

**Audited Consolidated Financial Statements
with Consolidating Information**

**NATIONAL TUBEROUS SCLEROSIS
ASSOCIATION & AFFILIATE**

December 31, 2018

National Tuberous Sclerosis Association & Affiliate

Contents

<i>Independent Auditor's Report on the Consolidated Financial Statements</i>	1 - 2
<i>Consolidated Financial Statements</i>	
Consolidated statement of financial position	3
Consolidated statement of activities	4
Consolidated statement of functional expense	5
Consolidated statement of cash flows	6
Notes to the consolidated financial statements	7 - 21
<i>Consolidating Information</i>	
Independent auditor's report on the consolidating information	22
Consolidating statement of financial position	23
Consolidating statement of activities	24



Independent Auditor’s Report on the Consolidated Financial Statements

To the Board of Directors
National Tuberous Sclerosis
Association & Affiliate

We have audited the accompanying consolidated financial statements of National Tuberous Sclerosis Association & Affiliate (the Alliance), which comprise the consolidated statement of financial position as of December 31, 2018 and the related consolidated statements of activities, functional expense, and cash flows for the year then ended, and the related notes to the consolidated financial statements.

Management’s Responsibility for the Consolidated 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 error or fraud.

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 perform the audit to obtain reasonable assurance about whether the consolidated financial statements are free of 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 Alliance’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 Alliance’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.

Opinion

In our opinion, the 2018 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, 2018 and the changes in its net assets and its cash flows for the year then ended in accordance with accounting principles generally accepted in the United States of America.

.....
2021 L STREET, NW

.....
SUITE 400

.....
WASHINGTON, DC

.....
20036

.....
TELEPHONE
202/293-2200

.....
FACSIMILE

.....
202/293-2208

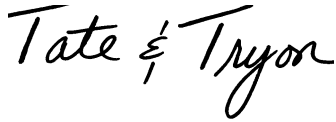
To the Board of Directors
March 21, 2019
Page 2 of 2

Prior Period Financial Statements

The 2017 consolidated financial statements of the Alliance as of December 31, 2017, were audited by other auditors a whose report dated April 2, 2018 expressed an unmodified opinion on those consolidated financial statements.

Emphasis of Matter

As described in Note P to the consolidated financial statements, the Alliance's net assets without donor restrictions and net assets with donor restrictions at January 1, 2018 have been restated. As a result of the restatement, there was no effect on total consolidated net assets.

The image shows a handwritten signature in black ink that reads "Tate & Tryon". The signature is written in a cursive, flowing style.

Washington, DC
March 21, 2019

National Tuberous Sclerosis Association & Affiliate

Consolidated Statement of Financial Position December 31, 2018

Assets

Cash and cash equivalents	\$	1,304,824
Investments		6,209,943
Accounts receivable		158,782
Promises to give		1,249,706
Prepaid expenses and other assets		263,093
Property and equipment		169,346

Total assets	\$	9,355,694
---------------------	-----------	------------------

Liabilities and Net Assets

Liabilities

Accounts payable and accrued expenses	\$	196,626
Accrued compensation		255,560
Deferred revenue		114,499
Deferred rent and lease incentive		35,378
Gift annuity obligations		73,943

Total liabilities		676,006
-------------------	--	---------

Net assets

Without donor restrictions		
Undesignated		235,336
Board-designated		4,789,541

Total without donor restrictions		5,024,877
----------------------------------	--	-----------

With donor restrictions		3,654,811
-------------------------	--	-----------

Total net assets		8,679,688
------------------	--	-----------

Total liabilities and net assets	\$	9,355,694
---	-----------	------------------

National Tuberos Sclerosis Association & Affiliate

Consolidated Statement of Activities Year Ended December 31, 2018

	Without Donor Restrictions	With Donor Restrictions	Total
Revenue and support			
Special events	\$ 1,660,285	\$ -	\$ 1,660,285
Costs of direct benefits to donors	(141,001)		(141,001)
Special events, net	1,519,284	-	1,519,284
Contributions	735,203	1,728,528	2,463,731
Contracts	1,126,302		1,126,302
World TSC Conference	743,427		743,427
Interest and dividends	122,186	19,960	142,146
Memorials and honorariums	77,552		77,552
Federated funding	44,107		44,107
Other income	15,118		15,118
	4,383,179	1,748,488	6,131,667
Net assets released from restrictions	1,585,118	(1,585,118)	-
Total revenue and support	5,968,297	163,370	6,131,667
Expense			
Program services			
Research	2,463,285		2,463,285
Family Services	770,313		770,313
World TSC Conference	767,575		767,575
Public health education	322,973		322,973
Government relations	149,340		149,340
Professional education	128,621		128,621
Total program services	4,602,107	-	4,602,107
Supporting services			
Fundraising	781,502		781,502
Management and general	528,655		528,655
Total supporting services	1,310,157	-	1,310,157
Total expense	5,912,264	-	5,912,264
Change in net assets from operations	56,033	163,370	219,403
Investment loss	(508,220)	(88,275)	(596,495)
Change in net assets	(452,187)	75,095	(377,092)
Net assets, January 1, 2018, as restated	5,477,064	3,579,716	9,056,780
Net assets, December 31, 2018	\$ 5,024,877	\$ 3,654,811	\$ 8,679,688

See notes to the consolidated financial statements.

National Tuberos Sclerosis Association & Affiliate

Consolidated Statement of Functional Expense Year Ended December 31, 2018

	Program Services							Supporting Services		Total
	Research	Family Services	Public Health Education	Government Relations	Professional Education	World Conference	Total	Fundraising	Management and General	
Salaries	\$ 391,730	\$ 362,010	\$ 132,868	\$ 26,289	\$ 53,744	\$ 28,146	\$ 994,787	\$ 349,960	\$ 295,890	\$ 1,640,637
Preclinical consortium	1,013,378						1,013,378			1,013,378
Training, conferences, and exhibits	10,116	58,185	1,664	78	17,529	527,896	615,468	4,443	1,182	621,093
Grants	451,689	12,000			500		464,189			464,189
Employee benefits and payroll taxes	68,479	96,784	26,513	5,987	13,980	7,541	219,284	87,662	65,602	372,548
Professional fees	22,645	33,757	50,788	108,237	309	31,401	247,137	60,840	60,619	368,596
Travel	33,202	107,629	9,189	2,090	30,751	98,677	281,538	30,899	4,257	316,694
Natural history database	170,893						170,893			170,893
Biosample repository	164,328						164,328			164,328
Printing and promotion	2,198	14,291	48,593	608	8	19,804	85,502	60,945	418	146,865
Equipment maintenance and rental	35,777	15,289	6,810	1,710	3,448	14,100	77,134	25,292	25,404	127,830
Rent	17,529	14,927	6,684	1,706	3,439	13,075	57,360	22,960	16,887	97,207
Depreciation and amortization	21,577	10,292	23,878	529	1,066	4,053	61,395	12,782	5,232	79,409
Bank, credit card, and transaction fees	147	77	35	9	18	68	354	57,699	15,905	73,958
Dues, fees, and subscriptions	7,345	12,062	2,426	134	219	834	23,020	22,316	14,751	60,087
Postage and shipping	2,719	11,399	7,943	468	1,442	6,405	30,376	24,481	2,836	57,693
Telephone	6,154	8,009	3,008	419	846	3,215	21,651	9,512	4,573	35,736
Clinical research consortium	35,203						35,203			35,203
Board and committee meetings	4,641	3,881	1,770	452	910	3,462	15,116	6,008	4,717	25,841
Other expense	1,232	6,950	46	373	21	7,021	15,643	1,282	4,319	21,244
Insurance	1,436	1,200	547	140	282	1,071	4,676	1,858	3,960	10,494
Supplies	867	1,571	211	111	109	806	3,675	2,563	2,103	8,341
Total	\$ 2,463,285	\$ 770,313	\$ 322,973	\$ 149,340	\$ 128,621	\$ 767,575	\$ 4,602,107	\$ 781,502	\$ 528,655	\$ 5,912,264

See notes to the consolidated financial statements.

National Tuberous Sclerosis Association & Affiliate

Consolidated Statement of Cash Flows Year Ended December 31, 2018

Cash flows from operating activities	
Change in net assets	\$ (377,092)
Adjustments to reconcile change in net assets to net cash provided by operating activities:	
Net loss on investments	569,269
Discount on promises to give	30,932
Depreciation and amortization	79,409
Change in value of gift annuity obligations	8,812
Changes in assets and liabilities:	
Accounts receivable	119,591
Promises to give	(291,339)
Prepaid expenses and other assets	83,433
Accounts payable and accrued expenses	(61,402)
Accrued compensation	40,899
Deferred revenue	(52,794)
Deferred rent and lease incentive	(25,206)
Total adjustments	501,604
Net cash provided by operating activities	124,512
Cash flows from investing activities	
Proceeds from sales and maturities of investments	26,631
Purchases of investments	(308,378)
Purchases of property and equipment	(62,754)
Net cash used in investing activities	(344,501)
Cash flows from financing activities	
Payments on gift annuity obligations	(12,530)
Net cash used in financing activities	(12,530)
Net decrease in cash and cash equivalents	(232,519)
Cash and cash equivalents, January 1, 2018	1,537,343
Cash and cash equivalents, December 31, 2018	\$ 1,304,824
 Schedule of noncash investing activities	
Donated securities	\$ 47,237

See notes to the consolidated financial statements.

National Tuberous Sclerosis Association & Affiliate

Notes to the Consolidated Financial Statements

A. ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

Organization: National Tuberous Sclerosis Association (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.

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

Income 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.

Basis of accounting: The accompanying consolidated financial statements have been prepared on the accrual basis of accounting. Revenue, other than contributions, is recognized when earned and expense when the obligation is incurred.

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

Cash and cash equivalents: For financial statement purposes, the Alliance classifies checking, demand deposit, and overnight sweep accounts as cash and cash equivalents. Money market funds and certificates of deposit held within the investment portfolio are classified as investments.

National Tuberous Sclerosis Association & Affiliate

Notes to the Consolidated Financial Statements

A. ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES - CONTINUED

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. However, bad debt expense was \$0 for the year ended December 31, 2018.

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

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, which include memorials and honorariums and federated funding, are recognized when unconditionally promised to, or received by, the Alliance. Contributions are recorded within activities without donor restrictions or within activities with donor restrictions depending upon the existence and/or nature of any donor restrictions. Net assets with donor restrictions are reclassified to net assets without donor restrictions when either the purpose restriction is satisfied, or the time restriction expires.

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) preclinical consortium testing of compounds that could be developed for future treatments, 2) a significant enhancement to the Natural History Database on TSC, 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.

Functional allocation of expense: Certain costs are allocated among multiple program services or supporting services activities. Allocable costs include operations, rent, human resources, finance, information technology support, Board of Directors, executive administration, and depreciation and amortization. The costs are allocated among program services and supporting services activities based on either employee effort or direct costs.

Program services: Program services include the following activities:

Research: Research program stimulates and supports basic, translational, and clinical research on the various manifestations of tuberous sclerosis complex (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.

National Tuberous Sclerosis Association & Affiliate

Notes to the Consolidated Financial Statements

A. ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES - CONTINUED

World TSC Conference: The 2018 World Tuberous Sclerosis Complex (TSC) Conference was co-hosted by the TS Alliance and Tuberous Sclerosis Complex International in Dallas, Texas from July 26-29, 2018. This event drew 933 total attendees from 26 countries. Ninety-nine scholarships were awarded to assist families/individuals with the cost. The success of this event is due to both the in-person and online participation. The conference consisted of four educational tracks: pediatric, transition, adult, and specialty. In addition, there were concurrently run group sessions (4) and meet-the-expert sessions (2). Group sessions provided a conversational forum to discuss topics relevant to a smaller population of those affected by TSC (e.g.: Women's Health Issues). Meet-the-expert sessions provided a question-and-answer format with six experts per session participating from various specialties. General sessions topics were selected based on hot topics that are applicable to the majority of TSC individuals and families and on international relevance.

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.

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 was 22% for the year ended December 31, 2018. Supporting services include the following activities:

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.

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

Change in accounting policies: TS Alliance adopted FASB Accounting Standards Update (ASU) No. 2016-14, *Not-for-Profit Entities: Presentation of Financial Statements of Not-for-Profit Entities*, during the year ended December 31, 2018. ASU 2016-04 refreshes current accounting standards by simplifying the presentation of net assets on the face of the consolidated financial statements and enhancing disclosures related to liquidity.

Subsequent events: Subsequent events have been evaluated through March 21, 2019, which is the date the consolidated financial statements were available to be issued.

National Tuberous Sclerosis Association & Affiliate

Notes to the Consolidated Financial Statements

B. CONCENTRATIONS

Credit risk: The Alliance maintains demand deposits with commercial banks and money market funds within its investment portfolio with financial institutions. At times, certain balances held within these accounts may not be fully guaranteed or insured by the U.S. federal government. Therefore, the failure of an underlying institution could result in financial loss to the Alliance. However, it is TS Alliance's policy to maximize the use of guarantees and FDIC insurance.

Market risk: 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.

C. INVESTMENTS

In accordance with U.S. GAAP, the Alliance uses the following prioritized input levels to measure fair value of investments. The input levels used for valuing investments are not necessarily an indication of risk.

Level 1 – Observable inputs that reflect quoted prices for identical assets or liabilities in active markets, such as stock quotes.

Level 2 – Includes inputs other than Level 1 inputs that are directly or indirectly observable in the marketplace, such as yield curves or other market data.

Level 3 – Unobservable inputs which reflect the reporting entity's assessment of the assumptions that market participants would use in pricing the asset or liability including assumptions about risk, such as bid/ask spreads and liquidity discounts.

TS Alliance investment policy statement: 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 instruments with the highest possible principal stability rating. Uninsured money markets are limited to 20% of gross operating funds. Balances held in bank accounts may in total exceed the FDIC insurance coverage by up to \$750,000, but every effort is made to keep the balance as close to \$250,000 as possible.

Endowment Fund investment policy statement: 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.

National Tuberous Sclerosis Association & Affiliate

Notes to the Consolidated Financial Statements

C. INVESTMENTS - CONTINUED

The fair values of mutual funds and exchange traded funds were determined using Level 1 inputs, which were based on quoted prices in active markets. Management believes the fair values of investments to be a reasonable approximation of their exit price.

Investments recorded at cost include money market funds and certificates of deposit. Investments at cost are not required to be classified in one of the Levels prescribed by the fair value hierarchy.

Investments consisted of the following at December 31, 2018:

Investments, at fair value (Level 1)	
Mutual funds	
Bonds	\$ 1,003,304
Domestic equity	2,770,619
International equity	696,549
Exchange traded funds	
Fixed income	<u>439,992</u>
Subtotal investments, at fair value (Level 1)	4,910,464
Investments, at cost	
Money market funds	1,072,156
Certificates of deposit	<u>227,323</u>
Subtotal investments, at cost	<u>1,299,479</u>
	<u>\$ 6,209,943</u>

Investment return consisted of the following for the year ended December 31, 2018:

Interest and dividends	\$ 142,146
Investment loss	
Net loss on investments	(569,269)
Investment management fees (donated)	<u>(27,226)</u>
	<u>(596,495)</u>
	<u>\$ (454,349)</u>

National Tuberos Sclerosis Association & Affiliate

Notes to the Consolidated Financial Statements

D. 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. Discounts were determined using the interest rates in effect when the promises were received for two-year to five-year U.S. Treasury bills plus 1%. 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.

Promises to give consisted of the following at December 31, 2018:

Amounts due in less than one year	\$ 913,638
Amounts due in one to five years	<u>367,000</u>
	1,280,638
Less discount to net present value	<u>(30,932)</u>
	<u>\$ 1,249,706</u>

E. LIQUIDITY

The Alliance regularly monitors liquidity required to meet its programmatic goals, operating needs, and other contractual commitments. Management submits cash flow projections for review by the Board of Directors and its Finance and Executive Committees periodically throughout the year. The cash flow projections are used to estimate future cash flows for 90 to 120-day periods during the year and provide estimated future cash flows for the next fiscal year as part of the annual budgeting process.

The Alliance strives to maintain sufficient cash to cover three months of core operating expenses, which are defined as all expenses excluding planned spending associated with research or clinical initiatives. Cash balances are reviewed no less than annually by the Finance Committee of the Board of Directors.

The Alliance receives significant contributions with donor restrictions to be used in accordance with associated purpose restrictions. It also receives substantial support without donor restrictions primarily from special events and individual donor contributions. In addition to grants, contributions, and program service revenue, the Alliance also generates investment income. The Alliance's investments are described in Note C and include both donor-restricted and board-designated funds.

National Tuberos Sclerosis Association & Affiliate

Notes to the Consolidated Financial Statements

E. LIQUIDITY - CONTINUED

The following provides a summary of financial assets available for general expenditures at December 31, 2018:

Cash and cash equivalents	\$ 1,304,824
Investments	6,209,943
Accounts receivable	158,782
Promises to give	<u>1,249,706</u>
Subtotal financial assets	8,923,255
Amounts not available for general expenditures:	
Investments held to fund charitable gift annuity	(66,502)
Promises to give, long-term	(336,068)
Board-designated net assets	(4,789,541)
Approved transfers to undesignated net assets	621,500
Net assets with donor restrictions	<u>(3,654,811)</u>
	<u>\$ 697,833</u>

F. 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 equipment and furniture – 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.

Property and equipment consisted of the following at December 31, 2018:

Software	\$ 118,056
Office equipment and furniture	155,880
Leasehold improvements	<u>156,545</u>
	430,481
Less accumulated depreciation and amortization	<u>(261,135)</u>
	<u>\$ 169,346</u>

National Tuberous Sclerosis Association & Affiliate

Notes to the Consolidated Financial Statements

G. 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 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 2.2% to 6.8% 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 \$73,943 at December 31, 2018.

H. NET ASSETS

Without donor restriction: Net assets without donor restrictions 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. Net assets without donor restriction consisted of the following at December 31, 2018:

Undesignated	\$	235,336
Board-designated		
Endowment fund		4,387,039
Grant commitments		402,502
		<hr/>
	\$	5,024,877

National Tuberos Sclerosis Association & Affiliate

Notes to the Consolidated Financial Statements

H. NET ASSETS - CONTINUED

With donor restrictions: Net assets with donor restrictions include those net assets whose use by the Alliance has been donor restricted by specified time or program restrictions. Net assets with donor restrictions consisted of the following as of and for the year ended December 31, 2018:

	Balance at January 1, 2018	Contributions & Investment Return	Net Assets Released from Restrictions	Balance at December 31, 2018
Unlock the Cure				
General	\$ 144,275	\$ 299,880	\$ (273,553)	\$ 170,602
Biorepository	850,199	51,918	(275,001)	627,116
Preclinical consortium	1,045,340	604,203	(455,079)	1,194,464
Indirect costs	129,276	146,084	(105,000)	170,360
Child epilepsy research	150,000			150,000
	2,319,090	1,102,085	(1,108,633)	2,312,542
Endowment fund	879,444	(68,315)	(4,234)	806,895
Clinical research consortium	-	166,246		166,246
Public education	76,421	86,500	(46,535)	116,386
Hall fund	221,749	8,681	(130,355)	100,075
TSC International	32,992	109,000	(54,825)	87,167
Family services	40,000	80,500	(55,000)	65,500
Rothberg Courage Fund	10,020		(10,020)	-
Nurses meeting	-	30,663	(30,663)	-
Research	-	144,853	(144,853)	-
	\$ 3,579,716	\$ 1,660,213	\$ (1,585,118)	\$ 3,654,811

I. 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. As required by generally accepted accounting principles, net assets associated with endowment funds are classified and reported based on the existence or absence of donor-imposed restrictions.

Interpretation of Relevant Law

The Alliance has interpreted the *Maryland Uniform Prudent Management of Institutional Funds Act of 2007 (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 net assets with donor restriction (a) the original value of gifts donated to the endowment, (b) the original value of subsequent gifts to the endowment, and (c) accumulations to the endowment made in accordance with the direction of the applicable donor gift instrument. Endowment funds are appropriated for expenditure by the Alliance in a manner consistent with the standard of prudence prescribed by MUPMIFA.

National Tuberous Sclerosis Association & Affiliate

Notes to the Consolidated Financial Statements

I. 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 to achieve its long-term return objectives within prudent risk constraints.

Spending Policy and How the 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 authorized spending amount for the board-designated endowment fund totaled \$285,000 during the year ended December 31, 2018. The actual contributions to TS Alliance totaled \$50,000 during the year ended December 31, 2018.

Annually the Endowment Fund authorizes an amount to be contributed to TS Alliance. At times, TS Alliance does not utilize all of the funds authorized. As of December 31, 2018, the accumulated amounts authorized but unused was \$399,500. Additionally, for the year ending December 31, 2019, the Endowment Fund has authorized a contribution of \$222,000 to TS Alliance.

Fund Deficiencies

From time to time, the fair value of assets associated with individual donor-restricted endowment funds may fall below the principal amount that the donor originally contributed in order to establish the endowment. In accordance with generally accepted accounting principles, deficiencies of this nature are reported within net assets with donor restrictions and typically result from unfavorable market fluctuations or continued appropriation. At December 31, 2018, the endowments had a total deficiency of \$82,411.

National Tuberos Sclerosis Association & Affiliate

Notes to the Consolidated Financial Statements

I. ENDOWMENT FUNDS - CONTINUED

Endowment funds consisted of the following at December 31, 2018:

	Without Donor Restrictions	With Donor Restrictions	Total
Board-designated	\$ 4,387,039	\$ -	\$ 4,387,039
Donor-restricted		806,895	806,895
	\$ 4,387,039	\$ 806,895	\$ 5,193,934

Changes in the endowment funds consisted of the following for the year ended December 31, 2018:

	Without Donor Restrictions	With Donor Restrictions	Total
Balance at January 1, 2018	\$ 4,776,111	\$ 879,444	\$ 5,655,555
Contributions	82,346		82,346
Investment return			
Interest and dividends	108,402	19,960	128,362
Net loss on investments	(479,408)	(88,275)	(567,683)
Investment management fees	(22,992)	(4,234)	(27,226)
	(393,998)	(72,549)	(466,547)
Appropriations and transfers			
Appropriation per spending policy	(50,000)		(50,000)
Supporting services	(27,420)		(27,420)
	(389,072)	(72,549)	(461,621)
Balance at December 31, 2018	\$ 4,387,039	\$ 806,895	\$ 5,193,934

National Tuberous Sclerosis Association & Affiliate

Notes to the Consolidated Financial Statements

J. DONATED SERVICES AND GOODS

Recorded amounts: Donated goods used for special events are included in the costs of direct benefit to donors and, other than investment management fees, 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 U.S. GAAP. 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 and would be included in other assets in the statement of financial position. 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.

In-kind contributions consisted of a combination of donated goods and services totaling \$67,724 for the year ended December 31, 2018.

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, U.S. GAAP does not allow such services to be recorded in the consolidated financial statements because the criteria for recording donated services have not been met.

K. 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 \$73,440 during the year ended December 31, 2018.

Joint costs were allocated to the following activities for the year ended December 31, 2018:

Family services	\$	36,720
Fundraising		<u>36,720</u>
	\$	<u>73,440</u>

National Tuberous Sclerosis Association & Affiliate

Notes to the Consolidated Financial Statements

L. PROFESSIONAL FEES

Professional fees consisted of the following for the year ended December 31, 2018:

Government relations consulting	\$	108,084
Marketing consulting		59,203
Legal fees		43,506
Video production expense		35,226
Events production consulting		26,500
Website		26,459
Audit and tax preparation fees		25,500
Recruiting and payroll fees		25,255
Other consulting		15,737
Temporary staffing fees		3,126
		<hr/>
	\$	368,596

M. RETIREMENT PLAN

The 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. The Alliance's contributions to the plan totaled \$47,037 for the year ended December 31, 2018.

N. 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 \$61,495 during the year ended December 31, 2018.

Affiliates: TS Alliance has a Global Alliance Affiliation Agreement with several parties (TS Alliance of Israel, Hungarian Foundation for Tuberous Sclerosis, TS Canada ST, TS Alliance of Mexico, TS Alliance Foundation (Thailand), and TS Alliance of India). The affiliation agreement stipulates certain rights, benefits, and obligations of both parties. Each affiliate has a separate governing board and the Alliance does not have the ability to appoint a majority interest in any affiliate's governing board. Thus, the affiliates are not consolidated within the financial statements.

National Tuberous Sclerosis Association & Affiliate

Notes to the Consolidated Financial Statements

O. COMMITMENTS AND CONTINGENCIES

Grant commitments: The Alliance's Board of Directors authorized research grants totaling \$402,502 as of December 31, 2018. The research grants extend through 2020 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. The conditional grants have been included within board-designated net assets and, if the contingencies are met, will be payable as follows:

Year Ending December 31,	Amount
2019	\$ 275,540
2020	<u>126,962</u>
	<u>\$ 402,502</u>

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 31, 2020. The lease required a security deposit of \$8,606, which is included in prepaid expenses and other assets in the consolidated statement of financial position at December 31, 2018. 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 \$35,378 and as of December 31, 2018.

Rent expense totaled \$97,207 for the year ended December 31, 2018.

Future minimum lease payments for the office lease are as follows:

Year Ending December 31,	Amount
2019	\$ 102,330
2020	<u>25,708</u>
	<u>\$ 128,038</u>

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.

National Tuberos Sclerosis Association & Affiliate

Notes to the Consolidated Financial Statements

O. COMMITMENTS AND CONTINGENCIES - CONTINUED

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.

P. RESTATEMENT OF PRIOR YEAR

Net assets with donor restrictions at January 1, 2018 was understated. During the years ended December 31, 2016 and 2017, the amount of net assets released from restriction had been overstated for both years. In particular, the Preclinical Consortium fund had been understated by \$498,885 at January 1, 2018. The Alliance's prior year consolidated financial statements have been restated as follows:

	Without Donor Restrictions	With Donor Restrictions	Total
Net assets, January 1, 2018, as reported	\$ 5,975,949	\$ 3,080,831	\$ 9,056,780
Restatement	(498,885)	498,885	-
Net assets, January 1, 2018, as restated	\$ 5,477,064	\$ 3,579,716	\$ 9,056,780

T A T E



T R Y O N

A Professional Corporation

Certified Public

Accountants

and Consultants

Independent Auditor's Report on the Consolidating Information

To the Board of Directors
National Tuberous Sclerosis
Association & Affiliate

We have audited the consolidated financial statements of National Tuberous Sclerosis Association & Affiliate (the Alliance) as of and for the year ended December 31, 2018 and have issued our report thereon dated March 21, 2019, which contained an unmodified opinion on those consolidated financial statements. Our audit was conducted for the purpose of forming an opinion on the consolidated financial statements as a whole. The consolidating information on the following pages is presented for purposes of additional analysis of the consolidated financial statements rather than to present the financial position, changes in net assets, and cash flows of the individual entities, and it is not a required part of the consolidated 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 consolidating 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 consolidating information is fairly stated, in all material respects, in relation to the consolidated financial statements as a whole.

Washington, DC
March 21, 2019

.....
2021 L STREET, NW

.....
SUITE 400

.....
WASHINGTON, DC

.....
20036

.....
TELEPHONE
202/293-2200

.....
FACSIMILE
202/293-2208

.....
WWW.TATETRYON.COM

National Tuberos Sclerosis Association & Affiliate

Consolidating Statement of Financial Position December 31, 2018

	TS Alliance	Endowment Fund	Eliminations	Total
Assets				
Cash and cash equivalents	\$ 1,245,550	\$ 59,274	\$ -	\$ 1,304,824
Investments	1,009,487	5,200,456		6,209,943
Due (to) from affiliate	(8,332)	8,332		-
Accounts receivable	158,782			158,782
Promises to give	1,249,706			1,249,706
Prepaid expenses and other assets	263,093			263,093
Interest in net assets of affiliate	5,193,934		(5,193,934)	-
Property and equipment	169,346			169,346
Total assets	\$ 9,281,566	\$ 5,268,062	\$ (5,193,934)	\$ 9,355,694
Liabilities and Net Assets				
Liabilities				
Accounts payable and accrued expenses	\$ 196,441	\$ 185	\$ -	\$ 196,626
Accrued compensation	255,560			255,560
Deferred revenue	114,499			114,499
Deferred rent and lease incentive	35,378			35,378
Gift annuity obligations		73,943		73,943
Total liabilities	601,878	74,128	-	676,006
Net assets				
Without donor restrictions				
Undesignated	235,336			235,336
Board-designated	4,789,541	4,387,039	(4,387,039)	4,789,541
Total without donor restrictions	5,024,877	4,387,039	(4,387,039)	5,024,877
With donor restrictions	3,654,811	806,895	(806,895)	3,654,811
Total net assets	8,679,688	5,193,934	(5,193,934)	8,679,688
Total liabilities and net assets	\$ 9,281,566	\$ 5,268,062	\$ (5,193,934)	\$ 9,355,694

**National Tuberos Sclerosis
Association & Affiliate**

**Consolidating Statement of Activities
Year Ended December 31, 2018**

	TS Alliance			Endowment Fund			Eliminations			Consolidated Total		
	Without Donor Restrictions	With Donor Restrictions	Total	Without Donor Restrictions	With Donor Restrictions	Total	Without Donor Restrictions	With Donor Restrictions	Total	Without Donor Restrictions	With Donor Restrictions	Total
Revenue and support												
Special events	\$ 1,660,235	\$ -	\$ 1,660,235	\$ 50	\$ -	\$ 50	\$ -	\$ -	\$ -	\$ 1,660,285	\$ -	\$ 1,660,285
Costs of direct benefits to donors	(141,001)		(141,001)			-				(141,001)		(141,001)
Special events, net	1,519,234	-	1,519,234	50	-	50	-	-	-	1,519,284	-	1,519,284
Contributions	712,864	1,728,528	2,441,392	72,339		72,339	(50,000)		(50,000)	735,203	1,728,528	2,463,731
Contracts	1,126,302		1,126,302			-			-	1,126,302		1,126,302
World TSC Conference	743,427		743,427			-			-	743,427		743,427
Interest and dividends	13,784		13,784	108,402	19,960	128,362			-	122,186	19,960	142,146
Memorials and honorariums	77,552		77,552			-			-	77,552		77,552
Federated funding	34,150		34,150	9,957		9,957			-	44,107		44,107
Other income	15,118		15,118			-			-	15,118		15,118
	4,242,431	1,728,528	5,970,959	190,748	19,960	210,708	(50,000)	-	(50,000)	4,383,179	1,748,488	6,131,667
Net assets released from restrictions	1,580,884	(1,580,884)	-	4,234	(4,234)	-			-	1,585,118	(1,585,118)	-
Total revenue and support	5,823,315	147,644	5,970,959	194,982	15,726	210,708	(50,000)	-	(50,000)	5,968,297	163,370	6,131,667
Expense												
Program services												
Research	2,463,285		2,463,285			-			-	2,463,285		2,463,285
Family services	770,313		770,313			-			-	770,313		770,313
World TSC Conference	767,575		767,575			-			-	767,575		767,575
Public health education	322,973		322,973			-			-	322,973		322,973
Government relations	149,340		149,340			-			-	149,340		149,340
Professional education	128,621		128,621			-			-	128,621		128,621
Contribution to TS Alliance			-	50,000		50,000	(50,000)		(50,000)			-
Total program services	4,602,107	-	4,602,107	50,000	-	50,000	(50,000)	-	(50,000)	4,602,107	-	4,602,107
Supporting services												
Fundraising	775,657		775,657	5,845		5,845			-	781,502		781,502
Management and general	507,080		507,080	21,575		21,575			-	528,655		528,655
Total supporting services	1,282,737	-	1,282,737	27,420	-	27,420	-	-	-	1,310,157	-	1,310,157
Total expense	5,884,844	-	5,884,844	77,420	-	77,420	(50,000)	-	(50,000)	5,912,264	-	5,912,264
Change in net assets from operations	(61,529)	147,644	86,115	117,562	15,726	133,288	-	-	-	56,033	163,370	219,403
Investment loss	(1,586)		(1,586)	(506,634)	(88,275)	(594,909)			-	(508,220)	(88,275)	(596,495)
Change in interest in affiliate	(389,072)	(72,549)	(461,621)			-	389,072	72,549	461,621			-
Change in net assets	(452,187)	75,095	(377,092)	(389,072)	(72,549)	(461,621)	389,072	72,549	461,621	(452,187)	75,095	(377,092)
Net assets, January 1, 2018, as restated	5,477,064	3,579,716	9,056,780	4,776,111	879,444	5,655,555	(4,776,111)	(879,444)	(5,655,555)	5,477,064	3,579,716	9,056,780
Net assets, December 31, 2018	\$ 5,024,877	\$ 3,654,811	\$ 8,679,688	\$ 4,387,039	\$ 806,895	\$ 5,193,934	\$ (4,387,039)	\$ (806,895)	\$ (5,193,934)	\$ 5,024,877	\$ 3,654,811	\$ 8,679,688