	2017	2016
Government relations consulting	\$ 105,960	\$ 104,376
Marketing consulting	54,484	56,768
Events production consulting	47,400	36,522
Audit and tax preparation fees	25,000	37,385
Legal fees	93,443	58,515
Website	20,369	15,351
Recruiting and payroll fees	11,987	7,862
Other consulting	25,658	2,186
Investment management services	27,262	24,761
Temporary accounting fees	12,628	-
International outreach consulting	5,851	-
Video production expense	19,796	-
	\$ 449,838	\$ 343,726

**NOTE 16: RELATED PARTY TRANSACTIONS**

**Board of Directors**

The Alliance has authorized research grants and database charges to institutions at which certain members of the Board of Directors are employed. In accordance with the Alliance's conflict of interest policy, these relationships are disclosed to all persons charged with responsibility for approving the transactions and the director or officer must recuse themselves from participation in discussion, approvals, or votes on such transactions. Grants provided to such institutions totaled \$111,700 and \$119,800 during the years ended December 31, 2017 and 2016, respectively.

---

**REPORT OF INDEPENDENT AUDITORS ON SUPPLEMENTAL INFORMATION**

---

To the Board of Directors  
National Tuberous Sclerosis Association &  
Affiliate

We have audited the consolidated financial statements of National Tuberous Sclerosis Association & Affiliate as of and for the year ended December 31, 2017, and our report thereon dated April 2, 2018 which expressed an unmodified opinion on those consolidated financial statements, appears on pages 1 - 2. Our audit was conducted for the purpose of forming an opinion on the consolidated financial statements as a whole. The accompanying consolidating statement of financial position and consolidating statement of activities are presented for purposes of additional analysis and are not a required part of the financial statements. Such information is the responsibility of management and was derived from and relates directly to the underlying accounting and other records used to prepare the consolidated financial statements. The information has been subjected to the auditing procedures applied in the audit of the consolidated financial statements and certain additional procedures, including comparing and reconciling such information directly to the underlying accounting and other records used to prepare the consolidated financial statements or to the consolidated financial statements themselves, and other additional procedures in accordance with auditing standards generally accepted in the United States of America. In our opinion, the information is fairly stated in all material respects in relation to the consolidated financial statements as a whole.



Bethesda, MD  
April 2, 2018



**NATIONAL TUBEROUS SCLEROSIS ASSOCIATION & AFFILIATE**  
**CONSOLIDATING STATEMENT OF FINANCIAL POSITION**  
**DECEMBER 31, 2017**

<u>ASSETS</u>	<u>TS Alliance</u>	<u>Endowment Fund</u>	<u>Elimination</u>	<u>Total</u>
<b>CURRENT ASSETS</b>				
Cash and cash equivalents	\$ 1,513,380	\$ 23,963	\$ -	\$ 1,537,343
Short-term investments	807,688	-	-	807,688
Accounts receivable	278,373	-	-	278,373
Promises to give - current portion	746,536	-	-	746,536
Prepaid expenses and other assets	344,133	2,393	-	346,526
Due (to) from affiliate	(17,128)	17,128	-	-
<b>TOTAL CURRENT ASSETS</b>	<b>3,672,982</b>	<b>43,484</b>	<b>-</b>	<b>3,716,466</b>
<b>PROPERTY AND EQUIPMENT</b>				
Property and equipment	372,051	-	-	372,051
Accumulated depreciation and amortization	(186,050)	-	-	(186,050)
<b>PROPERTY AND EQUIPMENT - NET</b>	<b>186,001</b>	<b>-</b>	<b>-</b>	<b>186,001</b>
<b>OTHER ASSETS</b>				
Long term investments	-	5,689,777	-	5,689,777
Promises to give - non-current portion	242,763	-	-	242,763
Interest in net assets of affiliate	5,655,555	-	(5,655,555)	-
<b>TOTAL OTHER ASSETS</b>	<b>5,898,318</b>	<b>5,689,777</b>	<b>(5,655,555)</b>	<b>5,932,540</b>
<b>TOTAL ASSETS</b>	<b>\$ 9,757,301</b>	<b>\$ 5,733,261</b>	<b>\$ (5,655,555)</b>	<b>\$ 9,835,007</b>
 <b><u>LIABILITIES AND NET ASSETS</u></b>				
<b>CURRENT LIABILITIES</b>				
Accounts payable and accrued expenses	\$ 257,983	\$ 45	\$ -	\$ 258,028
Accrued compensation	214,661	-	-	214,661
Deferred rent and lease incentive - current portion	25,206	-	-	25,206
Gift annuity obligations - current portion	-	12,530	-	12,530
Deferred revenue - current portion	167,293	-	-	167,293
<b>TOTAL CURRENT LIABILITIES</b>	<b>665,143</b>	<b>12,575</b>	<b>-</b>	<b>677,718</b>
<b>OTHER LIABILITIES</b>				
Deferred rent and lease incentive - non-current portion	35,378	-	-	35,378
Gift annuity obligations - non-current portion	-	65,131	-	65,131
<b>TOTAL OTHER LIABILITIES</b>	<b>35,378</b>	<b>65,131</b>	<b>-</b>	<b>100,509</b>
<b>TOTAL LIABILITIES</b>	<b>700,521</b>	<b>77,706</b>	<b>-</b>	<b>778,227</b>
<b>NET ASSETS</b>				
Unrestricted				
Undesignated	623,862	-	-	623,862
Designated	5,352,087	4,776,111	(4,776,111)	5,352,087
Total unrestricted	5,975,949	4,776,111	(4,776,111)	5,975,949
Temporarily restricted	2,201,387	-	-	2,201,387
Permanently restricted	879,444	879,444	(879,444)	879,444
<b>TOTAL NET ASSETS</b>	<b>9,056,780</b>	<b>5,655,555</b>	<b>(5,655,555)</b>	<b>9,056,780</b>
<b>TOTAL LIABILITIES AND NET ASSETS</b>	<b>\$ 9,757,301</b>	<b>\$ 5,733,261</b>	<b>\$ (5,655,555)</b>	<b>\$ 9,835,007</b>

**NATIONAL TUBEROUS SCLEROSIS ASSOCIATION & AFFILIATE**  
**CONSOLIDATING STATEMENT OF ACTIVITIES**  
**FOR THE YEAR ENDED DECEMBER 31, 2017**

	TS Alliance				Endowment Fund				Eliminations				Consolidated Total			
	Unrestricted	Temporarily Restricted	Permanently Restricted	Total	Unrestricted	Temporarily Restricted	Permanently Restricted	Total	Unrestricted	Temporarily Restricted	Permanently Restricted	Total	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
<b>REVENUE AND SUPPORT</b>																
Special events																
Special events	\$ 1,418,146	\$ 81,429	\$ -	\$ 1,499,575	\$ -	\$ -	\$ -	\$ -	\$ -	\$ -	\$ -	\$ -	\$ 1,418,146	\$ 81,429	\$ -	\$ 1,499,575
Costs of direct benefits to donors	(175,616)	-	-	(175,616)	-	-	-	-	-	-	-	-	(175,616)	-	-	(175,616)
Special events - net	1,242,530	81,429	-	1,323,959	-	-	-	-	-	-	-	-	1,242,530	81,429	-	1,323,959
Contributions	1,212,375	1,163,950	-	2,376,325	75,817	-	-	75,817	(403,000)	-	-	(403,000)	885,192	1,163,950	-	2,049,142
Contracts	824,241	-	-	824,241	-	-	-	-	-	-	-	-	824,241	-	-	824,241
Interest and dividend income	10,150	-	-	10,150	142,016	27,177	-	169,193	-	-	-	-	152,166	27,177	-	179,343
Memorials and honorariums	102,876	1,815	-	104,691	1,038	-	-	1,038	-	-	-	-	103,914	1,815	-	105,729
Federated funding	37,803	-	-	37,803	7,347	-	-	7,347	-	-	-	-	45,150	-	-	45,150
Other income	885	-	-	885	-	-	-	-	-	-	-	-	885	-	-	885
Sponsorships	86,865	-	-	86,865	-	-	-	-	-	-	-	-	86,865	-	-	86,865
Net assets released from restriction	2,023,640	(2,023,640)	-	-	224,532	(224,532)	-	-	-	-	-	-	2,248,172	(2,248,172)	-	-
<b>TOTAL REVENUE AND SUPPORT</b>	<b>5,541,365</b>	<b>(776,446)</b>	<b>-</b>	<b>4,764,919</b>	<b>450,750</b>	<b>(197,355)</b>	<b>-</b>	<b>253,395</b>	<b>(403,000)</b>	<b>-</b>	<b>-</b>	<b>(403,000)</b>	<b>5,589,115</b>	<b>(973,801)</b>	<b>-</b>	<b>4,615,314</b>
<b>EXPENSES</b>																
Program activities																
Research	2,745,515	-	-	2,745,515	-	-	-	-	-	-	-	-	2,745,515	-	-	2,745,515
Family services	773,656	-	-	773,656	27,425	-	-	27,425	-	-	-	-	801,081	-	-	801,081
Public health education	322,284	-	-	322,284	-	-	-	-	-	-	-	-	322,284	-	-	322,284
Government relations	147,996	-	-	147,996	-	-	-	-	-	-	-	-	147,996	-	-	147,996
Professional education	82,183	-	-	82,183	-	-	-	-	-	-	-	-	82,183	-	-	82,183
Contribution to TS Alliance	-	-	-	-	403,000	-	-	403,000	(403,000)	-	-	(403,000)	-	-	-	-
Total program activities	4,071,634	-	-	4,071,634	430,425	-	-	430,425	(403,000)	-	-	(403,000)	4,099,059	-	-	4,099,059
Supporting services																
Fundraising	756,020	-	-	756,020	5,407	-	-	5,407	-	-	-	-	761,427	-	-	761,427
Management and general	509,118	-	-	509,118	25,876	-	-	25,876	-	-	-	-	534,994	-	-	534,994
Total supporting services	1,265,138	-	-	1,265,138	31,283	-	-	31,283	-	-	-	-	1,296,421	-	-	1,296,421
<b>TOTAL EXPENSES</b>	<b>5,336,772</b>	<b>-</b>	<b>-</b>	<b>5,336,772</b>	<b>461,708</b>	<b>-</b>	<b>-</b>	<b>461,708</b>	<b>(403,000)</b>	<b>-</b>	<b>-</b>	<b>(403,000)</b>	<b>5,395,480</b>	<b>-</b>	<b>-</b>	<b>5,395,480</b>
<b>CHANGE IN NET ASSETS FROM OPERATIONS</b>																
Net gain (loss) on investments	863	-	-	863	478,340	91,539	-	569,879	-	-	-	-	479,203	91,539	-	570,742
Change in interest in affiliate	467,382	(105,816)	-	361,566	-	-	-	-	(467,382)	105,816	-	(361,566)	-	-	-	-
<b>CHANGE IN NET ASSETS</b>	<b>672,838</b>	<b>(882,262)</b>	<b>-</b>	<b>(209,424)</b>	<b>467,382</b>	<b>(105,816)</b>	<b>-</b>	<b>361,566</b>	<b>(467,382)</b>	<b>105,816</b>	<b>-</b>	<b>(361,566)</b>	<b>672,838</b>	<b>(882,262)</b>	<b>-</b>	<b>(209,424)</b>
<b>NET ASSETS AT BEGINNING OF YEAR</b>																
	5,303,111	3,083,649	879,444	9,266,204	4,308,729	105,816	879,444	5,293,989	(4,308,729)	(105,816)	(879,444)	(5,293,989)	5,303,111	3,083,649	879,444	9,266,204
<b>NET ASSETS AT END OF YEAR</b>																
	\$ 5,975,949	\$ 2,201,387	\$ 879,444	\$ 9,056,780	\$ 4,776,111	\$ -	\$ 879,444	\$ 5,655,555	\$ (4,776,111)	\$ -	\$ (879,444)	\$ (5,655,555)	\$ 5,975,949	\$ 2,201,387	\$ 879,444	\$ 9,056,780