

National Tuberous Sclerosis Association (d/b/a TSC Alliance) and Affiliate

Consolidated Financial Report
December 31, 2021

Contents

Independent auditor's report	1 - 2
------------------------------	-------

Financial statements	
Consolidated statements of financial position	3
Consolidated statements of activities	4
Consolidated statements of functional expenses	5-6
Consolidated statements of cash flows	7
Notes to the consolidated financial statements	8-26

Independent auditor's report on the supplementary information	27
---	----

Supplementary information	
Consolidating statements of financial position	28
Consolidating statement of activities	29

Independent Auditor's Report

Board of Directors
National Tuberous Sclerosis Association (d/b/a TSC Alliance)

Opinion

We have audited the consolidated financial statements of National Tuberous Sclerosis Association (d/b/a TSC Alliance) and Affiliate (collectively, the Alliance), which comprise the consolidated statements of financial position as of December 31, 2021 and 2020, the related consolidated statements of activities, functional expenses and cash flows for the years then ended, and the related notes to the consolidated financial statements (collectively, the financial statements).

In our opinion, the accompanying financial statements present fairly, in all material respects, the financial position of the Alliance as of December 31, 2021 and 2020, and the changes in their net assets and their cash flows for the years then ended in accordance with accounting principles generally accepted in the United States of America.

Basis for Opinion

We conducted our audits in accordance with auditing standards generally accepted in the United States of America (GAAS). Our responsibilities under those standards are further described in the Auditor's Responsibilities for the Audit of the Financial Statements section of our report. We are required to be independent of the Alliance and to meet our other ethical responsibilities, in accordance with the relevant ethical requirements relating to our audits. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Responsibilities of Management for the Financial Statements

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

In preparing the financial statements, management is required to evaluate whether there are conditions or events, considered in the aggregate, that raise substantial doubt about the Alliance's ability to continue as a going concern within one year after the date that the financial statements are issued (or within one year after the date that the financial statements are available to be issued when applicable).

Auditor's Responsibilities for the Audit of the Financial Statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not absolute assurance and therefore is not a guarantee that an audit conducted in accordance with GAAS will always detect a material misstatement when it exists. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control. Misstatements are considered material if there is a substantial likelihood that, individually or in the aggregate, they would influence the judgment made by a reasonable user based on the financial statements.

In performing an audit in accordance with GAAS, we:

- Exercise professional judgment and maintain professional skepticism throughout the audit.
- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, and design and perform audit procedures responsive to those risks. Such procedures include examining, on a test basis, evidence regarding the amounts and disclosures in the financial statements.
- Obtain an understanding of internal control relevant to the audit 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, no such opinion is expressed.
- Evaluate the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluate the overall presentation of the financial statements.
- Conclude whether, in our judgment, there are conditions or events, considered in the aggregate, that raise substantial doubt about the Alliance's ability to continue as a going concern for a reasonable period of time.

We are required to communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit, significant audit findings and certain internal control-related matters that we identified during the audit.

RSM US LLP

Washington, D.C.
April 8, 2022

National Tuberosus Sclerosis Association (d/b/a TSC Alliance) and Affiliate

**Consolidated Statements of Financial Position
December 31, 2021 and 2020**

	2021	2020
Assets		
Cash and cash equivalents	\$ 2,843,269	\$ 2,370,947
Investments	6,691,013	5,913,426
Accounts receivable	99,173	113,491
Promises to give, net	2,698,495	1,578,285
Prepaid expenses and other assets	620,148	403,498
Operating lease right of use asset, net	778,371	833,830
Property and equipment, net	437,169	510,367
	<u>2,843,269</u>	<u>5,913,426</u>
Total assets	<u>\$14,167,638</u>	<u>\$11,723,844</u>
Liabilities and Net Assets		
Liabilities:		
Accounts payable and accrued expenses	\$ 186,010	\$ 181,331
Accrued compensation	290,487	254,553
Deferred revenue	676,798	422,226
Operating lease liability, net	1,285,691	1,336,433
Gift annuity obligations, net	119,665	66,740
Total liabilities	<u>2,558,651</u>	<u>2,261,283</u>
Commitments and contingencies (Note 16)		
Net assets:		
Without donor restrictions:		
Undesignated (deficit)	(20,618)	189,609
Board-designated	6,601,224	5,764,868
Total net assets without donor restrictions	<u>6,580,606</u>	<u>5,954,477</u>
With donor restrictions	5,028,381	3,508,084
Total net assets	<u>11,608,987</u>	<u>9,462,561</u>
Total liabilities and net assets	<u>\$14,167,638</u>	<u>\$11,723,844</u>

See notes to the consolidated financial statements.

National Tuberosus Sclerosis Association (d/b/a TSC Alliance) and Af

Consolidated Statements of Activities Years Ended December 31, 2021 and 2020

	2021			2020		
	Without Donor Restrictions	With Donor Restrictions	Total	Without Donor Restrictions	With Donor Restrictions	Total
Revenue and support:						
Special events	\$ 1,169,138	\$ 55,434	\$ 1,224,572	\$ 1,160,425	\$ 126,886	\$ 1,287,311
Costs of direct benefits to donors	(46,439)	-	(46,439)	(59,986)	-	(59,986)
Special events, net	1,122,699	55,434	1,178,133	1,100,439	126,886	1,227,325
Contributions:						
Individuals, companies and foundations	1,198,857	3,330,407	4,529,264	1,353,452	1,422,050	2,775,502
Memorials and honorariums	135,221	1,018	136,239	107,148	2,949	110,097
Federated funding	54,696	-	54,696	38,743	-	38,743
Contracts	2,120,485	-	2,120,485	791,210	-	791,210
Interest and dividends	108,717	18,843	127,560	113,341	17,838	131,179
Conferences	113,777	-	113,777	1,475	-	1,475
Net assets released from restrictions	2,026,987	(2,026,987)	-	2,139,948	(2,139,948)	-
Total revenue and support	6,881,439	1,378,715	8,260,154	5,645,756	(570,225)	5,075,531
Expenses:						
Program services:						
Research	3,939,924	-	3,939,924	2,591,582	-	2,591,582
Family services	726,768	-	726,768	765,051	-	765,051
Public health education	524,284	-	524,284	503,125	-	503,125
Government relations	154,139	-	154,139	149,610	-	149,610
Professional education	122,600	-	122,600	24,320	-	24,320
Total program services	5,467,715	-	5,467,715	4,033,688	-	4,033,688
Supporting services:						
Fundraising	990,443	-	990,443	1,085,941	-	1,085,941
Management and general	549,013	-	549,013	517,311	-	517,311
Total supporting services	1,539,456	-	1,539,456	1,603,252	-	1,603,252
Total expenses	7,007,171	-	7,007,171	5,636,940	-	5,636,940
Change in net assets before other item	(125,732)	1,378,715	1,252,983	8,816	(570,225)	(561,409)
Realized and unrealized gain on investments, net of fees	751,861	141,582	893,443	223,314	44,069	267,383
Change in net assets	626,129	1,520,297	2,146,426	232,130	(526,156)	(294,026)
Net assets:						
Beginning	5,954,477	3,508,084	9,462,561	5,722,347	4,034,240	9,756,587
Ending	\$ 6,580,606	\$ 5,028,381	\$ 11,608,987	\$ 5,954,477	\$ 3,508,084	\$ 9,462,561

See notes to the consolidated financial statements.

National Tuberos Sclerosis Association (d/b/a TSC Alliance) and Affiliate

**Consolidated Statement of Functional Expenses
Year Ended December 31, 2021**

	Program Services					Supporting Services		Total
	Research	Family Services	Public Health Education	Government Relations	Professional Education	Fundraising	Management and General	
Salaries	\$ 572,478	\$ 439,104	\$ 183,117	\$ 26,818	\$ 59,961	\$ 431,681	\$ 326,854	\$ 2,040,013
Preclinical consortium	1,824,180	-	-	-	-	-	-	1,824,180
Grants	735,827	-	-	-	-	-	-	735,827
Professional fees	24,149	68,798	160,656	113,137	207	196,736	76,028	639,711
Employee benefits and payroll taxes	103,865	104,976	36,519	6,633	9,387	95,878	58,669	415,927
Clinical research consortium	212,409	-	-	-	-	-	-	212,409
Biosample repository	199,194	-	-	-	-	-	-	199,194
Equipment maintenance and rental	61,721	21,075	7,371	1,398	1,844	64,341	26,274	184,024
Operating lease	31,047	32,777	11,432	2,169	2,860	30,185	17,669	128,139
Printing and promotion	243	6,276	86,815	826	1,482	27,983	305	123,930
Training, conferences and exhibits	45,979	(2,454)	36	7	33,062	162	55	76,847
Depreciation and amortization	31,664	11,838	5,039	793	1,046	16,354	6,464	73,198
Natural history database	67,091	-	-	-	-	-	-	67,091
Telephone	13,281	12,887	13,353	456	1,486	12,849	6,672	60,984
Postage and shipping	2,481	11,363	13,537	369	1,129	22,853	1,385	53,117
Dues, fees and subscriptions	10,229	12,335	3,291	1,270	2,855	6,132	15,796	51,908
Costs of direct benefit to donors	-	-	-	-	-	46,439	-	46,439
Other expense	338	3,498	1,927	24	31	34,836	1,904	42,558
Bank, credit card and transaction fees	18	21	31	1	1	39,741	1,793	41,606
Insurance	2,737	2,852	1,008	191	252	2,624	4,403	14,067
Travel	549	785	73	32	6,977	3,783	1,692	13,891
Supplies	444	637	79	15	20	4,305	1,402	6,902
Board and committee meetings	-	-	-	-	-	-	1,648	1,648
	3,939,924	726,768	524,284	154,139	122,600	1,036,882	549,013	7,053,610
Less costs of direct benefit to donors	-	-	-	-	-	(46,439)	-	(46,439)
Total functional expenses	\$ 3,939,924	\$ 726,768	\$ 524,284	\$ 154,139	\$ 122,600	\$ 990,443	\$ 549,013	\$ 7,007,171

See notes to the consolidated financial statements.

National Tuberos Sclerosis Association (d/b/a TSC Alliance) and Affiliate

**Consolidated Statement of Functional Expenses
Year Ended December 31, 2020**

	Program Services					Supporting Services		Total
	Research	Family Services	Public Health Education	Government Relations	Professional Education	Fundraising	Management and General	
Salaries	\$ 590,959	\$ 373,681	\$ 201,260	\$ 22,005	\$ 17,207	\$ 440,540	\$ 322,071	\$ 1,967,723
Preclinical consortium	815,227	-	-	-	-	-	-	815,227
Grants	553,241	5,000	-	-	-	-	-	558,241
Professional fees	10,611	33,973	153,459	113,285	205	290,041	59,516	661,090
Employee benefits and payroll taxes	101,554	95,125	45,644	4,593	3,003	105,141	60,009	415,069
Clinical research consortium	127,550	-	-	-	-	-	-	127,550
Biosample repository	98,230	-	-	-	-	-	-	98,230
Equipment maintenance and rental	44,774	25,811	12,203	1,173	826	25,751	24,063	134,601
Operating lease	28,790	27,443	13,020	1,364	960	30,312	17,454	119,343
Printing and promotion	525	21,980	39,064	946	-	41,610	273	104,398
Training, conferences and exhibits	263	52,520	441	304	24	76	44	53,672
Depreciation and amortization	31,094	10,140	5,022	511	359	16,679	6,541	70,346
Natural history database	109,958	-	-	-	-	-	-	109,958
Telephone	9,966	9,397	13,296	265	187	9,117	3,973	46,201
Postage and shipping	1,005	13,673	10,485	415	27	25,000	1,446	52,051
Dues, fees and subscriptions	7,799	9,279	2,342	1,225	105	19,935	3,109	43,794
Costs of direct benefit to donors	-	-	-	-	-	59,986	-	59,986
Other expense	48,766	1,812	111	12	8	35,048	1,229	86,986
Bank, credit card and transaction fees	1	2	-	-	-	34,719	1,809	36,531
Insurance	1,954	1,837	884	93	65	2,032	3,811	10,676
Travel	8,529	82,394	5,383	3,331	1,328	8,257	664	109,886
Supplies	786	984	511	88	16	1,683	1,594	5,662
Board and committee meetings	-	-	-	-	-	-	9,705	9,705
	2,591,582	765,051	503,125	149,610	24,320	1,145,927	517,311	5,696,926
Less costs of direct benefit to donors	-	-	-	-	-	(59,986)	-	(59,986)
Total functional expenses	\$ 2,591,582	\$ 765,051	\$ 503,125	\$ 149,610	\$ 24,320	\$ 1,085,941	\$ 517,311	\$ 5,636,940

See notes to the consolidated financial statements.

National Tuberosus Sclerosis Association (d/b/a TSC Alliance) and Affiliate

**Consolidated Statements of Cash Flows
Years Ended December 31, 2021 and 2020**

	2021	2020
Cash flows from operating activities:		
Change in net assets	\$ 2,146,426	\$ (294,026)
Adjustments to reconcile change in net assets to net cash provided by operating activities:		
Realized and unrealized gain on investments	(931,698)	(297,022)
Discount on promises to give	45,934	(5,489)
Depreciation and amortization of property and equipment	73,198	70,346
Amortization of operating lease right of use asset, net	55,459	41,873
Establish operating lease right of use asset	-	(875,703)
Establish operating lease liability	-	1,282,575
Discount on new gift annuity	(45,990)	-
Change in value of gift annuity obligations	11,445	8,970
Change in assets and liabilities:		
(Increase) decrease:		
Accounts receivable	14,318	(103,248)
Promises to give	(1,166,144)	460,830
Prepaid expenses and other assets	(216,650)	(140,878)
Increase (decrease):		
Accounts payable and accrued expenses	4,679	(151,865)
Accrued compensation	35,934	54,247
Deferred revenue	254,572	367,526
Operating lease liability	(50,742)	46,682
Net cash provided by operating activities	230,741	464,818
Cash flows from investing activities:		
Proceeds from sales and maturities of investments	276,000	1,225,107
Purchases of investments	(121,889)	(899,516)
Purchases of property and equipment	-	(500,492)
Net cash provided by (used in) investing activities	154,111	(174,901)
Cash flows from financing activities:		
Proceeds from forgivable loans	380,595	371,820
Extinguishment of debt via forgiveness	(380,595)	(371,820)
Proceeds from new gift annuity	100,000	-
Payments on gift annuity obligations	(12,530)	(12,530)
Net cash provided by (used in) financing activities	87,470	(12,530)
Net increase in cash and cash equivalents	472,322	277,387
Cash and cash equivalents:		
Beginning	2,370,947	2,093,560
Ending	\$ 2,843,269	\$ 2,370,947
Supplemental disclosures of noncash investing activities:		
Acquisition of leasehold improvements via lease incentive	\$ -	\$ 414,048
Donated securities	\$ 250,515	\$ 87,545

See notes to the consolidated financial statements.

National Tuberous Sclerosis Association (d/b/a TSC Alliance) and Affiliate

Notes to Consolidated Financial Statements

Note 1. Nature of Activities and Significant Accounting Policies

Nature of activities: National Tuberous Sclerosis Association (d/b/a TSC Alliance) is a nonprofit organization incorporated in the state of California on March 15, 1975. TSC Alliance is dedicated to finding a cure for tuberous sclerosis complex (TSC) while improving the lives of those affected through accelerating research, improving access and quality of care, supporting and empowering constituents, educating and mobilizing to increase investment and building and strengthening organization. During the June 2020 meeting of TSC Alliance's Board of Directors, a motion was approved to change the doing business as (d/b/a) name from Tuberous Sclerosis Alliance to TSC Alliance. On March 23, 2021, TSC Alliance filed for a trade name change with the State of Maryland in accordance with the location of the national office. The trade name change was officially rolled out for use during May 2021.

TSC Alliance Endowment Fund, Inc. (the Endowment Fund) is a nonprofit 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 TSC Alliance. During the March 2021 meeting of the Endowment Fund's Board of Directors, a motion was approved to amend the articles of incorporation to change the legal name from Tuberous Sclerosis Alliance Endowment Fund, Inc. to TSC Alliance Endowment Fund, Inc. The Endowment Fund's articles of amendment related to the name change were approved by the state of Maryland on March 19, 2021.

Program services include the following activities:

Research: The research program stimulates and supports basic, translational and clinical research on the various manifestations of TSC to further the development of clinical therapies and, ultimately, a cure for TSC. The research program builds and fosters collaborations between basic and clinical researchers by collecting and distributing TSC natural history data and biosamples through collaborative preclinical and clinical research programs, and by hosting biennial International TSC Research Conferences.

The 2021 Virtual International TSC & LAM Research Conference: Driving Discoveries Beyond Boundaries was held in October 2021 and welcomed 179 people from 18 countries. Co-sponsored by the TSC Alliance and The LAM Foundation (LAM is short for lymphangiomyomatosis), the conference featured three plenary sessions with 17 oral presentations and two poster sessions with 14 posters. Additionally, two half-day sessions of "topic-based discussion" brought together clinical and basic science researchers to discuss cross-cutting topics, including big data and clinical translation.

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.

In 2021, the TSC Alliance launched the TSC Navigator, an easy-to-use, interactive online tool to help guide individuals and families through the complexities of TSC across their lifespan, proactively manage their care, and live their fullest lives. Users can access information based on the age of one's diagnosis, such as prenatal, childhood, or adult, to help determine which steps will help empower them throughout their individual journeys. Regardless of age, TSC Navigator also helps individuals with TSC and their caregivers face complex situations, overcome access issues, and address insurance barriers. The TSC Navigator launched on October 14, 2021, and received more than 2,700 visits between launch and year-end.

National Tuberous Sclerosis Association (d/b/a TSC Alliance) and Affiliate

Notes to Consolidated Financial Statements

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

To ensure the TSC community continued to receive updated information about TSC, TSC-Associated Neuropsychiatric Disorders (TAND), transition and research, the TSC Alliance developed an e-Webinar series. In 2021, the TSC Alliance hosted 27 e-Webinars with 1,219 cumulative live attendees, 5,567 cumulative recording views and 3,123 cumulative landing page visits. Additionally, the TSC Alliance held the following webinars: April COVID Vaccine Town Hall – 66 live attendees, 304 video views; ABC to SAP Webinar – 50 live attendees, 458 video views; August COVID Update Town Hall – 307 live attendees, 463 video views. Adding in live attendees from the additional webinars brought the total live audience for webinars to 1,642, total cumulative recording views totaled 6,792 with 3,123 cumulative landing page visits.

In 2020, TSC Alliance co-hosted 3 virtual conferences with The LAM Foundation. The virtual conferences featured regional professionals in Memphis, Gainesville and Denver. These events attracted a total of 818 registered attendees, including 636 attendees on the day of the conference, 1,106 subsequent video views, and 424 visits to the virtual exhibit halls. There were 21 speakers from 12 different institutes, representing TSC Clinics, TSC Centers of Excellence and LAM Clinics.

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

Government relations: Government relations efforts focus on increasing federal and state appropriations for TSC research, raising awareness and collaborating with government partners to drive TSC research forward and improve clinical care and treatment options for individuals with TSC.

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 include the following activities:

Fundraising: Fundraising includes activities that encourage and secure financial support.

Management and general: Management and general includes activities necessary for administrative processes and managing financial responsibilities.

Supporting services reflected in the accompanying consolidated statements of activities include both TSC Alliance and the Endowment Fund. However, on a separate entity basis, supporting services compared to total expense for TSC Alliance was 21% and 27% for the years ended December 31, 2021 and 2020, respectively.

A summary of significant accounting policies follows:

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

National Tuberos Sclerosis Association (d/b/a TSC Alliance) and Affiliate

Notes to Consolidated Financial Statements

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

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 the consolidated financial statements in conformity with generally accepted accounting principles (U.S. GAAP) requires management to make estimates and assumptions that affect the amounts reported in the consolidated financial statements and accompanying notes. Actual results could differ from those estimates.

Income tax status: TSC Alliance is exempt from the payment of income taxes on its exempt activities under Section 501(c)(3) of the Internal Revenue Code (IRC) and has been classified by the Internal Revenue Service (IRS) as other than a private foundation within the meaning of Section 509(a)(1) of the IRC.

The Endowment Fund is exempt from the payment of income taxes on its exempt activities under Section 501(c)(3) of the IRC and has been classified by the IRS as other than a private foundation within the meaning of Section 509(a)(3) of the IRC. 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, money market funds, certificates of deposit, donated stock liquidation accounts and overnight sweep accounts as cash and cash equivalents. Money market funds held within the Endowment Fund's investment portfolio are classified as investments.

To minimize market risk on the principal balance, operating funds classified as cash and cash equivalents are 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.

Investments: Investments with readily determinable fair values are reflected at fair value. To adjust the carrying value of these investments, the change in fair value is recorded in investment income, net of fees.

National Tuberous Sclerosis Association (d/b/a TSC Alliance) and Affiliate

Notes to Consolidated Financial Statements

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

Financial 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 TSC Alliance's policy to maximize the use of guarantees and FDIC insurance.

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 revenue earned in accordance with its contracts. 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, 2021 and 2020.

Promises to give: Unconditional promises to give that are expected to be collected within one year are recorded at net realizable value. Unconditional 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 using interest rates for two-year to five-year U.S. treasury bills plus 1%. Discount rates range from 1.14% to 3.75%.

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 a loss is recorded within donor restricted activities. Management believes that the use of the direct write-off method approximates the results that would be presented if an allowance for doubtful promises to give had been recorded. However, the loss on doubtful promises to give was \$0 for the years ended December 31, 2021 and 2020.

Operating lease right of use asset: The operating lease right of use asset equaled the present value of the operating lease payments net of the tenant improvement allowance on the commencement date of the office lease which is described in Note 15. The operating lease right of use asset is depreciated over the term of the operating lease, net of the amortization of the interest related to the present value of the operating lease payments, such that all lease costs are reported on a straight-line basis over the term of the lease.

Property and equipment: Acquisitions of property 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 – 3 to 10 years; office equipment and furniture – 3 to 10 years; and leasehold improvements over the lesser of the remaining life of the office lease or the estimated useful life of the improvements.

Valuation of long-lived assets: Long-lived property, such as operating lease right of use asset and leasehold improvements, that suffers a permanent impairment will be written down to fair value and an impairment loss equal to the difference between the property's carrying amount and fair value would be included as a reduction in the change in net assets without donor restrictions before other items.

National Tuberous Sclerosis Association (d/b/a TSC Alliance) and Affiliate

Notes to Consolidated Financial Statements

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

Accrued compensation: Accrued compensation consists of salaries, including related payroll tax withholding, and paid time off 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.

Operating lease liability: The Alliance recognized an operating lease liability equal to the present value of all lease payments in accordance with the terms of the operating lease, which is described in Note 15.

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. Special events may include elements of both revenue and support.

Revenue from contracts with customers includes performance obligations that are satisfied either at a point in time or over time, and most contracts have initial terms of one year or less. The Alliance performs an evaluation at contract inception focused on whether a performance obligation is satisfied over time or at a point in time. If a performance obligation meets certain specific criteria, the related revenue is recognized over time if the Alliance is able to reasonably measure its progress toward complete satisfaction of the performance obligation using reliable information. Output methods and input methods are used to measure progress for goods and services for which control has been transferred to the customer. If the certain criteria are met, revenue is recognized at a point in time.

Prices are specific to a distinct performance obligation and contracts with customers 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 in the consolidated financial statements. Periods of economic downturn resulting from any of the above factors may result in declines in future cash flows and recognized revenue of the Alliance or can have a positive impact on cash flows in favorable economic conditions.

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 sponsorships are conditional contributions whose conditions are met 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, during a typical year, would take place throughout the year and sponsorship revenue for these events would be recognized as the events occur. In 2021 and 2020, due to the COVID-19 pandemic, these 30 events were combined into one global event held online rather than in person. In 2021, a hybrid Comedy for a Cure fundraising event was held that allowed for live attendance in Los Angeles, California and a virtual component for those more comfortable participating remotely.

A portion of special events revenue relates to the costs of direct benefits to donors which are recognized at the point in time that the related event takes place. The costs of direct benefits to donors may include the following:

- (1) costs related to the venue, entertainment and refreshments in the case of a major event;
- (2) costs related to food, refreshments, t-shirts or other items provided to walk-a-thon participants; or
- (3) costs related to purchasing items to be raffled.

The costs of direct benefit to donors were greatly reduced during 2021 and 2020, since only a few events were held in person.

National Tuberous Sclerosis Association (d/b/a TSC Alliance) and Affiliate

Notes to Consolidated Financial Statements

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

Contributions: Unconditional contributions are recognized when received. 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, (2) preclinical consortium testing of compounds that could be developed for future treatments and (3) consulting services that provide the patient voice or review of patient facing materials for outside vendors. 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 revenue includes sponsorships and registration fees, both of which are recognized over the time that the related conference takes place. Amounts collected in advance of the conference are recorded as deferred revenue until the conference occurs.

Functional allocation of expenses: The costs of providing various program and supporting services have been summarized on a functional basis in the consolidated statements of activities. The consolidated statements of functional expense present the natural classification detail of expenses by function. The Alliance charges expenses directly incurred for a specific function to the appropriate program or supporting service category. Indirect costs are allocated among program and supporting services on a reasonable basis that is consistently applied. In particular, salaries and benefits are allocated based on employee effort, while other indirect costs, such as operating lease costs, human resources, finance, information technology support and depreciation and amortization are allocated based on either employee effort or direct costs.

Upcoming accounting pronouncement: FASB Accounting Standards Update (ASU) 2020-07, *Not-for-Profit Entities (Topic 958): Presentation and Disclosures by Not-for-Profit Entities for Contributed Nonfinancial Assets*, is intended to increase transparency of contributed nonfinancial assets for nonprofit entities through enhancements in presentation and disclosure requirements. Nonprofit entities will be required to present contributed nonfinancial assets as a separate line item in the consolidated statements of activities, apart from contributions of cash and other financial contributions. Nonprofit entities will also be required to disclose various information related to contributed nonfinancial assets. ASU 2020-07 is effective for fiscal years beginning after June 15, 2021. The Alliance is currently in the process of evaluating the impact of the new accounting guidance on its December 31, 2022, consolidated financial statements.

Subsequent events: Subsequent events have been evaluated through April 8, 2022, which is the date the consolidated financial statements were available to be issued.

National Tuberous Sclerosis Association (d/b/a TSC Alliance) and Affiliate

Notes to Consolidated Financial Statements

Note 2. Investments and Fair Value Measurements

In accordance with generally accepted accounting principles, the Alliance 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.

Investments valued using Level 1 inputs include mutual funds, exchange traded funds and preferred stock, the fair values of which were based on quoted prices for identical assets in active markets.

Investments valued using Level 2 inputs include corporate bonds, the fair values of 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 security.

Management believes the estimated value of investments to be a reasonable approximation of the exit price for the assets.

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 Tuberos Sclerosis Association (d/b/a TSC Alliance) and Affiliate

Notes to Consolidated Financial Statements

Note 2. Investments and Fair Value Measurements (Continued)

Investments valued at fair value on a recurring basis consisted of the following at December 31, 2021:

	Level 1	Level 2	Level 3	Total
Investments at fair value:				
Mutual funds:				
Bonds	\$ 36,869	\$ -	\$ -	\$ 36,869
Domestic equity	4,395,278	-	-	4,395,278
International equity	768,281	-	-	768,281
Exchange traded funds – fixed income	250,573	-	-	250,573
Preferred stock	121,175	-	-	121,175
Corporate bonds	-	707,054	-	707,054
	<u>\$ 5,572,176</u>	<u>\$ 707,054</u>	<u>\$ -</u>	<u>6,279,230</u>
Investments at cost:				
Money market funds				411,783
				<u>\$ 6,691,013</u>

Investments valued at fair value on a recurring basis consisted of the following at December 31, 2020:

	Level 1	Level 2	Level 3	Total
Investments at fair value:				
Mutual funds:				
Bonds	\$ 37,663	\$ -	\$ -	\$ 37,663
Domestic equity	3,764,099	-	-	3,764,099
International equity	695,271	-	-	695,271
Exchange traded funds – fixed income	256,990	-	-	256,990
Preferred stock	67,925	-	-	67,925
Corporate bonds	-	845,916	-	845,916
	<u>\$ 4,821,948</u>	<u>\$ 845,916</u>	<u>\$ -</u>	<u>5,667,864</u>
Investments at cost:				
Money market funds				245,562
				<u>\$ 5,913,426</u>

Net investment return consisted of the following for the years ended December 31, 2021 and 2020:

	2021	2020
Interest and dividends	\$ 127,560	\$ 131,179
Realized and unrealized gain on investments	931,698	297,022
Investment management fees	(38,255)	(29,639)
	<u>\$ 1,021,003</u>	<u>\$ 398,562</u>

National Tuberous Sclerosis Association (d/b/a TSC Alliance) and Affiliate

Notes to Consolidated Financial Statements

Note 3. Promises to Give

Promises to give (unconditional contributions receivable) consisted of the following at December 31, 2021 and 2020:

	2021	2020
Amounts due in less than one year	\$ 1,040,316	\$ 682,801
Amounts due in one to five years	1,801,744	993,115
	<u>2,842,060</u>	<u>1,675,916</u>
Less discount to net present value	(143,565)	(97,631)
	<u>\$ 2,698,495</u>	<u>\$ 1,578,285</u>

Note 4. Liquidity and Availability of Resources

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 the next twelve months 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 quarterly 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.

The following provides a summary of financial assets available for general expenditures within one year at December 31, 2021 and 2020:

	2021	2020
Cash and cash equivalents	\$ 2,843,269	\$ 2,370,947
Investments	6,691,013	5,913,426
Accounts receivable	99,173	113,491
Promises to give, net	2,698,495	1,578,285
	<u>12,331,950</u>	<u>9,976,149</u>
Less amounts not available for general expenditures:		
Cash and investments held to fund gift annuity obligations	(182,154)	(77,018)
Board-designated net assets	(6,601,224)	(5,764,868)
Net assets with donor restrictions	(5,028,381)	(3,508,084)
	<u>(11,811,759)</u>	<u>(9,349,970)</u>
Add amounts available for general expenditures:		
Unused transfers from board-designated to undesignated net assets	572,625	560,625
	<u>\$ 1,092,816</u>	<u>\$ 1,186,804</u>

National Tuberos Sclerosis Association (d/b/a TSC Alliance) and Affiliate

Notes to Consolidated Financial Statements

Note 4. Liquidity and Availability of Resources (Continued)

Unused transfers from board-designated to undesignated net assets: As disclosed in Note 8, TSC Alliance does not utilize all of the funds authorized to be transferred from board-designated to undesignated net assets. The accumulated transfers that were authorized but unused totaled \$334,625 and \$334,625 at December 31, 2021 and 2020, respectively. In accordance with the 5% spending policy, the expected appropriations for next year totaled \$238,000 and \$226,000 for the years ending December 31, 2022 and 2021, respectively. Furthermore, the cumulative authorized but unused transfers (contributions) from the Endowment Fund to TSC Alliance totaled \$572,625 and \$560,625 for the years ending December 31, 2021 and 2020, respectively.

Line of credit: During January 2022, the Alliance obtained a \$1,000,000 revolving line of credit which is due on demand. Certain assets, other than the assets related to the donor restricted net assets related to research, are considered to be collateral for any borrowings on the line of credit. Interest is calculated on draw downs in accordance with the line of credit agreement. The Alliance has not obtained any proceeds from the line of credit through April 8, 2022.

Note 5. Property and Equipment

Property and equipment consisted of the following at December 31, 2021 and 2020:

	2021	2020
Software	\$ 80,272	\$ 94,712
Office furniture and equipment	189,615	191,620
Leasehold improvements	449,272	449,272
	719,159	735,604
Less accumulated depreciation and amortization	(281,990)	(225,237)
	<u>\$ 437,169</u>	<u>\$ 510,367</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. The Alliance is aware of the regulations and requirements of each state, as applicable, and management believes the Alliance is in compliance with them.

Donated assets totaling \$182,154 and \$77,018 at December 31, 2021 and 2020, respectively, have been 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 to the beneficiaries as long as they live, after which the remaining assets are available for use in the Alliance's activities without donor restrictions.

Contribution revenue classified as without donor restrictions was recognized at the date the gift annuity 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 1.4% 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 National Vital Statistics Report from the Center for Disease Control. The net present value of the gift annuity obligations totaled \$119,665 and \$66,740 at December 31, 2021 and 2020, respectively.

National Tuberos Sclerosis Association (d/b/a TSC Alliance) and Affiliate

Notes to Consolidated Financial Statements

Note 7. Net Assets

Without donor restrictions: Net assets without donor restrictions consisted of the following at December 31, 2021 and 2020:

	2021	2020
Undesignated (deficit)	\$ (20,618)	\$ 189,609
Board-designated:		
Endowment fund	5,676,477	4,996,142
Grant commitments	924,747	768,726
	<u>6,601,224</u>	<u>5,764,868</u>
	<u>\$ 6,580,606</u>	<u>\$ 5,954,477</u>

With donor restrictions: Net assets with donor restrictions consisted of the following as of and for the year ended December 31, 2021:

	Balance at January 1, 2021	Contributions and Investment Return	Net Assets Released from Restrictions	Balance at December 31, 2021
Research:				
Preclinical consortium	\$ 3,153	\$ 954,987	\$ (3,153)	\$ 954,987
Research - indirect costs	324,723	451,427	(192,821)	583,329
Biorepository	958,221	59,777	(465,967)	552,031
Clinical research consortium	348,910	222,310	(138,306)	432,914
Bcureful travel fund	129,810	510,768	(225,000)	415,578
TAND	52,195	301,217	-	353,412
Child epilepsy research	135,000	146,625	(135,000)	146,625
New initiatives - 45th gala	137,205	-	(49,385)	87,820
Preclinical TAND	-	85,000	-	85,000
Whole genome sequencing	-	85,000	-	85,000
Ken Johnson Memorial fund	-	22,336	-	22,336
General	200,530	267,137	(467,667)	-
Keith Hall appeal	1,250	7,275	(8,525)	-
Subtotal research	<u>2,290,997</u>	<u>3,113,859</u>	<u>(1,685,824)</u>	<u>3,719,032</u>
Endowment fund	897,379	160,425	(44,869)	1,012,935
Public education	114,465	69,500	(79,885)	104,080
Family services	121,075	183,500	(206,577)	97,998
TSC International	84,168	20,000	(9,832)	94,336
	<u>\$ 3,508,084</u>	<u>\$ 3,547,284</u>	<u>\$ (2,026,987)</u>	<u>\$ 5,028,381</u>

National Tuberos Sclerosis Association (d/b/a TSC Alliance) and 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, 2020:

	Balance at January 1, 2020	Contributions and Investment Return	Net Assets Released from Restrictions	Balance at December 31, 2020
Research:				
Preclinical consortium	\$ 502,819	\$ -	\$ (499,666)	\$ 3,153
Research - indirect costs	348,964	89,473	(113,714)	324,723
Biorepository	1,269,223	153,764	(464,766)	958,221
Clinical research consortium	382,239	52,783	(86,112)	348,910
Bcureful travel fund	50,250	144,560	(65,000)	129,810
TAND	-	52,195	-	52,195
Child epilepsy research	100,000	85,000	(50,000)	135,000
New initiatives - 45th gala	137,205	-	-	137,205
General	129,484	650,377	(579,331)	200,530
Keith Hall appeal	-	6,300	(5,050)	1,250
Subtotal research	2,920,184	1,234,452	(1,863,639)	2,290,997
Endowment fund	879,444	61,907	(43,972)	897,379
Public education	76,985	114,433	(76,953)	114,465
Family services	53,000	203,000	(134,925)	121,075
TSC International	104,627	-	(20,459)	84,168
	<u>\$ 4,034,240</u>	<u>\$ 1,613,792</u>	<u>\$ (2,139,948)</u>	<u>\$ 3,508,084</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.

National Tuberos Sclerosis Association (d/b/a TSC Alliance) and Affiliate

Notes to Consolidated Financial Statements

Note 8. 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, which includes both board-designated funds and donor-restricted funds. Furthermore, 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 TSC Alliance from the Endowment Fund.

The authorized spending amount for the board-designated endowment fund totaled \$226,000 and \$224,000 during the years ended December 31, 2021 and 2020, respectively. The actual contributions to TSC Alliance totaled \$226,000 and \$330,875 during the years ended December 31, 2021 and 2020, respectively.

Annually the Endowment Fund authorizes an amount to be contributed to TSC Alliance. At times, TSC Alliance does not utilize all of the funds authorized to be transferred from board-designated to undesignated net assets. The accumulated transfers that were authorized but unused totaled \$334,625 and \$334,625 at December 31, 2021 and 2020, respectively. In accordance with the 5% spending policy, the expected appropriations for next year totaled \$238,000 and \$226,000 for the years ending December 31, 2022 and 2021, respectively. Furthermore, the cumulative authorized but unused transfers (contributions) from the Endowment Fund to TSC Alliance totaled \$572,625 and \$560,625 for the years ending December 31, 2021 and 2020, respectively.

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. However, there were no such deficiencies at December 31, 2021 and 2020.

National Tuberos Sclerosis Association (d/b/a TSC Alliance) and Affiliate

Notes to Consolidated Financial Statements

Note 8. Endowment Funds (Continued)

Endowment funds consisted of the following at December 31, 2021:

	Without Donor Restrictions	With Donor Restrictions		Total	Total Endowment Funds
		Available for Appropriation	Held in Perpetuity		
Board-designated	\$ 5,676,477	\$ -	\$ -	\$ -	\$ 5,676,477
Donor-restricted	-	133,491	879,444	1,012,935	1,012,935
	<u>\$ 5,676,477</u>	<u>\$ 133,491</u>	<u>\$ 879,444</u>	<u>\$ 1,012,935</u>	<u>\$ 6,689,412</u>

Endowment funds consisted of the following December 31, 2020:

	Without Donor Restrictions	With Donor Restrictions		Total	Total Endowment Funds
		Available for Appropriation	Held in Perpetuity		
Board-designated	\$ 4,996,142	\$ -	\$ -	\$ -	\$ 4,996,142
Donor-restricted	-	17,935	879,444	897,379	897,379
	<u>\$ 4,996,142</u>	<u>\$ 17,935</u>	<u>\$ 879,444</u>	<u>\$ 897,379</u>	<u>\$ 5,893,521</u>

Changes in the endowment funds consisted of the following as of and for the year ended December 31, 2021:

	Without Donor Restrictions	With Donor Restrictions		Total	Total Endowment Funds
		Available for Appropriation	Held in Perpetuity		
Beginning	\$ 4,996,142	\$ 17,935	\$ 879,444	\$ 897,379	\$ 5,893,521
Contributions	110,140	-	-	-	110,140
Net investment return	854,908	160,425	-	160,425	1,015,333
Appropriations and transfers:					
Appropriation per spending policy	(226,000)	-	-	-	(226,000)
Program and supporting services	(58,713)	(44,869)	-	(44,869)	(103,582)
Ending	<u>\$ 5,676,477</u>	<u>\$ 133,491</u>	<u>\$ 879,444</u>	<u>\$ 1,012,935</u>	<u>\$ 6,689,412</u>

Changes in the endowment funds consisted of the following as of and for the year ended December 31, 2020:

	Without Donor Restrictions	With Donor Restrictions		Total	Total Endowment Funds
		Available for Appropriation	Held in Perpetuity		
Beginning	\$ 5,036,361	\$ -	\$ 879,444	\$ 879,444	\$ 5,915,805
Contributions	54,645	-	-	-	54,645
Net investment return	324,885	61,907	-	61,907	386,792
Appropriations and transfers:					
Appropriation per spending policy	(330,875)	-	-	-	(330,875)
Program and supporting services	(88,874)	(43,972)	-	(43,972)	(132,846)
Ending	<u>\$ 4,996,142</u>	<u>\$ 17,935</u>	<u>\$ 879,444</u>	<u>\$ 897,379</u>	<u>\$ 5,893,521</u>

National Tuberos Sclerosis Association (d/b/a TSC Alliance) and Affiliate

Notes to Consolidated Financial Statements

Note 9. In-Kind Contributions

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 consolidated statements 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, 2021 and 2020:

	2021	2020
Donated goods	\$ 724	\$ 3,482
Donated services:		
Research	-	48,500
Event and advertising services	34,028	38,404
Investment management fees	34,024	29,639
	<u>\$ 68,776</u>	<u>\$ 120,025</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. Paycheck Protection Program Loans

In April 2020, the Alliance obtained a loan totaling \$371,820, pursuant to the Paycheck Protection Program (PPP) under the Coronavirus Aid, Relief, and Economic Security Act (CARES Act) of March 27, 2020. The loan was scheduled to mature in April 2022 but was forgiven by the Small Business Administration (SBA) during the year ended December 31, 2020.

In March 2021, the Alliance obtained a second PPP loan totaling \$380,595. The loan was scheduled to mature in March 2026 but was forgiven by the SBA during the year ended December 31, 2021.

The Alliance elected to account for the PPP loans as conditional contributions in accordance with ASC 958-605. Upon receiving formal notification of forgiveness from the SBA, the PPP loans became unconditional contributions. Therefore, the Alliance recognized the contributions on the consolidated statements of activities totaling \$380,595 and \$371,820 during the years ended December 31, 2021 and 2020, respectively.

National Tuberos Sclerosis Association (d/b/a TSC Alliance) and Affiliate

Notes to Consolidated Financial Statements

Note 11. 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 totaled \$33,150 and \$66,240 during the years ended December 31, 2021 and 2020, respectively.

Joint costs were allocated to the following activities for the years ended December 31, 2021 and 2020:

	2021	2020
Family services	\$ 16,575	\$ 33,120
Fundraising	16,575	33,120
	<u>\$ 33,150</u>	<u>\$ 66,240</u>

Note 12. Professional Fees

Professional fees consisted of the following for the years ended December 31, 2021 and 2020:

	2021	2020
Professional fundraising consulting	\$ 189,113	\$ 213,750
Marketing consulting	155,698	170,130
Government relations consulting	112,980	112,980
Legal fees	53,261	26,097
Website	46,027	26,843
Audit and tax preparation fees	33,419	34,189
Recruiting and payroll fees	19,698	4,917
Other consulting (includes cybersecurity study in 2020)	19,515	39,684
Events production consulting	10,000	32,500
	<u>\$ 639,711</u>	<u>\$ 661,090</u>

Note 13. 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 \$60,399 and \$56,884 for the years ended December 31, 2021 and 2020, respectively.

National Tuberous Sclerosis Association (d/b/a TSC Alliance) and Affiliate

Notes to Consolidated Financial Statements

Note 14. 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 \$257,213 and \$222,679 during the years ended December 31, 2021 and 2020, respectively.

Affiliates: TSC Alliance has a Global Alliance Affiliation Agreement with several parties (TSC Alliance of Israel, Hungarian Foundation for Tuberous Sclerosis, TS Canada ST, TSC Alliance of Mexico, TSC Alliance Foundation (Thailand) and TSC 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.

Note 15. Operating Leases

Operating lease (801 Roeder Road): The Alliance had an operating lease office space at 801 Roeder Road which expired on March 31, 2020. Related to the implementation of ASC 842 on January 1, 2020, this operating lease did not have a material impact on the Alliance's consolidated financial statements.

Operating lease (8737 Colesville Road): The Alliance signed an operating lease for office space at 8737 Colesville Road with a lease commencement date of April 1, 2020 and an expiration date of March 31, 2031. The Alliance has no plans to terminate the operating lease early. The operating lease includes a rent abatement for month 1 through month 12, with rent commencing on April 1, 2021 and an escalation clause that adjusts annual base rentals. The lease also indicated that real estate taxes and operating expenses would be passed through and not included in base rentals. In addition, the landlord provided a build-out allowance totaling \$414,048 as an incentive to lease the office space. In accordance with ASC 842, U.S. GAAP requires that an operating lease right of use asset be recorded equal to the present value of the operating lease payments, net of the tenant improvement allowance which totaled \$875,703 on April 1, 2020. The operating lease right of use asset is amortized on a straight-line basis over the term of the operating lease, net of the amortization of the interest related to the present value of the operating lease payments. U.S. GAAP also requires that the net present value of all lease payments over the term of the lease be recorded as an operating lease liability, which was determined over the entire term of the lease since the Alliance does not plan to terminate the lease early. The discount rate used for the calculation of the net present value of the operating lease liability approximated an incremental borrowing rate which was 4.75%. The net present value of operating lease payments totaled \$1,289,751 on April 1, 2020. The weighted average remaining lease term was 9.25 and 10.25 years at December 31, 2021 and 2020, respectively, and the weighted average discount rate was 4.75%. The operating lease right of use asset, net of amortization, totaled \$833,830 and \$778,371 at December 31, 2021 and 2020, respectively. The operating lease liability totaled \$1,336,433 and \$1,285,691 at December 31, 2021 and 2020, respectively.

National Tuberos Sclerosis Association (d/b/a TSC Alliance) and Affiliate

Notes to Consolidated Financial Statements

Note 15. Operating Leases (Continued)

The maturity analysis of future payments along with a reconciliation to the operating lease liability for 8737 Colesville Road is as follows:

Years ending December 31:	
2022	\$ 154,258
2023	158,501
2024	162,859
2025	167,338
2026	171,940
Thereafter	784,595
	<u>1,599,491</u>
Discount to net present value	(313,800)
	<u>\$ 1,285,691</u>

Rent expense, including operating pass through costs, related to operating leases consisted of the following for the years ended December 31, 2021 and 2020:

	<u>2021</u>	<u>2020</u>
Operating lease (8737 Colesville Road)	\$ 128,139	\$ 88,555
Operating lease (801 Roeder Road)	-	30,788
	<u>\$ 128,139</u>	<u>\$ 119,343</u>

Note 16. Commitments and Contingencies

Grant commitments: The Alliance's Board of Directors has authorized research grants totaling \$924,747 and \$768,726 as of December 31, 2021 and 2020, 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, these grants are considered to be conditional and, as such, no liability has been recorded for these grants. However, the grant commitments have been included within board-designated net assets and, if the contingencies are met, will be payable as follows:

Years ending December 31:	
2022	\$ 643,585
2023	281,162
	<u>\$ 924,747</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 Tuberous Sclerosis Association (d/b/a TSC Alliance) and Affiliate

Notes to Consolidated Financial Statements

Note 16. 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.

PPP loans: The SBA has the right to audit recipients of PPP loans for up to six years from the date of forgiveness. However, management does not believe a material risk exists related to the SBA's right to audit.

COVID-19 pandemic: On January 30, 2020, the World Health Organization declared the outbreak of the coronavirus (COVID-19) a "Public Health Emergency of International Concern" and, on March 11, 2020, declared it to be a pandemic. Actions taken around the world to help mitigate the spread of COVID-19 include restrictions on travel, quarantines in certain areas and forced closures for certain types of public places and businesses. COVID-19 and actions taken to mitigate it have had and are expected to continue to have an adverse impact on the economies and financial markets of many countries, including the geographical area in which the Alliance operates. It is unknown how long these conditions will last and what the complete financial affect will be to the Alliance and it is reasonably possible that the Alliance is vulnerable to the risk of a near-term severe impact.



RSM US LLP

Independent Auditor's Report on the Supplementary Information

Board of Directors
National Tuberous Sclerosis Association (d/b/a TSC Alliance)

We have audited the consolidated financial statements of National Tuberous Sclerosis Association (d/b/a TSC Alliance) and Affiliate (the Alliance) as of and for the years ended December 31, 2021 and 2020 and have issued our report thereon dated April 8, 2022, which contained an unmodified opinion on those consolidated financial statements. See pages 1 and 2. Our audits were 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 audits 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, D.C.
April 8, 2022

National Tuberos Sclerosis Association (d/b/a TSC Alliance) and Affiliate

**Consolidating Statement of Financial Position
December 31, 2021**

	TSC Alliance	Endowment	Eliminations	Total
Assets				
Cash and cash equivalents	\$ 2,701,765	\$ 141,504	\$ -	\$ 2,843,269
Investments	-	6,691,013	-	6,691,013
Due from affiliate	-	3,342	(3,342)	-
Accounts receivable	99,173	-	-	99,173
Promises to give, net	2,698,495	-	-	2,698,495
Prepaid expenses and other assets	620,148	-	-	620,148
Interest in net assets of affiliate	6,711,748	-	(6,711,748)	-
Operating lease right of use asset, net	778,371	-	-	778,371
Property and equipment, net	437,169	-	-	437,169
Total assets	\$ 14,046,869	\$ 6,835,859	\$ (6,715,090)	\$ 14,167,638
Liabilities and Net Assets				
Liabilities:				
Accounts payable and accrued expenses	\$ 181,564	\$ 4,446	\$ -	\$ 186,010
Due to affiliate	3,342	-	(3,342)	-
Accrued compensation	290,487	-	-	290,487
Deferred revenue	676,798	-	-	676,798
Operating lease liability, net	1,285,691	-	-	1,285,691
Gift annuity obligations, net	-	119,665	-	119,665
Total liabilities	2,437,882	124,111	(3,342)	2,558,651
Net assets:				
Without donor restrictions:				
Undesignated (deficit)	(20,618)	-	-	(20,618)
Board-designated	6,601,224	5,676,477	(5,676,477)	6,601,224
Total net assets without donor restrictions	6,580,606	5,676,477	(5,676,477)	6,580,606
With donor restrictions	5,028,381	1,035,271	(1,035,271)	5,028,381
Total net assets	11,608,987	6,711,748	(6,711,748)	11,608,987
Total liabilities and net assets	\$ 14,046,869	\$ 6,835,859	\$ (6,715,090)	\$ 14,167,638

National Tuberous Sclerosis Association (d/b/a TSC Alliance) and Affiliate

Consolidating Statement of Activities Year Ended December 31, 2021

	TSC Alliance			Endowment Fund			Eliminations			Consolidated Total		
	Without Donor	With Donor	Total	Without Donor	With Donor	Total	Without Donor	With Donor	Total	Without Donor	With Donor	Total
	Restrictions	Restrictions		Restrictions	Restrictions		Restrictions	Restrictions		Restrictions		
Revenue and support:												
Special events	\$ 1,169,138	\$ 55,434	\$ 1,224,572	\$ -	\$ -	\$ -	\$ -	\$ -	\$ -	\$ 1,169,138	\$ 55,434	\$ 1,224,572
Costs of direct benefits to donors	(46,439)	-	(46,439)	-	-	-	-	-	-	(46,439)	-	(46,439)
Special events, net	1,122,699	55,434	1,178,133	-	-	-	-	-	-	1,122,699	55,434	1,178,133
Contributions:												
Individuals, companies and foundations	1,341,253	3,308,071	4,649,324	83,604	22,336	105,940	(226,000)	-	(226,000)	1,198,857	3,330,407	4,529,264
Memorials and honorariums	112,785	1,018	113,803	22,436	-	22,436	-	-	-	135,221	1,018	136,239
Federated funding	50,596	-	50,596	4,100	-	4,100	-	-	-	54,696	-	54,696
Contracts	2,120,485	-	2,120,485	-	-	-	-	-	-	2,120,485	-	2,120,485
Interest and dividends	3,809	-	3,809	104,908	18,843	123,751	-	-	-	108,717	18,843	127,560
Conferences	113,777	-	113,777	-	-	-	-	-	-	113,777	-	113,777
Net assets released from restrictions	1,982,118	(1,982,118)	-	44,869	(44,869)	-	-	-	-	2,026,987	(2,026,987)	-
Total revenue and support	6,847,522	1,382,405	8,229,927	259,917	(3,690)	256,227	(226,000)	-	(226,000)	6,881,439	1,378,715	8,260,154
Expenses:												
Program services:												
Research	3,939,924	-	3,939,924	-	-	-	-	-	-	3,939,924	-	3,939,924
Family services	726,768	-	726,768	-	-	-	-	-	-	726,768	-	726,768
Public health education	522,356	-	522,356	1,928	-	1,928	-	-	-	524,284	-	524,284
Government relations	154,139	-	154,139	-	-	-	-	-	-	154,139	-	154,139
Professional education	122,600	-	122,600	-	-	-	-	-	-	122,600	-	122,600
Contribution to TSC Alliance	-	-	-	226,000	-	226,000	(226,000)	-	(226,000)	-	-	-
Total program services	5,465,787	-	5,465,787	227,928	-	227,928	(226,000)	-	(226,000)	5,467,715	-	5,467,715
Supporting services:												
Fundraising	919,901	-	919,901	70,542	-	70,542	-	-	-	990,443	-	990,443
Management and general	517,901	-	517,901	31,112	-	31,112	-	-	-	549,013	-	549,013
Total supporting services	1,437,802	-	1,437,802	101,654	-	101,654	-	-	-	1,539,456	-	1,539,456
Total expenses	6,903,589	-	6,903,589	329,582	-	329,582	(226,000)	-	(226,000)	7,007,171	-	7,007,171
Change in net assets before other items	(56,067)	1,382,405	1,326,338	(69,665)	(3,690)	(73,355)	-	-	-	(125,732)	1,378,715	1,252,983
Realized and unrealized gain on investments, net of fees	1,861	-	1,861	750,000	141,582	891,582	-	-	-	751,861	141,582	893,443
Change in interest in affiliate	680,335	137,892	818,227	-	-	-	(680,335)	(137,892)	(818,227)	-	-	-
Change in net assets	626,129	1,520,297	2,146,426	680,335	137,892	818,227	(680,335)	(137,892)	(818,227)	626,129	1,520,297	2,146,426
Net assets:												
Beginning	5,954,477	3,508,084	9,462,561	4,996,142	897,379	5,893,521	(4,996,142)	(897,379)	(5,893,521)	5,954,477	3,508,084	9,462,561
Ending	\$ 6,580,606	\$ 5,028,381	\$ 11,608,987	\$ 5,676,477	\$ 1,035,271	\$ 6,711,748	\$ (5,676,477)	\$ (1,035,271)	\$ (6,711,748)	\$ 6,580,606	\$ 5,028,381	\$ 11,608,987