




**NATIONAL TUBEROUS SCLEROSIS ASSOCIATION  
(D/B/A TSC ALLIANCE) AND AFFILIATE**

CONSOLIDATED FINANCIAL STATEMENTS

DECEMBER 31, 2022





**NATIONAL TUBEROUS SCLEROSIS ASSOCIATION  
(D/B/A TSC ALLIANCE) AND AFFILIATE**

CONSOLIDATED FINANCIAL STATEMENTS

YEARS ENDED DECEMBER 31, 2022 AND 2021

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## INDEPENDENT AUDITOR'S REPORT

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

### Opinion

We have audited the accompanying consolidated financial statements of the National Tuberous Sclerosis Association (d/b/a TSC Alliance) and Affiliate (collectively, the Alliance), which comprise the consolidated statement of financial position as of December 31, 2022, and the related consolidated statement of activities, functional expenses, and cash flows for the year then ended, and the related notes to the consolidated financial statements.

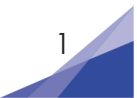
In our opinion, the consolidated financial statements referred to above present fairly, in all material respects, the financial position of National Tuberous Sclerosis Association (d/b/a TSC Alliance) and Affiliate as of December 31, 2022, and the changes in its net assets and its cash flows for the year then ended in accordance with accounting principles generally accepted in the United States of America.

### Basis for Opinion

We conducted our audit in accordance with auditing standards generally accepted in the United States of America. 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.

### Prior Period Consolidated Financial Statements

The consolidated financial statements of the National Tuberous Sclerosis Association (d/b/a TSC Alliance) and Affiliate as of and for the year ended December 31, 2021, were audited by other auditors whose report dated April 8, 2022, expressed an unmodified opinion on those statements.





## **Responsibilities of Management for the Consolidated Financial Statements**

Management is responsible for the preparation and fair presentation of these consolidated financial statements in accordance with accounting principles generally accepted in the United States of America; 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 consolidated 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 available to be issued.

## **Auditor's Responsibilities for the Audit of the Consolidated Financial Statements**

Our objectives are to obtain reasonable assurance about whether the consolidated 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 generally accepted auditing standards 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, including omissions, 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 consolidated financial statements.

In performing an audit in accordance with generally accepted auditing standards, we:

- Exercise professional judgment and maintain professional skepticism throughout the audit.
- Identify and assess the risks of material misstatement of the consolidated 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 consolidated 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 consolidated 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.

### **Report on Consolidating Information**

Our audit was conducted for the purpose of forming an opinion on the consolidated financial statements as a whole. The consolidating statements of financial position and activities as of and for the year ended December 31, 2022 are presented for purposes of additional analysis of the consolidated financial statements rather than to present the financial position and changes in net assets of the individual entities, and 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 2022 consolidated financial statements and certain additional procedures, including comparing and reconciling such information directly to the underlying accounting and other records used to prepare the consolidated financial statements or to the consolidated financial statements themselves, and other additional procedures in accordance with auditing standards generally accepted in the United States of America. In our opinion, the information is fairly stated in all material respects in relation to the 2022 consolidated financial statements as a whole.

*CaliberCPAGroup, PLLC*

Bethesda, MD  
April 10, 2023

**NATIONAL TUBEROUS SCLEROSIS ASSOCIATION  
(D/B/A TSC ALLIANCE) AND AFFILIATE**

CONSOLIDATED STATEMENTS OF FINANCIAL POSITION

DECEMBER 31, 2022 AND 2021

	2022	2021
<b>Assets</b>		
<b>Assets</b>		
Cash and cash equivalents	\$ 2,440,085	\$ 2,843,269
Investments	5,577,848	6,691,013
Accounts receivable	181,490	99,173
Promises to give, net	5,280,316	2,698,495
Prepaid expenses and other assets	279,571	620,148
Operating lease right of use assets, net	718,708	778,371
Property and equipment, net	463,272	437,169
Total assets	\$ 14,941,290	\$ 14,167,638
<b>Liabilities and Net Assets</b>		
<b>Liabilities</b>		
Accounts payable and accrued expenses	\$ 599,548	\$ 186,010
Accrued compensation	298,339	290,487
Deferred revenue	285,264	676,798
Operating lease liability, net	1,189,842	1,285,691
Gift annuity obligations, net	113,451	119,665
Total liabilities	2,486,444	2,558,651
<b>Net assets</b>		
Without donor restrictions		
Undesignated (deficit)	(158,002)	(20,618)
Board-designated	5,309,341	6,601,224
Total net assets without donor restrictions	5,151,339	6,580,606
With donor restrictions	7,303,507	5,028,381
Total net assets	12,454,846	11,608,987
Total liabilities and net assets	\$ 14,941,290	\$ 14,167,638

See accompanying notes to consolidated financial statements.

# NATIONAL TUBEROUS SCLEROSIS ASSOCIATION (D/B/A TSC ALLIANCE) AND AFFILIATE

## CONSOLIDATED STATEMENTS OF ACTIVITIES

YEARS ENDED DECEMBER 31, 2022 AND 2021

	2022			2021		
	Without Donor Restrictions	With Donor Restrictions	Total	Without Donor Restrictions	With Donor Restrictions	Total
<b>Support and revenue</b>						
Special events	\$ 1,446,809	\$ 112,339	\$ 1,559,148	\$ 1,134,386	\$ 55,434	\$ 1,189,820
Cost of direct benefits to donors	(125,478)	-	(125,478)	(46,439)	-	(46,439)
Special events, net	1,321,331	112,339	1,433,670	1,087,947	55,434	1,143,381
Contributions						
Individuals, companies and foundations	750,333	4,753,965	5,504,298	1,164,833	3,330,407	4,495,240
Memorials and honorariums	105,306	12,160	117,466	135,221	1,018	136,239
Federated funding	52,175	-	52,175	54,696	-	54,696
Contributed nonfinancial assets	33,843	-	33,843	68,776	-	68,776
Contracts	1,906,672	-	1,906,672	2,120,485	-	2,120,485
Interest and dividends	140,009	24,559	164,568	108,717	18,843	127,560
Conferences	813,645	-	813,645	113,777	-	113,777
Other revenue	15,492	-	15,492	-	-	-
Net assets released from restrictions	2,473,109	(2,473,109)	-	2,026,987	(2,026,987)	-
Total support and revenue	7,611,915	2,429,914	10,041,829	6,881,439	1,378,715	8,260,154
<b>Expenses</b>						
Program services						
Research	3,794,438	-	3,794,438	3,939,924	-	3,939,924
Family services	1,701,754	-	1,701,754	726,768	-	726,768
Public health education	520,210	-	520,210	524,284	-	524,284
Government relations	162,771	-	162,771	154,139	-	154,139
Professional education	105,471	-	105,471	122,600	-	122,600
Total program services	6,284,644	-	6,284,644	5,467,715	-	5,467,715
Supporting services						
Fundraising	1,178,795	-	1,178,795	990,443	-	990,443
Management and general	672,392	-	672,392	549,013	-	549,013
Total supporting services	1,851,187	-	1,851,187	1,539,456	-	1,539,456
Total expenses	8,135,831	-	8,135,831	7,007,171	-	7,007,171
<b>Change in net assets before other item</b>	(523,916)	2,429,914	1,905,998	(125,732)	1,378,715	1,252,983
<b>Realized and unrealized gain (loss) on investments, net of fees</b>	(905,351)	(154,788)	(1,060,139)	751,861	141,582	893,443
<b>Change in net assets</b>	(1,429,267)	2,275,126	845,859	626,129	1,520,297	2,146,426
<b>Net assets</b>						
Beginning of year	6,580,606	5,028,381	11,608,987	5,954,477	3,508,084	9,462,561
End of year	\$ 5,151,339	\$ 7,303,507	\$ 12,454,846	\$ 6,580,606	\$ 5,028,381	\$ 11,608,987

See accompanying notes to consolidated financial statements.

## NATIONAL TUBEROUS SCLEROSIS ASSOCIATION (D/B/A TSC ALLIANCE) AND AFFILIATE

### CONSOLIDATED STATEMENT OF FUNCTIONAL EXPENSES

YEAR ENDED DECEMBER 31, 2022

	Program Services					Supporting Services		Total
	Research	Family Services	Public Health Education	Government Relations	Professional Education	Fundraising	Management and General	
Salaries	\$ 695,965	\$ 495,965	\$ 187,116	\$ 29,781	\$ 42,055	\$ 533,878	\$ 412,985	\$ 2,397,745
Preclinical consortium	1,407,092	-	-	-	-	-	-	1,407,092
Grants	660,727	-	-	-	-	-	-	660,727
World conference	-	794,399	-	-	-	-	-	794,399
Professional fees	11,040	14,870	109,262	116,684	178	147,760	61,713	461,507
Employee benefits and payroll taxes	122,524	116,124	38,685	7,483	6,954	121,293	85,536	498,599
Clinical research consortium	371,428	-	-	-	-	-	-	371,428
Biosample repository	239,818	-	-	-	-	-	-	239,818
Equipment maintenance and rental	74,881	27,068	9,749	1,754	972	71,971	29,318	215,713
Operating lease	33,057	31,544	9,928	2,413	1,338	31,554	23,002	132,836
Printing and promotion	906	9,056	81,054	1,006	1,822	51,184	1,581	146,609
Training, conferences and exhibits	4,988	74,177	12,776	132	39,117	34,164	2,703	168,057
Depreciation and amortization	27,685	11,254	4,445	872	484	15,811	8,315	68,866
Natural history database	81,552	-	-	-	-	-	-	81,552
Telephone	12,464	14,480	21,509	439	1,013	16,412	11,093	77,410
Postage and shipping	1,243	8,668	20,210	476	873	25,166	1,968	58,604
Dues, fees, and subscriptions	8,784	2,377	5,019	504	295	12,127	14,875	43,981
Costs of direct benefit to donors	-	-	-	-	-	125,478	-	125,478
Other expenses	574	2,267	75	15	8	11,188	1,929	16,056
Bank, credit card, and transaction fees	17	47	4	1	-	47,838	4,654	52,561
Insurance	2,910	2,740	874	212	118	2,741	4,962	14,557
Travel	30,146	91,192	17,643	612	10,029	44,243	3,105	196,970
Supplies	1,733	908	388	29	16	6,846	1,142	11,062
Board and committee meetings	4,904	4,618	1,473	358	199	4,619	3,511	19,682
	<u>3,794,438</u>	<u>1,701,754</u>	<u>520,210</u>	<u>162,771</u>	<u>105,471</u>	<u>1,304,273</u>	<u>672,392</u>	<u>8,261,309</u>
Less costs of direct benefit to donors	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>(125,478)</u>	<u>-</u>	<u>(125,478)</u>
Total functional expenses	<u>\$ 3,794,438</u>	<u>\$ 1,701,754</u>	<u>\$ 520,210</u>	<u>\$ 162,771</u>	<u>\$ 105,471</u>	<u>\$ 1,178,795</u>	<u>\$ 672,392</u>	<u>\$ 8,135,831</u>

See accompanying notes to consolidated financial statements.



## NATIONAL TUBEROUS 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	31,046	32,777	11,432	2,169	2,860	30,185	17,669	128,138
Printing and promotion	244	6,276	86,815	826	1,482	27,983	305	123,931
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 expenses	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
	<u>3,939,924</u>	<u>726,768</u>	<u>524,284</u>	<u>154,139</u>	<u>122,600</u>	<u>1,036,882</u>	<u>549,013</u>	<u>7,053,610</u>
Less costs of direct benefit to donors	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>(46,439)</u>	<u>-</u>	<u>(46,439)</u>
Total functional expenses	<u>\$ 3,939,924</u>	<u>\$ 726,768</u>	<u>\$ 524,284</u>	<u>\$ 154,139</u>	<u>\$ 122,600</u>	<u>\$ 990,443</u>	<u>\$ 549,013</u>	<u>\$ 7,007,171</u>

See accompanying notes to consolidated financial statements.

**NATIONAL TUBEROUS SCLEROSIS ASSOCIATION  
(D/B/A TSC ALLIANCE) AND AFFILIATE**

CONSOLIDATED STATEMENTS OF CASH FLOWS

YEARS ENDED DECEMBER 31, 2022 AND 2021

	2022	2021
<b>Cash flows from operating activities</b>		
Change in net assets	\$ 845,859	\$ 2,146,426
Adjustments to reconcile change in net assets to net cash provided by (used for) operating activities		
Realized and unrealized gain (loss) on investments	1,021,968	(931,698)
Discount on promises to give	127,841	45,934
Depreciation and amortization of property and equipment	68,866	73,198
Amortization of operating lease right of use assets, net	59,663	55,459
Discount on new gift annuity	-	(45,990)
Change in value of gift annuity obligations	11,429	11,445
Change in assets and liabilities		
Accounts receivable	(82,317)	14,318
Promises to give	(2,709,662)	(1,166,144)
Prepaid expenses and other assets	340,577	(216,650)
Accounts payable and accrued expenses	413,538	4,679
Accrued compensation	7,852	35,934
Deferred revenue	(391,534)	254,572
Operating lease liability	(95,849)	(50,742)
Net cash provided by (used for) operating activities	(381,769)	230,741
<b>Cash flows from investing activities</b>		
Proceeds from sales and maturities of investments	50,000	276,000
Purchases of investments	41,197	(121,889)
Purchases of property and equipment	(94,969)	-
Net cash provided by (used for) investing activities	(3,772)	154,111
<b>Cash flows from financing activities</b>		
Proceeds from forgivable loans	-	380,595
Extinguishment of debt via forgiveness	-	(380,595)
Proceeds from new gift annuity	-	100,000
Payments on gift annuity obligations	(17,643)	(12,530)
Net cash provided by (used for) financing activities	(17,643)	87,470
<b>Net change in cash and cash equivalents</b>	(403,184)	472,322
<b>Cash and cash equivalents</b>		
Beginning of year	2,843,269	2,370,947
End of year	\$ 2,440,085	\$ 2,843,269
<b>Supplemental disclosures of noncash investing activities</b>		
Donated securities	\$ 46,058	\$ 250,515

See accompanying notes to consolidated financial statements.



## NATIONAL TUBEROUS SCLEROSIS ASSOCIATION (D/B/A TSC ALLIANCE) AND AFFILIATE

### NOTES TO FINANCIAL STATEMENTS

YEARS ENDED DECEMBER 31, 2022 AND 2021

#### NOTE 1. NATURE OF ACTIVITIES AND SIGNIFICANT ACCOUNTING POLICIES

**Nature of Activities** - National Tuberos Sclerosis Association (d/b/a TSC Alliance) and Affiliate (the 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 Tuberos 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 Tuberos 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.



## NOTE 1. NATURE OF ACTIVITIES AND SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

**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.

The 2022 World Tuberous Sclerosis Complex Conference was co-hosted by the TSC Alliance and TSC International in Dallas, Texas from July 27-30, 2022. This event drew 997 total attendees from 23 countries, and 119 speakers donated 309 hours. Ninety-five 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 five different learning paths: panel presentations, workshops, large group lectures, specific topic presentations and discussion groups. This multi-pronged approach allowed the TSC community to select engagement opportunities, whether as parents of a newly diagnosed infant or an adult with TSC. Sessions covered topics such as medical challenges, behavioral management, life skills, community support, transition issues and educational resources as well as financial considerations. There were 35 track sessions, three general sessions and two large-scale Q&A opportunities. In addition, there were nine meet-and-greet groups, a sibling workshop, a teen lounge and evening outings for TSC moms, dads, adults and young adults, and parent and dependent adults. There were also gatherings for international attendees as well as a new multicultural event. The exhibit hall consisted of 11 non-profit and 15 for-profit vendors.

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 5,700 visits between launch and year-end.

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 2022, the TSC Alliance hosted five research webinars with 268 live attendees, 919 cumulative recording views and 553 cumulative landing page visits. Additionally, the TSC Alliance's podcast series, called TSC Now, produced 10 episodes with 2,248 total listens. Six issues of the electronic TSC Matters newsletter were distributed to 17,173 recipients. The TSC Alliance's website increases awareness and provides extensive education through an average of more than 23,000 unique visitors each month.

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; and August COVID Update Town Hall - 307 live attendees, 463 video views.



## NOTE 1. NATURE OF ACTIVITIES AND SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

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 2021.

**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 relation 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 22% and 21% for the years ended December 31, 2022 and 2021, 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.

**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.



## NOTE 1. NATURE OF ACTIVITIES AND SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

**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 U.S. 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 consist of cash held for long-term purposes, mutual funds, fixed income and reported at fair value. Fair value is the price that would be received to sell an asset or paid to transfer a liability in an orderly transaction between market participants at the measurement date. Purchases and sales of investments are reported on a trade-date basis. Interest and dividends are recognized as they are earned. Unrealized gains and losses are included in the change in net assets in the accompanying consolidated statements of activities. All investment income is reported net of related investment expenses.





## 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, 2022 and 2021.

**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 seven-year U.S. treasury bills plus 2%. Discount rates range from 2.13% to 6.27%.

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, 2022 and 2021.

**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.



## NOTE 1. NATURE OF ACTIVITIES AND SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

**Property and Equipment** - Acquisitions of property and equipment greater than \$3,000 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.

**Accrued Compensation** - Accrued compensation consists of salaries, including related payroll tax withholding, employee 401(k) contributions 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.





## NOTE 1. NATURE OF ACTIVITIES AND SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

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 various 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 2022, the Alliance hosted three live walks for Step Forward to Cure TSC® in California, Texas and Pennsylvania. In 2021 due to the COVID-19 pandemic, these events were combined into one global event held virtually rather than in person.

In 2022, Comedy for a Cure fundraising event returned to an in-person event held in Hollywood, California. 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.

**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 and clinical 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 the period of the contract which is usually one year.



## NOTE 1. NATURE OF ACTIVITIES AND SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

The performance obligations include allowing participating companies the opportunity to conduct approved studies and to share consortium data. Contract revenue related to preclinical and clinical 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 expenses 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.

**New Accounting Pronouncement Adopted** - During the year ended December 31, 2022, the Alliance adopted the provisions of Accounting Standards Update 2020-07, *Presentation and Disclosures by Not-for-Profit Entities for Contributed Nonfinancial Assets* (the Update). The Update requires a not-for-profit to present contributed nonfinancial assets as a separate line item in the consolidated statements of activities, apart from contributions of cash or other financial assets. The Update also increases the disclosure requirements around contributed nonfinancial assets, including disaggregating by category the types of contributed nonfinancial assets a nonprofit entity has received. The change in accounting principle resulting from ASU 2020-07 was adopted and applied retrospectively to each prior reporting period presented.

## NOTE 2. INVESTMENTS AND FAIR VALUE MEASUREMENTS

In accordance with U.S. 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 such as quoted prices in active markets for identical assets or liabilities.

Level 2 - Observable inputs other than Level 1 prices, such as quoted prices for similar assets or liabilities in active markets, quoted prices for identical assets or liabilities in inactive markets, or model-derived valuations in which all significant inputs are observable or can be derived principally from, or corroborated by, observable market data.

## NOTE 2. INVESTMENTS AND FAIR VALUE MEASUREMENTS (CONTINUED)

Level 3 - Unobservable inputs are used when little or no market data is available.

Following are descriptions of the valuation methodologies used for assets measured at fair value. There have been no changes in the methodologies used at December 31, 2022 and 2021.

*Mutual funds, exchange traded funds and preferred stock* - the fair values of which were based on quoted prices for identical assets in active markets.

*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.

Investments valued at fair value on a recurring basis consisted of the following at December 31, 2022:

	December 31, 2022			
	Total	Level 1	Level 2	Level 3
Investments at fair value				
Mutual funds				
Bonds	\$ 31,792	\$ 31,792	\$ -	\$ -
Domestic equity	3,609,113	3,609,113	-	-
International equity	644,688	644,688	-	-
Exchange traded funds - fixed income	233,368	233,368	-	-
Preferred stock	109,869	109,869	-	-
Corporate bonds	<u>577,008</u>	<u>-</u>	<u>577,008</u>	<u>-</u>
	5,205,838	<u>\$ 4,628,830</u>	<u>\$ 577,008</u>	<u>\$ -</u>
Investments at cost				
Money market funds	<u>372,010</u>			
	<u>\$ 5,577,848</u>			

## 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:

	December 31, 2021			
	Total	Level 1	Level 2	Level 3
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	<u>707,054</u>	<u>-</u>	<u>707,054</u>	<u>-</u>
	6,279,230	<u>\$ 5,572,176</u>	<u>\$ 707,054</u>	<u>\$ -</u>
Investments at cost				
Money market funds	<u>411,783</u>			
	<u>\$ 6,691,013</u>			

Net investment return consisted of the following for the years ended December 31, 2022 and 2021:

	2022	2021
Interest and dividends	\$ 164,568	\$ 127,560
Realized and unrealized gain (loss) on investments	(1,021,968)	931,698
Investment management fees	<u>(38,171)</u>	<u>(38,255)</u>
Total	<u>\$ (895,571)</u>	<u>\$ 1,021,003</u>

## NOTE 3. PROMISES TO GIVE

Promises to give (unconditional contributions receivable) consisted of the following at December 31, 2022 and 2021:

	2022	2021
Amounts due in less than one year	\$ 3,520,091	\$ 1,040,316
Amounts due in one to five years	<u>2,031,631</u>	<u>1,801,744</u>
	5,551,722	2,842,060
Less discount to net present value	<u>(271,406)</u>	<u>(143,565)</u>
Total	<u>\$ 5,280,316</u>	<u>\$ 2,698,495</u>

#### NOTE 4. LIQUIDITY AND AVAILABILITY OF FINANCIAL 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, 2022 and 2021.

	<u>2022</u>	<u>2021</u>
Cash and cash equivalents	\$ 2,440,085	\$ 2,843,269
Investments	5,577,848	6,691,013
Accounts receivable	181,490	99,173
Promises to give, net	<u>5,280,316</u>	<u>2,698,495</u>
	<u>13,479,739</u>	<u>12,331,950</u>
Less amounts not available for general expenditures		
Cash and investments held to fund gift annuity obligations	(177,382)	(182,154)
Board-designated net assets	(5,309,341)	(6,601,224)
Net assets with donor restrictions	<u>(7,303,507)</u>	<u>(5,028,381)</u>
	<u>(12,790,230)</u>	<u>(11,811,759)</u>
Add amounts available for general expenditures		
Unused transfers from board-designated to undesignated net assets	<u>572,625</u>	<u>572,625</u>
	<u>\$ 1,262,134</u>	<u>\$ 1,092,816</u>

**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 at December 31, 2022 and 2021. In accordance with the 5% spending policy, the expected appropriations

#### NOTE 4. LIQUIDITY AND AVAILABILITY OF FINANCIAL RESOURCES (CONTINUED)

for next year totaled \$238,000 for the years ending December 31, 2022 and 2021. Furthermore, the cumulative authorized but unused transfers (contributions) from the Endowment Fund to TSC Alliance totaled \$572,625 for the years ending December 31, 2022 and 2021.

**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 December 31, 2022.

#### NOTE 5. PROPERTY AND EQUIPMENT

Property and equipment consisted of the following at December 31, 2022 and 2021:

	<u>2022</u>	<u>2021</u>
Software	\$ 80,272	\$ 80,272
Office furniture and equipment	281,726	189,615
Leasehold improvements	<u>449,272</u>	<u>449,272</u>
	811,270	719,159
Less: accumulated depreciation and amortization	<u>(347,998)</u>	<u>(281,990)</u>
	<u>\$ 463,272</u>	<u>\$ 437,169</u>

#### NOTE 6. CONTRACT ASSETS AND LIABILITIES

The timing of billings, cash collections, and revenue recognition result in contract assets and contract liabilities associated with revenue from exchange transactions. contract assets consist entirely of trade accounts receivable, which are recognized only to the extent it is probable that the association will collect substantially all of the consideration to which it is entitled in exchange for the goods or services that will be or have been transferred. contract liabilities consist entirely of deferred revenue that results when the association receives advance payments from customers before revenue is recognized.

Such deferred revenue is substantially recognizable within one year. balances in these accounts as of the beginning and end of the year ended December 31, 2022 are as follows:

	<u>2022</u>	<u>2021</u>
Accounts receivable	<u>\$ 181,490</u>	<u>\$ 99,173</u>
Deferred revenue	<u>\$ 285,264</u>	<u>\$ 676,798</u>

## NOTE 7. 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 \$177,382 and \$182,154 at December 31, 2022 and 2021, 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 \$113,451 and \$119,665 at December 31, 2022 and 2021, respectively.

## NOTE 8. NET ASSETS

**Without donor restrictions:** Net assets without donor restrictions consisted of the following at December 31, 2022 and 2021:

	<u>2022</u>	<u>2021</u>
Undesignated (deficit)	\$ (158,002)	\$ (20,618)
Board-designated		
Endowment fund	4,634,432	5,676,477
Grant commitments	<u>674,909</u>	<u>924,747</u>
	<u>5,309,341</u>	<u>6,601,224</u>
	<u>\$ 5,151,339</u>	<u>\$ 6,580,606</u>



## NOTE 8. NET ASSETS (CONTINUED)

**With donor restrictions:** Net assets with donor restrictions consisted of the following as of and for the year ended December 31, 2022:

	Balance at January 1, 2022	Contributions and Investment Return	Net Assets Released from Restrictions	Balance at December 31, 2022
Restricted by program:				
Research	\$ 3,719,032	\$ 4,566,857	\$ (2,088,708)	\$ 6,197,181
Endowment fund	1,012,935	(130,230)	(50,647)	832,058
Public education	104,080	159,608	(141,460)	122,228
Family services	97,998	152,000	(151,336)	98,662
TSC International	94,336	-	(40,958)	53,378
	<u>\$ 5,028,381</u>	<u>\$ 4,748,235</u>	<u>\$ (2,473,109)</u>	<u>\$ 7,303,507</u>

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
Restricted by program:				
Research	\$ 2,290,997	\$ 3,113,859	\$ (1,685,824)	\$ 3,719,032
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>

## NOTE 9. 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 U.S. 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.





## NOTE 9. 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 \$238,000 and \$226,000 during the years ended December 31, 2022 and 2021, respectively. The actual contributions to TSC Alliance totaled \$308,000 and \$226,000 during the years ended December 31, 2022 and 2021, 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 at December 31, 2022 and 2021. In accordance with the 5% spending policy, the expected appropriations for next year totaled \$238,000 for the years ending December 31, 2022 and 2021. Furthermore, the cumulative authorized but unused transfers (contributions) from the Endowment Fund to TSC Alliance totaled \$572,625 for the years ending December 31, 2022 and 2021.

## NOTE 9. ENDOWMENT FUNDS (CONTINUED)

**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 U.S. 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, 2022 and 2021.

Endowment funds consisted of the following at December 31, 2022:

	Without Donor Restrictions	With Donor Restrictions			Other Temporary Net Assets	Total with Donor Restriction	Total Endowment Funds
		Endowment investments					
		Available for Appropriation	Held in Perpetuity	Total			
Board-designated	\$ 4,634,432	\$ -	\$ -	\$ -	\$ -	\$ -	\$ 4,634,432
Donor-restricted	-	(47,386)	879,444	832,058	33,897	865,955	865,955
	<u>\$ 4,634,432</u>	<u>\$ (47,386)</u>	<u>\$ 879,444</u>	<u>\$ 832,058</u>	<u>\$ 33,897</u>	<u>\$ 865,955</u>	<u>\$ 5,500,387</u>

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

	Without Donor Restrictions	With Donor Restrictions			Other Temporary Net Assets	Total with Donor Restriction	Total Endowment Funds
		Endowment investments					
		Available for Appropriation	Held in Perpetuity	Total			
Board-designated	\$ 5,676,477	\$ -	\$ -	\$ -	\$ -	\$ -	\$ 5,676,477
Donor-restricted	-	133,491	879,444	1,012,935	22,336	1,035,271	1,035,271
	<u>\$ 5,676,477</u>	<u>\$ 133,491</u>	<u>\$ 879,444</u>	<u>\$ 1,012,935</u>	<u>\$ 22,336</u>	<u>\$ 1,035,271</u>	<u>\$ 6,711,748</u>

Changes in the endowment funds consisted of the following as of and for the year ended December 31, 2022:

	Without Donor Restrictions	With Donor Restrictions			Other Temporary Net Assets	Total with Donor Restriction	Total Endowment Funds
		Endowment investments					
		Available for Appropriation	Held in Perpetuity	Total			
Beginning	\$ 5,676,477	\$ 133,491	\$ 879,444	\$ 1,012,935	\$ 22,336	\$ 1,035,271	\$ 6,711,748
Contributions	56,862	-	-	-	11,561	11,561	68,423
Net investment return	(729,806)	(130,230)	-	(130,230)	-	(130,230)	(860,036)
Appropriations and transfers							
Appropriation per spending policy	(238,000)	-	-	-	-	-	(238,000)
Program and supporting services	(131,101)	(50,647)	-	(50,647)	-	(50,647)	(181,748)
Ending	<u>\$ 4,634,432</u>	<u>\$ (47,386)</u>	<u>\$ 879,444</u>	<u>\$ 832,058</u>	<u>\$ 33,897</u>	<u>\$ 865,955</u>	<u>\$ 5,500,387</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			Other Temporary Net Assets	Total with Donor Restriction	Total Endowment Funds
		Endowment investments					
		Available for Appropriation	Held in Perpetuity	Total			
Beginning	\$ 4,996,142	\$ 17,935	\$ 879,444	\$ 897,379	\$ -	\$ 897,379	\$ 5,893,521
Contributions	110,140	-	-	-	22,336	22,336	132,476
Net investment return	854,908	160,425	-	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)	-	(44,869)	(103,582)
Ending	<u>\$ 5,676,477</u>	<u>\$ 133,491</u>	<u>\$ 879,444</u>	<u>\$ 1,012,935</u>	<u>\$ 22,336</u>	<u>\$ 1,035,271</u>	<u>\$ 6,711,748</u>

## NOTE 10. CONTRIBUTED NONFINANCIAL ASSETS

**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. Contributed services recognized comprise professional services from investment managers and event organizers. Contributed services are valued and are recorded at the estimated fair value in the consolidated statements based on current rates for similar professional services. Contributed nonfinancial assets did not have donor-imposed restrictions. They are used for supporting services.

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.

Contributed nonfinancial assets consisted of the following for the years ended December 31, 2022 and 2021:

	<u>2022</u>	<u>2021</u>
Donated goods	\$ -	\$ 724
Donated services		
Event and advertising services	10,000	34,028
Investment management fees	<u>23,843</u>	<u>34,024</u>
	<u>\$ 33,843</u>	<u>\$ 68,776</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 11. PAYCHECK PROTECTION PROGRAM LOAN

In March 2021, the Alliance obtained a PPP loan totaling \$380,595. The loan was scheduled to mature in March 2026 but was forgiven by the Small Business Administration (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 loan became unconditional contribution. Therefore, the Alliance recognized the contribution on the consolidated statements of activities totaling \$380,595 during the year ended December 31, 2021.

## NOTE 12. 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 \$36,068 and \$33,150 during the years ended December 31, 2022 and 2021, respectively.

Joint costs were allocated to the following activities for the years ended December 31, 2022 and 2021:

	<u>2022</u>	<u>2021</u>
Family services	\$ 18,034	\$ 16,575
Fundraising	<u>18,034</u>	<u>16,575</u>
	<u>\$ 36,068</u>	<u>\$ 33,150</u>

## NOTE 13. PROFESSIONAL FEES

Professional fees consisted of the following for the years ended December 31, 2022 and 2021:

	<u>2022</u>	<u>2021</u>
Professional fundraising consulting	\$ 122,652	\$ 189,113
Marketing consulting	97,000	155,698
Government relations consulting	116,364	112,980
Legal fees	36,436	53,261
Website	24,715	46,027
Audit and tax preparation fees	34,421	33,419
Recruiting and payroll fees	7,138	19,698
Other consulting	12,781	19,515
Events production consulting	<u>10,000</u>	<u>10,000</u>
	<u>\$ 461,507</u>	<u>\$ 639,711</u>



## NOTE 14. 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 \$67,217 and \$60,399 for the years ended December 31, 2022 and 2021, respectively.

## NOTE 15. 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 \$163,749 and \$257,213 during the years ended December 31, 2022 and 2021, 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 16. OPERATING LEASES

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.

## NOTE 16. OPERATING LEASES (CONTINUED)

The weighted average remaining lease term was 8.25 and 9.25 years at December 31, 2022 and 2021, respectively, and the weighted average discount rate was 4.75%. The operating lease right of use asset, net of amortization, totaled \$718,708 and \$778,371 at December 31, 2022 and 2021, respectively. The operating lease liability totaled \$1,189,842 and \$1,285,691 at December 31, 2022 and 2021, respectively.

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

Year Ending December 31,	
2023	\$ 158,501
2024	162,859
2025	167,338
2026	171,940
2027	176,668
Thereafter	<u>607,927</u>
	1,445,233
Discount to net present value	<u>(255,391)</u>
	<u>\$ 1,189,842</u>

Rent expense, including operating pass through costs, related to operating leases was \$132,836 and \$128,138 for the years ended December 31, 2022 and 2021, respectively.

## NOTE 17. COMMITMENTS AND CONTINGENCIES

**Grant commitments:** The Alliance's Board of Directors has authorized research grants totaling \$674,909 and \$924,747 as of December 31, 2022 and 2021, respectively. The research grants extend through 2024 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:

Year Ending December 31,	
2023	\$ 506,159
2024	<u>168,750</u>
	<u>\$ 674,909</u>



## NOTE 17. COMMITMENTS AND CONTINGENCIES (CONTINUED)

**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.

**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

## NOTE 18. SUBSEQUENT EVENTS REVIEW

Subsequent events have been evaluated through April 10, 2023, which is the date the consolidated financial statements were available to be issued. This review and evaluation revealed no material event or transaction which would require an adjustment to or disclosure in the accompanying consolidated financial statements.



## **SUPPLEMENTAL INFORMATION**





## NATIONAL TUBEROUS SCLEROSIS ASSOCIATION (D/B/A TSC ALLIANCE) AND AFFILIATE

### CONSOLIDATING STATEMENT OF FINANCIAL POSITION

DECEMBER 31, 2022

	TSC Alliance	Endowment	Eliminations	Total
<b>Assets</b>				
<b>Assets</b>				
Cash and cash equivalents	\$ 2,406,068	\$ 34,017	\$ -	\$ 2,440,085
Investments	-	5,577,848	-	5,577,848
Due from affiliate	-	6,484	(6,484)	-
Accounts receivable	181,490	-	-	181,490
Promises to give, net	5,280,316	-	-	5,280,316
Prepaid expenses and other assets	277,696	1,875	-	279,571
Interest in net assets of affiliate	5,500,387	-	(5,500,387)	-
Operating lease right of use asset, net	718,708	-	-	718,708
Property and equipment, net	<u>463,272</u>	<u>-</u>	<u>-</u>	<u>463,272</u>
Total assets	<u>\$ 14,827,937</u>	<u>\$ 5,620,224</u>	<u>\$ (5,506,871)</u>	<u>\$ 14,941,290</u>
<b>Liabilities and Net Assets</b>				
<b>Liabilities</b>				
Accounts payable and accrued expenses	\$ 593,162	\$ 6,386	\$ -	\$ 599,548
Due to affiliate	6,484	-	(6,484)	-
Accrued compensation	298,339	-	-	298,339
Deferred revenue	285,264	-	-	285,264
Operating lease liability, net	1,189,842	-	-	1,189,842
Gift annuity obligations, net	<u>-</u>	<u>113,451</u>	<u>-</u>	<u>113,451</u>
Total liabilities	<u>2,373,091</u>	<u>119,837</u>	<u>(6,484)</u>	<u>2,486,444</u>
<b>Net assets</b>				
Without donor restrictions				
Undesignated (deficit)	(158,002)	-	-	(158,002)
Board designated	<u>5,309,341</u>	<u>4,634,432</u>	<u>(4,634,432)</u>	<u>5,309,341</u>
Total net assets without donor restrictions	5,151,339	4,634,432	(4,634,432)	5,151,339
With donor restrictions	<u>7,303,507</u>	<u>865,955</u>	<u>(865,955)</u>	<u>7,303,507</u>
Total net assets	<u>12,454,846</u>	<u>5,500,387</u>	<u>(5,500,387)</u>	<u>12,454,846</u>
Total liabilities and net assets	<u>\$ 14,827,937</u>	<u>\$ 5,620,224</u>	<u>\$ (5,506,871)</u>	<u>\$ 14,941,290</u>

# NATIONAL TUBEROUS SCLEROSIS ASSOCIATION (D/B/A TSC ALLIANCE) AND AFFILIATE

## CONSOLIDATING STATEMENT OF ACTIVITIES

YEAR ENDED DECEMBER 31, 2022

	TSC Alliance			Endowment Fund			Eliminations			Consolidated Totals		
	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
<b>Support and revenue</b>												
Special events	\$ 1,446,809	\$ 112,339	\$ 1,559,148	\$ -	\$ -	\$ -	\$ -	\$ -	\$ -	\$ 1,446,809	\$ 112,339	\$ 1,559,148
Cost of direct benefits to donors	(125,478)	-	(125,478)	-	-	-	-	-	-	(125,478)	-	(125,478)
Special events, net	1,321,331	112,339	1,433,670	-	-	-	-	-	-	1,321,331	112,339	1,433,670
Contributions												
Individuals, companies and foundations	1,037,670	4,753,965	5,791,635	20,663	-	20,663	(308,000)	-	(308,000)	750,333	4,753,965	5,504,298
Memorials and honorariums	105,306	600	105,906	-	11,560	11,560	-	-	-	105,306	12,160	117,466
Federated funding	51,247	-	51,247	928	-	928	-	-	-	52,175	-	52,175
Contributed nonfinancial assets	10,000	-	10,000	23,843	-	23,843	-	-	-	33,843	-	33,843
Contracts	1,906,672	-	1,906,672	-	-	-	-	-	-	1,906,672	-	1,906,672
Interest and dividends	2,382	-	2,382	137,627	24,559	162,186	-	-	-	140,009	24,559	164,568
Conferences	813,645	-	813,645	-	-	-	-	-	-	813,645	-	813,645
Other revenue	15,492	-	15,492	-	-	-	-	-	-	15,492	-	15,492
Net assets released from restrictions	2,422,462	(2,422,462)	-	50,647	(50,647)	-	-	-	-	2,473,109	(2,473,109)	-
Total support and revenue	7,686,207	2,444,442	10,130,649	233,708	(14,528)	219,180	(308,000)	-	(308,000)	7,611,915	2,429,914	10,041,829
<b>Expenses</b>												
Program services												
Research	3,794,438	-	3,794,438	-	-	-	-	-	-	3,794,438	-	3,794,438
Family services	1,701,754	-	1,701,754	-	-	-	-	-	-	1,701,754	-	1,701,754
Public health education	520,210	-	520,210	-	-	-	-	-	-	520,210	-	520,210
Government relations	162,771	-	162,771	-	-	-	-	-	-	162,771	-	162,771
Professional education	105,471	-	105,471	-	-	-	-	-	-	105,471	-	105,471
Contribution to TSC Alliance	-	-	-	308,000	-	308,000	(308,000)	-	(308,000)	-	-	-
Total program services	6,284,644	-	6,284,644	308,000	-	308,000	(308,000)	-	(308,000)	6,284,644	-	6,284,644
Supporting services												
Fundraising	1,140,483	-	1,140,483	38,312	-	38,312	-	-	-	1,178,795	-	1,178,795
Management and general	648,556	-	648,556	23,836	-	23,836	-	-	-	672,392	-	672,392
Total supporting services	1,789,039	-	1,789,039	62,148	-	62,148	-	-	-	1,851,187	-	1,851,187
Total expenses	8,073,683	-	8,073,683	370,148	-	370,148	(308,000)	-	(308,000)	8,135,831	-	8,135,831
<b>Change in net assets before other item</b>	(387,476)	2,444,442	2,056,966	(136,440)	(14,528)	(150,968)	-	-	(308,000)	(523,916)	2,429,914	1,905,998
<b>Realized and unrealized gain (loss) on investments, net of fees</b>	254	-	254	(905,605)	(154,788)	(1,060,393)	-	-	-	(905,351)	(154,788)	(1,060,139)
<b>Change in interest in affiliate</b>	(1,042,045)	(169,316)	(1,211,361)	-	-	-	1,042,045	169,316	1,211,361	-	-	-
<b>Change in net assets</b>	(1,429,267)	2,275,126	845,859	(1,042,045)	(169,316)	(1,211,361)	1,042,045	169,316	1,211,361	(1,429,267)	2,275,126	845,859
<b>Net assets</b>												
Beginning of year	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
End of year	\$ 5,151,339	\$ 7,303,507	\$ 12,454,846	\$ 4,634,432	\$ 865,955	\$ 5,500,387	\$ (4,634,432)	\$ (865,955)	\$ (5,500,387)	\$ 5,151,339	\$ 7,303,507	\$ 12,454,846