

National Tuberous Sclerosis Association & Affiliate

Consolidated Financial Statements
December 31, 2019

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RSM US LLP

Independent Auditor's Report

Board of Directors
National Tuberous Sclerosis Association & Affiliate

Report on the Consolidated Financial Statements

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, 2019, 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 (collectively, the financial statements).

Management's Responsibility for the Consolidated Financial Statements

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

Auditor's Responsibility

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

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the Alliance's preparation and fair presentation of the financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the 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 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 2019 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, 2019, 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.

Other Matter

The 2018 consolidated financial statements of the Alliance, as of and for the year ended December 31, 2018, were audited by other auditors whose report dated March 21, 2019, expressed an unmodified opinion on those consolidated financial statements.

RSM US LLP

Washington, DC
April 22, 2020

National Tuberos Sclerosis Association & Affiliate

**Consolidated Statements of Financial Position
December 31, 2019 and 2018**

	2019	2018
Assets		
Cash and cash equivalents	\$ 1,045,437	\$ 1,304,824
Investments	6,990,118	6,209,943
Accounts receivable	10,243	158,782
Promises to give	2,033,626	1,249,706
Prepaid expenses and other assets	262,620	263,093
Property and equipment	80,221	169,346
	<u> </u>	<u> </u>
Total assets	\$ 10,422,265	\$ 9,355,694
Liabilities and Net Assets		
Liabilities:		
Accounts payable and accrued expenses	\$ 333,196	\$ 196,626
Accrued compensation	200,306	255,560
Deferred revenue	54,700	114,499
Deferred rent and lease incentive	7,176	35,378
Gift annuity obligations	70,300	73,943
	<u> </u>	<u> </u>
Total liabilities	665,678	676,006
Net assets:		
Without donor restrictions:		
Undesignated (deficit)	(214,362)	235,336
Board-designated	5,936,709	4,789,541
	<u> </u>	<u> </u>
Total net assets without donor restrictions	5,722,347	5,024,877
With donor restrictions:		
	<u>4,034,240</u>	<u>3,654,811</u>
Total net assets	9,756,587	8,679,688
	<u> </u>	<u> </u>
Total liabilities and net assets	\$ 10,422,265	\$ 9,355,694

See notes to the consolidated financial statements.

National Tuberosus Sclerosis Association & Affiliate

Consolidated Statements of Activities Years Ended December 31, 2019 and 2018

	2019			2018		
	Without Donor Restrictions	With Donor Restrictions	Total	Without Donor Restrictions	With Donor Restrictions	Total
Revenue and support:						
Special events	\$ 2,318,140	\$ 388,454	\$ 2,706,594	\$ 1,660,285	\$ -	\$ 1,660,285
Costs of direct benefits to donors	(285,156)	-	(285,156)	(141,001)	-	(141,001)
Special events, net	2,032,984	388,454	2,421,438	1,519,284	-	1,519,284
Contributions	725,432	2,296,500	3,021,932	735,203	1,728,528	2,463,731
Contracts	247,384	-	247,384	1,126,302	-	1,126,302
Interest and dividends	168,000	23,528	191,528	122,186	19,960	142,146
Conferences	174,381	-	174,381	743,427	-	743,427
Memorials and honorariums	101,864	386	102,250	77,552	-	77,552
Federated funding	45,664	-	45,664	44,107	-	44,107
Other income	714	-	714	15,118	-	15,118
	3,496,423	2,708,868	6,205,291	4,383,179	1,748,488	6,131,667
Net assets released from restrictions	2,443,437	(2,443,437)	-	1,585,118	(1,585,118)	-
Total revenue and support	5,939,860	265,431	6,205,291	5,968,297	163,370	6,131,667
Expense:						
Program services:						
Research	2,590,463	-	2,590,463	2,463,285	-	2,463,285
Family Services	929,277	-	929,277	770,313	-	770,313
Public health education	439,992	-	439,992	322,973	-	322,973
Government relations	165,225	-	165,225	149,340	-	149,340
Professional education	92,979	-	92,979	128,621	-	128,621
World TSC Conference	-	-	-	767,575	-	767,575
Total program services	4,217,936	-	4,217,936	4,602,107	-	4,602,107
Supporting services:						
Fundraising	1,135,609	-	1,135,609	781,502	-	781,502
Management and general	542,410	-	542,410	528,655	-	528,655
Total supporting services	1,678,019	-	1,678,019	1,310,157	-	1,310,157
Total expense	5,895,955	-	5,895,955	5,912,264	-	5,912,264
Change in net assets from operations	43,905	265,431	309,336	56,033	163,370	219,403
Investment income (loss)	653,565	113,998	767,563	(508,220)	(88,275)	(596,495)
Change in net assets	697,470	379,429	1,076,899	(452,187)	75,095	(377,092)
Net assets:						
Beginning of year	5,024,877	3,654,811	8,679,688	5,477,064	3,579,716	9,056,780
End of year	\$ 5,722,347	\$ 4,034,240	\$ 9,756,587	\$ 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, 2019

	Program Services					Total	Supporting Services		Total
	Research	Family Services	Public Health Education	Government Relations	Professional Education		Fundraising	Management and General	
Salaries	\$ 504,162	\$ 344,255	\$ 176,398	\$ 28,592	\$ 38,813	\$ 1,092,220	\$ 421,408	\$ 292,597	\$ 1,806,225
Preclinical consortium	700,583	-	-	-	-	700,583	-	-	700,583
Professional fees	11,656	55,167	84,016	111,231	235	262,305	210,801	68,066	541,172
Grants	459,568	64,000	-	-	500	524,068	-	-	524,068
Employee benefits and payroll taxes	88,924	98,302	43,568	7,942	5,914	244,650	110,630	62,450	417,730
Travel	127,949	125,721	14,053	4,516	11,662	283,901	57,163	3,302	344,366
Training, conferences, and exhibits	107,420	100,464	3,847	748	30,920	243,399	10,313	4,988	258,700
Biosample repository	195,907	-	-	-	-	195,907	-	-	195,907
Printing and promotion	20,777	22,453	39,007	1,951	560	84,748	94,295	218	179,261
Equipment maintenance and rental	45,262	31,816	13,214	2,654	1,320	94,266	44,742	32,923	171,931
Natural history database	159,120	-	-	-	-	159,120	-	-	159,120
Depreciation and amortization	28,977	17,055	23,355	973	484	70,844	18,075	6,521	95,440
Rent	19,671	21,856	9,172	2,206	1,097	54,002	24,175	14,790	92,967
Clinical research consortium	92,691	-	-	-	-	92,691	-	-	92,691
Bank, credit card, and transaction fees	2,382	414	96	23	11	2,926	62,675	10,769	76,370
Postage and shipping	3,618	21,310	9,109	930	851	35,818	31,229	3,012	70,059
Dues, fees, and subscriptions	8,182	10,436	2,315	1,432	140	22,505	30,902	16,282	69,689
Telephone	7,711	8,892	19,252	495	246	36,596	9,206	3,738	49,540
Board and committee meetings	931	1,017	434	1,104	52	3,538	1,127	15,452	20,117
Supplies	2,237	2,671	1,011	222	71	6,212	5,251	1,219	12,682
Insurance	1,711	1,869	798	192	95	4,665	2,071	3,891	10,627
Other expense	1,024	1,579	347	14	8	2,972	1,546	2,192	6,710
Total functional expense	\$ 2,590,463	\$ 929,277	\$ 439,992	\$ 165,225	\$ 92,979	\$ 4,217,936	\$ 1,135,609	\$ 542,410	\$ 5,895,955

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
Professional fees	22,645	33,757	50,788	108,237	309	31,401	247,137	60,840	60,619	368,596
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
Travel	33,202	107,629	9,189	2,090	30,751	98,677	281,538	30,899	4,257	316,694
Training, conferences, and exhibits	10,116	58,185	1,664	78	17,529	527,896	615,468	4,443	1,182	621,093
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
Natural history database	170,893	-	-	-	-	-	170,893	-	-	170,893
Depreciation and amortization	21,577	10,292	23,878	529	1,066	4,053	61,395	12,782	5,232	79,409
Rent	17,529	14,927	6,684	1,706	3,439	13,075	57,360	22,960	16,887	97,207
Clinical research consortium	35,203	-	-	-	-	-	35,203	-	-	35,203
Bank, credit card, and transaction fees	147	77	35	9	18	68	354	57,699	15,905	73,958
Postage and shipping	2,719	11,399	7,943	468	1,442	6,405	30,376	24,481	2,836	57,693
Dues, fees, and subscriptions	7,345	12,062	2,426	134	219	834	23,020	22,316	14,751	60,087
Telephone	6,154	8,009	3,008	419	846	3,215	21,651	9,512	4,573	35,736
Board and committee meetings	4,641	3,881	1,770	452	910	3,462	15,116	6,008	4,717	25,841
Supplies	867	1,571	211	111	109	806	3,675	2,563	2,103	8,341
Insurance	1,436	1,200	547	140	282	1,071	4,676	1,858	3,960	10,494
Other expense	1,232	6,950	46	373	21	7,021	15,643	1,282	4,319	21,244
Total functional expense	\$ 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 Tuberosus Sclerosis Association & Affiliate

Consolidated Statements of Cash Flows
Years Ended December 31, 2019 and 2018

	2019	2018
Cash flows from operating activities:		
Change in net assets	\$ 1,076,899	\$ (377,092)
Adjustments to reconcile change in net assets to net cash (used by) provided by operating activities:		
Net (gain) loss on investments	(795,419)	569,269
Discount on promises to give	72,188	30,932
Depreciation and amortization	95,440	79,409
Change in value of gift annuity obligations	8,887	8,812
Changes in assets and liabilities:		
(Increase) decrease:		
Accounts receivable	148,539	119,591
Promises to give	(856,108)	(291,339)
Prepaid expenses and other assets	473	83,433
Increase (decrease):		
Accounts payable and accrued expenses	136,570	(61,402)
Accrued compensation	(55,254)	40,899
Deferred revenue	(59,799)	(52,794)
Deferred rent and lease incentive	(28,202)	(25,206)
Net cash (used in) provided by operating activities	(255,786)	124,512
Cash flows from investing activities:		
Proceeds from sales and maturities of investments	1,457,376	26,631
Purchases of investments	(1,442,132)	(308,378)
Purchases of property and equipment	(6,315)	(62,754)
Net cash provided by (used in) investing activities	8,929	(344,501)
Cash flows from financing activities:		
Payments on gift annuity obligations	(12,530)	(12,530)
Net cash used in financing activities	(12,530)	(12,530)
Net decrease in cash and cash equivalents	(259,387)	(232,519)
Cash and cash equivalents:		
Beginning of year	1,304,824	1,537,343
End of year	\$ 1,045,437	\$ 1,304,824
Supplemental disclosures of cash flow information:		
Donated securities	\$ 45,256	\$ 47,237

See notes to the consolidated financial statements.

National Tuberous Sclerosis Association & Affiliate

Notes to Consolidated Financial Statements

Note 1. Nature of Activities and Significant Accounting Policies

Nature of activities: 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.

Program services provided by the Alliance are as follows:

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.

The 2019 International TSC Research Conference: Changing the Course of TSC held June 20-22, 2019, welcomed 251 people from 28 countries to the Chelsea Hotel in Toronto, Canada. Sponsored by the TS Alliance, Tuberous Sclerosis Canada Sclérose Tubéreuse (TSCST) and the TS Alliance of Mexico, the conference featured 34 oral presentations and 62 posters. Additionally, three breakout groups of clinical and basic science researchers discussed timely topics of induced pluripotent stem cell applications for TSC, genetic heterogeneity and modifiers, and clinical trial design for neurological aspects of TSC. On June 22, an educational meeting for TSC community members, in parallel with the scientific sessions, attracted more than 70 people to learn from international experts. TSC International held an Improving Care Workshop with participants from 25 countries. The conference's closing session was a joint session including individuals and families affected by TSC together with researchers in a discussion of priorities for important and timely clinical studies in TSC. Thirty-seven attendees registered for the educational meeting only, and 51 of the 214 who registered for the full conference were early career researchers. A symposium specifically for—and organized by—early career researchers was held June 20 before the full conference began to provide an opportunity for them to get feedback from each other and from senior scientists on selected oral presentations and career-development topics.

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 Consolidated Financial Statements

Note 1. Nature of Activities and Significant Accounting Policies (Continued)

In 2019, the TS Alliance co-hosted five regional conferences with The LAM Foundation in Boston, St. Louis, Chicago, Atlanta and Los Angeles. These conferences 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 events drew 503 total attendees from 29 states. The conferences included two general sessions at the beginning and end of the day and three breakout tracks with presentations specific to children with TSC (Pediatric Track), transitioning from childhood to adulthood (Transition Track) and adult sessions for TSC and LAM (Adult Track). The opening session focused on research updates and upcoming clinical trials. Regional conferences provide much-needed forums for the growing number of people facing the challenges of TSC and LAM.

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.

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 session topics were selected based on hot topics that are applicable to the majority of TSC individuals and families and on international relevance.

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 27% and 22% for the years ended December 31, 2019 and 2018, respectively. 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.

National Tuberous Sclerosis Association & Affiliate

Notes to Consolidated Financial Statements

Note 1. Nature of Activities and Significant Accounting Policies (Continued)

A summary of significant accounting policies follows:

Principles of consolidation: The consolidated financial statements include the accounts of TS Alliance and the Endowment Fund (collectively referred to as the Alliance). Significant intra-entity transactions have been eliminated in consolidation.

Basis of accounting: The consolidated financial statements of the Alliance are presented on the accrual basis of accounting. Consequently, revenue, other than contributions, is recognized when earned and expense when obligations are incurred.

Basis of presentation: The Alliance follows the accounting requirements of the Not-for-Profit Entities topic of the Financial Accounting Standards Board (FASB) Accounting Standards Codification (ASC). Under the FASB ASC, the Alliance is required to report information regarding its net assets and its activities according to two categories: 1) net assets without donor restrictions and 2) net assets with donor restrictions.

Without donor restrictions: 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.

With donor restrictions: Net assets with donor restrictions include those net assets whose use is subject to donor-imposed restrictions. Donor restrictions may be for a specified time or purpose limitation or the donor may specify that the corpus of their original and certain subsequent gifts be maintained in perpetuity. Donor-imposed restrictions are released when a restriction expires, that is, when the stipulated time has elapsed, when the stipulated purpose for which the resource was restricted has been fulfilled, or both.

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.

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.

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.

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.

National Tuberous Sclerosis Association & Affiliate

Notes to Consolidated Financial Statements

Note 1. Nature of Activities and Significant Accounting Policies (Continued)

Investments: Investments with readily determinable fair values are reflected at fair market value. To adjust the carrying value of these investments, the change in fair market value is charged or credited to current operations net of related fees.

The Alliance invests in a professionally managed portfolio that contains various types of marketable securities. Such investments are exposed to market and credit risks and may be subject to significant fluctuations in fair value. As a result, the investment balances reported in the accompanying consolidated financial statements may not be reflective of the portfolio's value during subsequent periods.

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 years ended December 31, 2019 and 2018.

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. However, bad debt expense was \$0 for the years ended December 31, 2019 and 2018.

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.

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

Deferred revenue: The Alliance records deferred revenue in situations when amounts are paid in advance of the Alliance satisfying the applicable performance obligations. Such revenue is recognized when all performance obligations are complete. There were no significant changes in the timing of special events, contracts, and conferences that would affect the seasonality of deferred revenue.

National Tuberous Sclerosis Association & Affiliate

Notes to Consolidated Financial Statements

Note 1. Nature of Activities and Significant Accounting Policies (Continued)

Revenue and support: Revenue includes contracts and conferences because these are line items that have performance obligations and are considered contracts with customers. Support includes contributions, memorials and honorariums, and federated funding. Special events may include elements of both revenue and support.

Revenue from contracts with customers primarily includes performance obligations that are satisfied over time and most contracts have initial terms of one year or less. Prices are specific to a distinct performance obligation and contracts do not have multiple performance obligations. Economic factors driven by consumer confidence, employment, inflation, and other world events impact the timing and level of revenue recognized by the Alliance. Periods of economic downturn resulting from any of the above factors may result in declines in revenue recognized by the Alliance.

Special events: A portion of special event revenue relates to sponsorships, which are recognized as revenue at the point in time that the related events take place because the performance obligation is satisfied when the event occurs. In addition, the Alliance also has sponsorship bundles related to the approximately 30 events referred to as Step Forward to Cure TSC® which take place throughout the year. Revenue for these events is recognized as the events occur. Finally, the revenue associated with the costs of direct benefits to donors is recognized at the point in time that the related event takes place.

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 classified 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: The Alliance has several contracts for services with various terms to provide services to the TSC community. Contracts for services include 1) preclinical consortium participation fees, and 2) preclinical consortium testing of compounds that could be developed for future treatments. Contract revenue related to the preclinical consortium participation fees is recognized ratably over period of the contract which is usually one year. The performance obligations include allowing participating companies the opportunity to conduct approved studies and to share consortium data. Contract revenue related to preclinical consortium testing is recognized based upon the phases of the research testing and as reports are completed by the researchers.

Conferences: Conference registration are recognized at the point in time that the related conference takes place. Registration is generally collected in advance of the conference and recorded as deferred revenue until the conference occurs.

Functional allocation of expense: The costs of providing various program and supporting services have been summarized on a functional basis in the consolidated statements of activities. The statements of functional expense present the natural classification detail of expenses by function. Accordingly, rent, human resources, finance, information technology support, and depreciation and amortization. The costs are allocated among program services and supporting services activities based on either employee effort or direct costs.

National Tuberos Sclerosis Association & Affiliate

Notes to Consolidated Financial Statements

Note 1. Nature of Activities and Significant Accounting Policies (Continued)

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

Recent accounting pronouncements adopted: Financial Accounting Standards Board (FASB) Accounting Standards Update (ASU) 2014-09, *Revenue from Contracts with Customers* (ASU 2014-09) requires that the Alliance recognize the amount of revenue to which it expects to be entitled for the transfer of promised goods and services to customers. ASU 2014-09 replaces most existing revenue recognition guidance in GAAP. The ASU also requires expanded disclosures relating to the nature, amount, timing and uncertainty of revenue and cash flows from contracts from customers. The Alliance adopted the new standard, effective for the year ended December 31, 2019, using the full retrospective method. Special events, contracts, and conferences are those line items affected by this standard. Based on management's review of its contracts with customers, the timing of the amount of revenue recognized previously is consistent with how revenue is recognized under this new standard. Therefore, the adoption of this standard had no impact on the Alliance's consolidated financial statements but the standard does require additional disclosures.

In June 2018, FASB also issued ASU 2018-08, *Not-for-Profit Entities (Topic 958): Clarifying the Scope and the Accounting Guidance for Contributions Received and Contributions Made*. ASU 2018-08 clarifies the guidance for evaluating whether a transaction is reciprocal (an exchange transaction) or nonreciprocal (a contribution). ASU 2018-08 also provided guidance for distinguishing between conditional and unconditional contributions. The Alliance adopted the contributions received portion of the new standard effective for the year ended December 31, 2019, using the full retrospective method. The Alliance will adopt the contributions made portion of the new standard when it is required during the year ending December 31, 2020. Based on management's review of its contributions, the timing of the amount of contributions recognized previously is consistent with how contributions are recognized under this new standard. Therefore, the adoption of this standard had no impact on the Alliance's consolidated financial statements but the standard does require additional disclosures.

Upcoming accounting pronouncement: In February 2016, the FASB issued ASU 2016-02, *Leases (Topic 842)*. The guidance in this ASU supersedes the leasing guidance in Topic 840, *Leases*. Under the new guidance, lessees are required to recognize lease assets and lease liabilities on the balance sheet for all leases with terms longer than 12 months. Leases will be classified as either finance or operating with classification affecting the pattern of expense recognition in the statement of activities. The new standard is effective for the Alliance's year ending December 31, 2021. A modified retrospective transition approach is required for lessees for capital and operating leases existing at, or entered into after, the beginning of the earliest comparative period presented in the financial statements, with certain practical expedients available. The Alliance anticipates early adopting the new standard during the year ending December 31, 2020 and is currently evaluating the impact of the early adoption of the new standard on the consolidated financial statements.

National Tuberous Sclerosis Association & Affiliate

Notes to Consolidated Financial Statements

Note 2. Investments

The Alliance follows the accounting standards topic regarding fair value measurements, which establishes a framework for measuring fair value in accordance with U.S. GAAP and expands disclosures about fair value measurements. This standard uses the following prioritized input levels to measure fair value. 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 \$1,000,000 provided the financial institutions maintain an S&P rating of A or better.

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.

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

The fair values of corporate bonds were determined using Level 2 inputs which were determined by pricing vendors using outside data. In determining the fair value of the investments, the pricing vendors use a market approach and pricing spreads based on the credit risk of the issuer, maturity, current yield, and other terms and conditions of each fixed income security.

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.

National Tuberos Sclerosis Association & Affiliate

Notes to Consolidated Financial Statements

Note 2. Investments (Continued)

Investments consisted of the following at December 31, 2019:

	Total	Level 1	Level 2	Level 3
Investments, at fair value:				
Mutual funds:				
Bonds	\$ 36,076	\$ 36,076	\$ -	\$ -
Domestic equity	3,385,433	3,385,433	-	-
International equity	822,166	822,166	-	-
Exchange traded funds - fixed income	249,891	249,891	-	-
Preferred stock	69,063	69,063	-	-
Corporate bonds	920,927	-	920,927	-
Subtotal investments, at fair value	<u>5,483,556</u>	<u>4,562,629</u>	<u>920,927</u>	<u>-</u>
Investments, at cost:				
Money market funds	1,274,982			
Certificates of deposit	231,580			
Subtotal investments, at cost	<u>1,506,562</u>			
	<u>\$ 6,990,118</u>			

Investments consisted of the following at December 31, 2018:

	Total	Level 1	Level 2	Level 3
Investments, at fair value:				
Mutual funds:				
Bonds	\$ 1,003,304	\$ 1,003,304	\$ -	\$ -
Domestic equity	2,770,619	2,770,619	-	-
International equity	696,549	696,549	-	-
Exchange traded funds - fixed income	439,992	439,992	-	-
Subtotal investments, at fair value	<u>4,910,464</u>	<u>4,910,464</u>	<u>-</u>	<u>-</u>
Investments, at cost:				
Money market funds	1,072,156			
Certificates of deposit	227,323			
Subtotal investments, at cost	<u>1,299,479</u>			
	<u>\$ 6,209,943</u>			

National Tuberous Sclerosis Association & Affiliate

Notes to Consolidated Financial Statements

Note 2. Investments (Continued)

Investment return consisted of the following for the years ended December 31:

	2019	2018
Interest and dividends	\$ 191,528	\$ 142,146
Investment income (loss):		
Net gain (loss) on investments	795,419	(569,269)
Investment management fees (donated)	(27,856)	(27,226)
	<u>767,563</u>	<u>(596,495)</u>
	<u>\$ 959,091</u>	<u>\$ (454,349)</u>

Note 3. Promises to Give

Promises to give consisted of the following at December 31:

	2019	2018
Amounts due in less than one year	\$ 851,296	\$ 913,638
Amounts due in one to five years	1,285,450	367,000
	<u>2,136,746</u>	<u>1,280,638</u>
Less discount to net present value	(103,120)	(30,932)
	<u>\$ 2,033,626</u>	<u>\$ 1,249,706</u>

Note 4. 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 2 and include both donor-restricted and board-designated funds.

National Tuberous Sclerosis Association & Affiliate

Notes to Consolidated Financial Statements

Note 4. Liquidity (Continued)

The following provides a summary of financial assets available for general expenditures within one year at December 31:

	2019	2018
Financial assets:		
Cash and cash equivalents	\$ 1,045,437	\$ 1,304,824
Investments	6,990,118	6,209,943
Accounts receivable	10,243	158,782
Promises to give	2,033,626	1,249,706
Subtotal financial assets	<u>10,079,424</u>	<u>8,923,255</u>
Less amounts not available for general expenditures:		
Investments held to fund charitable gift annuity	(73,913)	(66,502)
Board-designated net assets	(5,936,709)	(4,789,541)
Unused transfers to undesignated net assets *	665,500	621,500
Net assets with donor restrictions	<u>(4,034,240)</u>	<u>(3,654,811)</u>
	<u>\$ 700,062</u>	<u>\$ 1,033,901</u>

* As disclosed in Note 8, TS Alliance does not utilize all of the funds authorized to be transferred to undesignated net assets. As of December 31, 2019 and 2018, the accumulated amount authorized but unused totaled \$441,500 and \$399,500, respectively. In addition, the Endowment Fund authorized a contribution of \$224,000 to TS Alliance for the year ending December 31, 2020.

Note 5. Property and Equipment

Property and equipment consisted of the following at December 31:

	2019	2018
Software	\$ 79,231	\$ 118,056
Office equipment and furniture	155,880	155,880
Leasehold improvements	156,545	156,545
	<u>391,656</u>	<u>430,481</u>
Less accumulated depreciation and amortization	(311,435)	(261,135)
	<u>\$ 80,221</u>	<u>\$ 169,346</u>

Note 6. 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.

National Tuberosclerosis Association & Affiliate

Notes to Consolidated Financial Statements

Note 6. Gift Annuity Obligations (Continued)

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 \$70,300 and \$73,943 at December 31, 2019 and 2018, respectively.

Note 7. Net Assets

Without donor restrictions: Net assets without donor restrictions consisted of the following at December 31:

	2019	2018
Undesignated (deficit)	\$ (214,362)	\$ 235,336
Board-designated:		
Endowment fund	5,036,361	4,387,039
Grant commitments	900,348	402,502
	<u>\$ 5,722,347</u>	<u>\$ 5,024,877</u>

With donor restrictions: Net assets with donor restrictions consisted of the following as of and for the year ended December 31, 2019:

	Balance at January 1, 2019	Contributions and Investment Return	Net Assets Released from Restrictions	Balance at December 31, 2019
Research:				
General	\$ 170,602	\$ 388,944	\$ (430,062)	\$ 129,484
Biorepository	627,116	1,127,951	(485,844)	1,269,223
Preclinical consortium	1,194,464	167,455	(859,100)	502,819
Clinical research consortium	166,246	316,228	(100,235)	382,239
Child epilepsy research	150,000	-	(50,000)	100,000
Bcureful travel fund	-	100,250	(50,000)	50,250
New initiatives - 45th gala	-	137,205	-	137,205
Hall fund	100,075	4,635	(104,710)	-
Indirect costs	170,360	259,172	(80,568)	348,964
Subtotal research	<u>2,578,863</u>	<u>2,501,840</u>	<u>(2,160,519)</u>	<u>2,920,184</u>
Endowment fund	806,895	137,526	(64,977)	879,444
Public education	116,386	29,000	(68,401)	76,985
TSC International	87,167	67,500	(50,040)	104,627
Family services	65,500	87,000	(99,500)	53,000
	<u>\$ 3,654,811</u>	<u>\$ 2,822,866</u>	<u>\$ (2,443,437)</u>	<u>\$ 4,034,240</u>

National Tuberos Sclerosis Association & Affiliate

Notes to Consolidated Financial Statements

Note 7. Net Assets (Continued)

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 and Investment Return	Net Assets Released from Restrictions	Balance at December 31, 2018
Research:				
General	\$ 144,275	\$ 444,733	\$ (418,406)	\$ 170,602
Biorepository	850,199	51,918	(275,001)	627,116
Preclinical consortium	1,045,340	604,203	(455,079)	1,194,464
Clinical research consortium	-	166,246	-	166,246
Hall fund	221,749	8,681	(130,355)	100,075
Child epilepsy research	150,000	-	-	150,000
Indirect costs	129,276	146,084	(105,000)	170,360
Subtotal research	<u>2,540,839</u>	<u>1,421,865</u>	<u>(1,383,841)</u>	<u>2,578,863</u>
Endowment fund	879,444	(68,315)	(4,234)	806,895
Public education	76,421	86,500	(46,535)	116,386
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)	-
	<u>\$ 3,579,716</u>	<u>\$ 1,660,213</u>	<u>\$ (1,585,118)</u>	<u>\$ 3,654,811</u>

Note 8. 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.

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.

National Tuberous Sclerosis Association & Affiliate

Notes to Consolidated Financial Statements

Note 8. Endowment Funds (Continued)

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 \$222,000 and \$285,000 during the years ended December 31, 2019 and 2018, respectively. The actual contributions to TS Alliance totaled \$180,000 and \$50,000 during the years ended December 31, 2019 and 2018, respectively.

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 to be transferred to undesignated net assets. As of December 31, 2019 and 2018, the accumulated amount authorized but unused totaled \$441,500 and \$399,500, respectively. In addition, the Endowment Fund authorized a contribution of \$224,000 to TS Alliance for the year ending December 31, 2020.

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, 2019 and 2018, the endowments had a total deficiency of \$0 and \$72,549, respectively.

Endowment funds consisted of the following at December 31:

		2019				
		With Donor Restrictions				
	Without Donor Restrictions	Available for Spending	Held in Perpetuity	Total	Total	
Board-designated	\$ 5,036,361	\$ -	\$ -	\$ -	\$ 5,036,361	
Donor-restricted	-	-	879,444	879,444	879,444	
	<u>\$ 5,036,361</u>	<u>\$ -</u>	<u>\$ 879,444</u>	<u>\$ 879,444</u>	<u>\$ 5,915,805</u>	
		2018				
		With Donor Restrictions				
	Without Donor Restrictions	Available for Spending	Held in Perpetuity	Total	Total	
Board-designated	\$ 4,387,039	\$ -	\$ -	\$ -	\$ 4,387,039	
Donor-restricted	-	-	806,895	806,895	806,895	
	<u>\$ 4,387,039</u>	<u>\$ -</u>	<u>\$ 806,895</u>	<u>\$ 806,895</u>	<u>\$ 5,193,934</u>	

National Tuberos Sclerosis Association & Affiliate

Notes to Consolidated Financial Statements

Note 8. Endowment Funds (Continued)

Changes in the endowment funds consisted of the following as of and for the year ended December 31, 2019:

	2019				
	Without Donor Restrictions	With Donor Restrictions			Total
		Available for Spending	Held in Perpetuity	Total	
Balance at January 1, 2019	\$ 4,387,039	\$ -	\$ 806,895	\$ 806,895	\$ 5,193,934
Contributions	78,962	-	-	-	78,962
Investment return:					
Interest and dividends	140,556	11,116	12,412	23,528	164,084
Net gain on investments	681,039	53,861	60,137	113,998	795,037
Investment management fees	(23,862)	(3,994)	-	(3,994)	(27,856)
	797,733	60,983	72,549	133,532	931,265
Appropriations and transfers:					
Appropriation per spending policy	(180,000)	-	-	-	(180,000)
Program and supporting services	(47,373)	(60,983)	-	(60,983)	(108,356)
Change in endowment fund net assets	649,322	-	72,549	72,549	721,871
Balance at December 31, 2019	\$ 5,036,361	\$ -	\$ 879,444	\$ 879,444	\$ 5,915,805

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

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

National Tuberous Sclerosis Association & Affiliate

Notes to Consolidated Financial Statements

Note 9. 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 the following for the years ended December 31:

	2019	2018
Donated goods	\$ 6,639	\$ 15,016
Donated services:		
Research	121,090	5,400
Event and advertising services	37,174	20,082
Investment management	27,856	27,226
	<u>\$ 192,759</u>	<u>\$ 67,724</u>

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.

Note 10. Allocation of Joint Costs

The Alliance incurred joint costs relating to the Family services program. This program service activity, specifically the series of Step Forward to Cure TSC Walks, included both program content and appeals for contributions. Therefore, joint costs allocated between program and supporting services amounted to \$79,826 and \$73,440 during the years ended December 31, 2019 and 2018, respectively.

Joint costs were allocated to the following activities for the years ended December 31:

	2019	2018
Family services	\$ 39,913	\$ 36,720
Fundraising	39,913	36,720
	<u>\$ 79,826</u>	<u>\$ 73,440</u>

National Tuberous Sclerosis Association & Affiliate

Notes to Consolidated Financial Statements

Note 11. Professional Fees

Professional fees consisted of the following for the years ended December 31:

	2019	2018
Professional fundraising consulting	\$ 160,000	\$ -
Government relations consulting	110,760	108,084
Marketing consulting	73,921	59,203
Website	54,853	26,459
Legal fees	36,440	43,506
Audit and tax preparation fees	30,895	25,500
Events production consulting	26,500	26,500
Recruiting and payroll fees	13,183	25,255
Other consulting	13,140	15,737
Temporary staffing fees	10,980	3,126
Video production expense	10,500	35,226
	<u>\$ 541,172</u>	<u>\$ 368,596</u>

Note 12. 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 \$51,965 and \$47,037 for the years ended December 31, 2019 and 2018, respectively.

Note 13. Related Party Transactions

Board of Directors: The Alliance has authorized research grants and natural history 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 and natural history database charges provided to such institutions totaled \$196,272 and \$61,495 during the years ended December 31, 2019 and 2018, respectively.

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 agreements stipulate 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 included in the accompanying consolidated financial statements.

National Tuberosclerosis Association & Affiliate

Notes to Consolidated Financial Statements

Note 14. Commitments and Contingencies

Grant commitments: The Alliance's Board of Directors has authorized research grants totaling \$900,348 and \$402,502 as of December 31, 2019 and 2018 respectively. The research grants extend through 2023 and payment of the grants to awardees is contingent upon (1) a positive review by the Grant Review Committee and (2) sufficient funding availability in the year of the research grant. Therefore, no liability has been recorded relating to the research grants. The grant commitments have been included within board-designated net assets and, if the contingencies are met, will be payable as follows:

	<u>Amount</u>
Year ending December 31,	
2020	\$ 559,371
2021	226,159
2022	57,409
2023	57,409
	<u>\$ 900,348</u>

The Alliance intends to adopt the contributions made provisions of ASU 2018-08, which is related to grants, during the year ending December 31, 2020. ASU 2018-08 clarified the conditional nature of both contributions received and contributions made and indicates that a conditional contribution exists only when the following two elements are present in the terms of a written agreement: 1) a measurable barrier that must be overcome and 2) a right of return in the event of non-performance.

Office leases: The Alliance's operating lease for its current office space 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, 2019 and 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.

GAAP requires that the cost of the build-out be capitalized and depreciated or amortized as property and equipment. 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 \$7,176 and \$35,378 and as of December 31, 2019 and 2018, respectively.

Rent expense related to the current operating lease totaled \$92,966 and \$97,207 for the years ended December 31, 2019 and 2018, respectively.

During August 2019, the Alliance signed a new operating lease for office space in a different building. The new lease commencement date is expected to be April 1, 2020. The new office lease expires March 31, 2031, and includes twelve months rent abatement plus a tenant improvement allowance of approximately \$414,000.

National Tuberous Sclerosis Association & Affiliate

Notes to Consolidated Financial Statements

Note 14. Commitments and Contingencies (Continued)

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

	Current Lease	New Lease	Total
Years ending December 31,			
2020	\$ 25,708	\$ -	\$ 25,708
2021	-	137,872	137,872
2022	-	154,258	154,258
2023	-	158,501	158,501
2024	-	162,859	162,859
Thereafter	-	1,123,873	1,123,873
	<u>\$ 25,708</u>	<u>\$ 1,737,363</u>	<u>\$ 1,763,071</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.

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 15. Subsequent Events

Subsequent events have been evaluated through April 22, 2020, which is the date the consolidated financial statements were available to be issued.

On January 30, 2020, the World Health Organization declared the coronavirus outbreak (COVID-19) a "Public Health Emergency of International Concern" and on March 10, 2020, declared COVID-19 a pandemic. The impact of COVID-19 could negatively impact TS Alliance's operations, suppliers or vendors, and donor or customer base. The extent to which the coronavirus impacts TS Alliance's results will depend on future developments, which are highly uncertain and cannot be predicted, including new information which may emerge concerning the severity of the coronavirus and actions taken to contain the coronavirus or its impact, among other factors.

Fair value of investments: Subsequent to December 31, 2019, the financial markets experienced a high degree of volatility as a result of the pandemic. Therefore, the investment balances presented in the accompanying consolidated financial statements do not include subsequent increases or decreases in fair value due to fluctuations in the financial markets.

Events postponed: One of the Alliance's events, which is referred to as Comedy for a Cure, was originally scheduled to occur on April 5, 2020. However, due to the pandemic, the event has been postponed until later in the year. In addition, 16 Step Forward to Cure TSC Walks have been rescheduled to September through November 2020. The National Walk on the Mall in Washington DC will become a virtual walk, taking place in late summer 2020. The impact on the Alliance's operations in 2020 resulting from either lost revenue or unrecoverable costs incurred leading up to the event has not yet been estimated.



RSM US LLP

Independent Auditor's Report

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, 2019, and have issued our report thereon dated April 22, 2020, which contained an unmodified opinion on those consolidated financial statements. Our audit was performed 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.

RSM US LLP

Washington, DC
April 22, 2020

National Tuberos Sclerosis Association & Affiliate

**Consolidating Statements of Financial Position
December 31, 2019 and 2018**

	TS Alliance	Endowment Fund	Eliminations	Total
Assets				
Cash and cash equivalents	\$ 1,015,924	\$ 29,513	\$ -	\$ 1,045,437
Investments	1,048,123	5,941,995	-	6,990,118
Due from affiliate	-	3,996	(3,996)	-
Accounts receivable	10,243	-	-	10,243
Promises to give	2,033,626	-	-	2,033,626
Prepaid expenses and other assets	251,370	11,250	-	262,620
Interest in net assets of affiliate	5,915,805	-	(5,915,805)	-
Property and equipment	80,221	-	-	80,221
Total assets	\$ 10,355,312	\$ 5,986,754	\$ (5,919,801)	\$ 10,422,265
Liabilities and Net Assets				
Liabilities:				
Accounts payable and accrued expenses	\$ 332,547	\$ 649	\$ -	\$ 333,196
Due to affiliate	3,996	-	(3,996)	-
Accrued compensation	200,306	-	-	200,306
Deferred revenue	54,700	-	-	54,700
Deferred rent and lease incentive	7,176	-	-	7,176
Gift annuity obligations	-	70,300	-	70,300
Total liabilities	598,725	70,949	(3,996)	665,678
Net assets:				
Without donor restrictions:				
Undesignated (deficit)	(214,362)	-	-	(214,362)
Board-designated	5,936,709	5,036,361	(5,036,361)	5,936,709
Total net assets without donor restrictions	5,722,347	5,036,361	(5,036,361)	5,722,347
With donor restrictions:	4,034,240	879,444	(879,444)	4,034,240
Total net assets	9,756,587	5,915,805	(5,915,805)	9,756,587
Total liabilities and net assets	\$ 10,355,312	\$ 5,986,754	\$ (5,919,801)	\$ 10,422,265

National Tuberosclerosis Association & Affiliate

Consolidating Statement of Activities
Year Ended December 31, 2019

	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	\$ 2,318,140	\$ 388,454	\$ 2,706,594	\$ -	\$ -	\$ -	\$ -	\$ -	\$ -	\$ 2,318,140	\$ 388,454	\$ 2,706,594
Costs of direct benefits to donors	(285,156)	-	(285,156)	-	-	-	-	-	-	(285,156)	-	(285,156)
Special events, net	2,032,984	388,454	2,421,438	-	-	-	-	-	-	2,032,984	388,454	2,421,438
Contributions	837,653	2,296,500	3,134,153	67,779	-	67,779	(180,000)	-	(180,000)	725,432	2,296,500	3,021,932
Contracts	247,384	-	247,384	-	-	-	-	-	-	247,384	-	247,384
Interest and dividends	27,444	-	27,444	140,556	23,528	164,084	-	-	-	168,000	23,528	191,528
Conferences	174,381	-	174,381	-	-	-	-	-	-	174,381	-	174,381
Memorials and honorariums	100,869	386	101,255	995	-	995	-	-	-	101,864	386	102,250
Federated funding	35,476	-	35,476	10,188	-	10,188	-	-	-	45,664	-	45,664
Other income	714	-	714	-	-	-	-	-	-	714	-	714
	3,456,905	2,685,340	6,142,245	219,518	23,528	243,046	(180,000)	-	(180,000)	3,496,423	2,708,868	6,205,291
Net assets released from restrictions	2,378,460	(2,378,460)	-	64,977	(64,977)	-	-	-	-	2,443,437	(2,443,437)	-
Total revenue and support	5,835,365	306,880	6,142,245	284,495	(41,449)	243,046	(180,000)	-	(180,000)	5,939,860	265,431	6,205,291
Expense:												
Program services:												
Research	2,590,463	-	2,590,463	-	-	-	-	-	-	2,590,463	-	2,590,463
Family services	929,277	-	929,277	-	-	-	-	-	-	929,277	-	929,277
Public health education	438,744	-	438,744	1,248	-	1,248	-	-	-	439,992	-	439,992
Government relations	165,225	-	165,225	-	-	-	-	-	-	165,225	-	165,225
Professional education	92,979	-	92,979	-	-	-	-	-	-	92,979	-	92,979
Contribution to TS Alliance	-	-	-	180,000	-	180,000	(180,000)	-	(180,000)	-	-	-
Total program services	4,216,688	-	4,216,688	181,248	-	181,248	(180,000)	-	(180,000)	4,217,936	-	4,217,936
Supporting services:												
Fundraising	1,048,641	-	1,048,641	86,968	-	86,968	-	-	-	1,135,609	-	1,135,609
Management and general	522,270	-	522,270	20,140	-	20,140	-	-	-	542,410	-	542,410
Total supporting services	1,570,911	-	1,570,911	107,108	-	107,108	-	-	-	1,678,019	-	1,678,019
Total expense	5,787,599	-	5,787,599	288,356	-	288,356	(180,000)	-	(180,000)	5,895,955	-	5,895,955
Change in net assets from operations	47,766	306,880	354,646	(3,861)	(41,449)	(45,310)	-	-	-	43,905	265,431	309,336
Investment income	382	-	382	653,183	113,998	767,181	-	-	-	653,565	113,998	767,563
Change in interest in affiliate	649,322	72,549	721,871	-	-	-	(649,322)	(72,549)	(721,871)	-	-	-
Change in net assets	697,470	379,429	1,076,899	649,322	72,549	721,871	(649,322)	(72,549)	(721,871)	697,470	379,429	1,076,899
Net assets, January 1, 2019	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
Net assets, December 31, 2019	\$ 5,722,347	\$ 4,034,240	\$ 9,756,587	\$ 5,036,361	\$ 879,444	\$ 5,915,805	\$ (5,036,361)	\$ (879,444)	\$ (5,915,805)	\$ 5,722,347	\$ 4,034,240	\$ 9,756,587