

CONSOLIDATED FINANCIAL STATEMENTS

DECEMBER 31, 2023





## CONSOLIDATED FINANCIAL STATEMENTS

#### YEARS ENDED DECEMBER 31, 2023 AND 2022

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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 statements of financial position as of December 31, 2023 and 2022, and 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.

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, 2023 and 2022, and the changes in its net assets and its 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. Our responsibilities under those standards are further described in the Auditor's Responsibilities for the Audit of the Consolidated 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 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 consolidated 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 consolidated 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 audits were 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, 2023 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 2023 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 2023 consolidated financial statements as a whole.

Calibre CPA Group, PLLC

Bethesda, MD April 5, 2024



## CONSOLIDATED STATEMENTS OF FINANCIAL POSITION

#### DECEMBER 31, 2023 AND 2022

		2023		2022
Assets				
Assets				
Cash and cash equivalents	\$	2,305,166	\$	2,440,085
Investments		7,898,056		5,577,848
Accounts receivable		350,534		181,490
Promises to give, net		4,306,013		5,280,316
Prepaid expenses and other assets		283,821		279,571
Operating lease right-of-use assets, net		654,282		718,708
Property and equipment, net		393,961		463,272
Total assets	\$	16,191,833	<u>\$</u>	14,941,290
Liabilities and Net Assets				
Liabilities				
Accounts payable and accrued expenses	\$	519,162	\$	599,548
Accrued compensation		310,445		298,339
Deferred revenue		189,493		285,264
Operating lease liability, net		1,084,988		1,189,842
Gift annuity obligations, net		90,397		113,451
Total liabilities		2,194,485		2,486,444
Net assets				
Without donor restrictions				
Undesignated		779,859		(158,002)
Board-designated		5,593,099		5,309,341
Total net assets without donor restrictions		6,372,958		5,151,339
With donor restrictions		7,624,390		7,303,507
Total net assets		13,997,348		12,454,846
Total liabilities and net assets	<u>\$</u>	16,191,833	<u>\$</u>	14,941,290



CONSOLIDATED STATEMENTS OF ACTIVITIES

## YEARS ENDED DECEMBER 31, 2023 AND 2022

		2023			2022	
	Without			Without		
	Donor	With Donor		Donor	With Donor	
	Restrictions	Restrictions	Total	Restrictions	Restrictions	Total
Support and revenue						
Special events	\$ 1,308,033	\$ 130,107	\$ 1,438,140	\$ 1,446,809	\$ 112,339	\$ 1,559,148
Cost of direct benefits to donors	(164,132)	-	(164,132)	(125,478)	-	(125,478)
Special events, net	1,143,901	130,107	1,274,008	1,321,331	112,339	1,433,670
Contributions						
Individuals, companies and foundations	1,302,612	3,676,704	4,979,316	750,333	4,753,965	5,504,298
Memorials and honorariums	85,722	1,900	87,622	105,306	12,160	117,466
Federated funding	48,667	-	48,667	52,175	-	52,175
Contributed nonfinancial assets	36,799	-	36,799	33,843	-	33.843
Contracts	2,548,976	-	2,548,976	1,906,672	-	1,906,672
Interest and dividends	180,486	25,622	206,108	140,009	24,559	164,568
Conferences	266.377		266,377	813,645	,	813,645
Other revenue	995	-	995	15,492	-	15,492
Net assets released from restrictions	3,616,501	(3,616,501)	-	2,473,109	(2,473,109)	-
Total support and revenue	9,231,036	217,832	9,448,868	7,611,915	2,429,914	10,041,829
Expenses						
Program services						
Research	5,022,281	-	5,022,281	3,794,438	-	3,794,438
Family services	895,227	-	895,227	1,701,754	-	1,701,754
Public health education	554,030	-	554,030	520,210	-	520,210
Government relations	188,742	-	188,742	162,771	-	162,771
Professional education	100,161	-	100,161	105,471	-	105,471
Total program services	6,760,441	-	6,760,441	6,284,644	-	6,284,644
Supporting services						
Fundraising	1,202,389	-	1,202,389	1,178,795	-	1,178,795
Management and general	580,436	-	580,436	672,392	-	672,392
Total supporting services	1,782,825	-	1,782,825	1,851,187	-	1,851,187
Total expenses	8,543,266	-	8,543,266	8,135,831	-	8,135,831
·						
Change in net assets before other item	687,770	217,832	905,602	(523,916)	2,429,914	1,905,998
-				,		
Realized and unrealized gain (loss) on investments,						
net of fees	533,849	103,051	636,900	(905,351)	(154,788)	(1,060,139)
Change in net assets	1,221,619	320,883	1,542,502	(1,429,267)	2,275,126	845,859
Net assets						
Beginning of year	5,151,339	7,303,507	12,454,846	6,580,606	5,028,381	11,608,987
	¢ (070.0		A 10 007 0 17	A 51510	A 7000 5	
End of year	<u>\$ 6,372,958</u>	\$ 7,624,390	<u>\$ 13,997,348</u>	<u>\$ 5,151,339</u>	\$ 7,303,507	<u>\$ 12,454,846</u>



### CONSOLIDATED STATEMENT OF FUNCTIONAL EXPENSES

## YEAR ENDED DECEMBER 31, 2023

		F	Progra	am Services						Supporting Services						
		Family	Puk	olic Health	Go	vernment	Pro	fessional			Ма	nagement				
	Research	 ervices	E	ducation	R	elations	Ed	Education		Education		ndraising	and General			Total
Salaries	\$ 819,062	\$ 410,811	\$	252,619	\$	36,789	\$	45,536	\$	577,214	\$	363,625	\$	2,505,656		
Preclinical consortium	2,321,442	-		-		-		-		-		-		2,321,442		
Grants	543,309	-		-		-		-		-		-		543,309		
Professional fees	12,985	13,649		98,011		116,638		214		109,110		73,492		424,099		
Employee benefits and payroll taxes	151,777	100,426		61,109		8,756		8,143		128,718		59,790		518,719		
Clinical research consortium	301,983	-		-		-		-		-		-		301,983		
Biosample repository	215,816	-		-		-		-		-		-		215,816		
Equipment maintenance and rental	56,890	19,232		10,647		1,189		929		71,919		18,058		178,864		
Operating lease	41,591	29,106		16,781		2,511		1,961		36,211		16,592		144,753		
Printing and promotion	13,324	15,663		57,144		1,267		47		59,813		138		147,396		
Training, conferences and exhibits	239,861	109,287		3,220		11,944		30,246		30,870		2,709		428,137		
Depreciation and amortization	36,329	9,016		6,029		795		621		11,267		5,254		69,311		
Natural history database	112,570	-		-		-		-		-		-		112,570		
Telephone	12,551	14,792		14,972		428		1,244		14,102		5,088		63,177		
Postage and shipping	2,115	12,770		16,152		477		604		28,973		1,411		62,502		
Dues, fees, and subscriptions	7,637	1,140		2,385		2,191		377		13,731		15,645		43,106		
Costs of direct benefit to donors	-	-		-		-		-		164,132		-		164,132		
Other expenses	1,536	1,409		966		377		25		4,770		1,944		11,027		
Bank, credit card, and transaction fees	190	269		64		9		7		49,469		1,219		51,227		
Insurance	3,789	2,593		1,529		229		179		3,240		4,701		16,260		
Travel	120,656	149,447		9,699		4,752		9,715		53,178		5,314		352,761		
Supplies	2,279	2,476		851		113		97		5,879		356		12,051		
Board and committee meetings	4,589	 3,141		1,852		277		216		3,925		5,100		19,100		
	5,022,281	895,227		554,030		188,742		100,161		1,366,521		580,436		8,707,398		
Less costs of direct benefit to donors		 						-		(164,132)				(164,132)		
Total functional expenses	<u>\$ 5,022,281</u>	\$ 895,227	\$	554,030	\$	188,742	\$	100,161	\$	1,202,389	<u>\$</u>	580,436	\$	8,543,266		

See accompanying notes to consolidated financial statements.





## CONSOLIDATED STATEMENT OF FUNCTIONAL EXPENSES

## YEAR ENDED DECEMBER 31, 2022

			F	Progra	am Services						Supporting Services					
			Family	Puk	lic Health	Go	vernment	Pro	fessional			Mc	inagement			
	Research		Services	Ec	ducation	R	elations	Ec	lucation	Fu	ndraising	and General			Total	
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	
2	3,794,438		1,701,754		520,210		162,771		105,471		1,304,273		672,392		8,261,309	
Less costs of direct benefit to donors			-		-		-		-		(125,478)		-		(125,478)	
Total functional expenses	<u>\$ 3,794,438</u>	<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	

See accompanying notes to consolidated financial statements.





CONSOLIDATED STATEMENTS OF CASH FLOWS

### YEARS ENDED DECEMBER 31, 2023 AND 2022

		2023		2022
Cash flows from operating activities				
Change in net assets	\$	1,542,502	\$	845,859
Adjustments to reconcile change in net assets to net cash				
provided by (used for) operating activities				1 001 0 /0
Realized and unrealized (gain) loss on investments		(384,260)		1,021,968
Discount on promises to give		145,196		127,841
Depreciation and amortization of property and equipment		69,311		68,866
Amortization of operating lease right of use assets, net		64,426		59,663
Change in value of gift annuity obligations		(8,474)		11,429
Change in assets and liabilities				
Accounts receivable		(169,044)		(82,317)
Promises to give		829,107		(2,709,662)
Prepaid expenses and other assets		(4,250)		340,577
Accounts payable and accrued expenses		(80,386)		413,538
Accrued compensation		12,106		7,852
Deferred revenue		(95,771)		(391,534)
Operating lease liability		(104,854)		(95,849)
Net cash provided by (used for) operating activities		1,815,609		(381,769)
Cash flows from investing activities				
Proceeds from sales and maturities of investments		1,240,311		50,000
Purchases of investments		(3,176,259)		41,197
Purchases of property and equipment		-		(94,969)
Net cash used for investing activities	_	(1,935,948)		(3,772)
Cash flows from financing activities				
Payments on gift annuity obligations		(14,580)		(17,643)
Net cash used for financing activities		(14,580)		(17,643)
Net change in cash and cash equivalents		(134,919)		(403,184)
Cash and cash equivalents				
Beginning of year		2,440,085		2,843,269
End of year	\$	2,305,166	\$	2,440,085
Supplemental disclosures of noncash investing activities				
Donated securities	\$	203,136	\$	46,058
	Ψ	200,100	Ψ	10,000



NOTES TO CONSOLIDATED FINANCIAL STATEMENTS

YEARS ENDED DECEMBER 31, 2023 AND 2022

### 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 improves quality of life for everyone affected by tuberous sclerosis complex by catalyzing new treatments, driving research toward a cure, and expanding access to lifelong support. 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.

In 2023, the TSC Alliance hosted its biennial International TSC Research Conference: Fueling the Future. Fifteen percent of attendees self-identified as members of groups historically underrepresented in biomedical research. The conference featured an Early Career Research Symposium, a keynote speech from Dr. Martina Bebin, 30 oral presentations, 59 posters, a TSC International workshop, and a combined closing session with Regional TSC and LAM Conference participants. The conference also featured four

breakout working group sessions (Transition from Pediatric to Adult, Neurodevelopment and Early Intervention, Cellular Energetics and Metabolism, and Big Data and Single Cell Approaches/Analysis) to allow time for attendees to meet with others in their field and work toward solutions for current issues in their area.

**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 donating 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, 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 2023, the TSC Alliance also partnered with the LAM Foundation to co-host four educational conference series held in Seattle, WA; Denver, CO; Birmingham, AL; Washington, D.C. These conferences attracted 350-plus participants.

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 2023, the TSC Alliance hosted seven research and corporate partner webinars with 312 live attendees, 832 cumulative recording views and 801 landing page visits. Additionally, the TSC Alliance's podcast series, TSC Now, produced eight episodes with 2,180 total listens. Five issues of the electronic TSC Matters newsletter were distributed to 17,514 recipients. The TSC Alliance's website increases awareness and provides extensive education through an average of more than 26,000 unique visitors each month.

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

**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.

**Global outreach:** Global outreach works to address unmet needs within the global TSC community. The program provides the opportunity for the TSC Alliance to share experiences and assist in the start-up of support of TSC-related organizations in other countries. A Global Alliance is a structured group of empowered and caring volunteers who work closely with the TSC Alliance to facilitate local connections for individuals and families affected by TSC and raise revenue and awareness while supporting the mission of the organization.

**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 22% for the years ended December 31, 2023 and 2022, 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.

**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, and donated stock liquidation 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., Federal Deposit Insurance Corporation (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.

**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. The Alliance writes off receivables when there is information that indicates the debtor is facing significant financial difficulty and there is no possibility of recovery. If any recoveries are made from any accounts previously written off, they will be recognized in income or an offset to credit loss expense in the year of recovery, in accordance with the entity's accounting policy election. The total amount of write-offs was immaterial to the financial statements as a whole for the years ending December 31, 2023 and 2022.

**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 7.12%.

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, 2023 and 2022.

**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 14. 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 \$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-ofuse 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 14.

**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 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 2023, the Alliance hosted 14 live walks for Step Forward to Cure TSC® in California, Texas and Pennsylvania

In 2023 and 2022, Comedy for a Cure fundraising event returned to an in-person event held in Hollywood, California.

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 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 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 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.

**New Accounting Pronouncement Adopted** - During the year ended December 31, 2023, the Alliance adopted the provisions of Accounting Standards Update (ASU) 2016-13, *Financial Instruments* – *Credit Losses* (Topic 326). This ASU replaced the incurred loss methodology with an expected loss methodology that is referred as the current expected credit loss (CECL) methodology. The ASU requires nonprofit entities the immediate recognition of estimated expected credit losses over the life of a financial instrument, including trade receivables, membership dues, and events receivables. The estimate of expected credit losses considers not only historical information, but also current and future economic conditions and events. The Alliance adopted the ASU effective January 1, 2023. The impact of the adoption was not considered material to the consolidated financial statements and primarily resulted in additional disclosures.

#### 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 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.
- 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, 2023 and 2022.

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 and U.S Treasury Notes - 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.



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

Investments valued at fair value on a recurring basis consisted of the following at December 31, 2023 and 2022:

	December 31, 2023							
	Total	Level 1	Level 2	Level 3				
Investments at fair value								
Mutual funds								
Bonds	\$ 126,458	\$ 126,458	\$ -	\$ -				
Domestic equity	3,319,942	3,319,942	-	-				
International equity	810,385	810,385	-	-				
Exchange traded funds	516,329	516,329	-	-				
Preferred stock	49,813	49,813	-	-				
U.S Treasury notes	1,722,087	-	1,722,087	-				
Corporate bonds	538,626		538,626					
	7,083,640	<u>\$ 4,822,927</u>	<u>\$2,260,713</u>	<u>\$                                    </u>				
Investments at cost								
Money market funds	814,416							
	<u>\$ 7,898,056</u>							

	December 31, 2022							
	Total		L	Level 1		Level 2		vel 3
Investments at fair value								
Mutual funds								
Bonds	\$	31,792	\$	31,792	\$	-	\$	-
Domestic equity		3,609,113	3	6,609,113		-		-
International equity		644,688		644,688		-		-
Exchange traded funds - fixed income		233,368		233,368		-		-
Preferred stock		109,869		109,869		-		-
Corporate bonds		577,008		-		577,008		-
		5,205,838	\$ 4	,628,830	\$	577,008	\$	-
Investments at cost								
Money market funds		372,010						
	\$ .	5,577,848						

Net Investment return consisted of the following for the years ended December 31, 2023 and 2022:

	 2023		2022
Interest and dividends	\$ 206,108	\$	164,568
Realized and unrealized gain (loss) on investments	674,987		(1,021,968)
Investment management fees	 (38,087)		<u>(38,171</u> )
Total	\$ 843,008	<u>\$</u>	<u>(895,571</u> )

### NOTE 3. PROMISES TO GIVE

Promises to give (unconditional contributions receivable) consisted of the following at December 31, 2023 and 2022:

	2023	2022
Amounts due in less than one year Amounts due in one to five years	\$ 2,005,935 2,716,680	\$ 3,520,091 2,031,631
Less discount to net present value	4,722,615 (416,602)	5,551,722 (271,406)
Total	<u>\$ 4,306,013</u>	<u>\$ 5,280,316</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 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.

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

The following provides a summary of financial assets available for general expenditures within one year at December 31, 2023 and 2022.

	2023	2022
Cash and cash equivalents	\$ 2,305,166	\$ 2,440,085
Investments	7,898,056	5,577,848
Accounts receivable	350,534	181,490
Promises to give, net	4,306,013	5,280,316
	14,859,769	13,479,739
Less amounts not available for general expenditures		
Cash and investments held to fund gift annuity obligations	(188,111)	(177,382)
Board-designated net assets	(5,593,099)	(5,309,341)
Net assets with donor restrictions	(7,624,390)	(7,303,507)
	(13,405,600)	(12,790,230)
Add amounts available for general expenditures Unused transfers from board-designated to undesignated		
net assets	573,625	572,625
	<u>\$ 2,027,794</u>	<u>\$ 1,262,134</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, 2023 and 2022. In accordance with the 5% spending policy, the expected appropriations for next year totaled \$239,000 and \$572,625 for the years ending December 31, 2023 and 2022, respectively. Furthermore, the cumulative authorized but unused transfers (contributions) from the Endowment Fund to TSC Alliance totaled \$573,625 for the years ending December 31, 2023 and 2022.

**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, 2023.

## NOTE 5. PROPERTY AND EQUIPMENT

	 2023		2022
Software	\$ 80,272	\$	80,272
Office furniture and equipment	281,726		281,726
Leasehold improvements	 449,272		449,272
	811,270		811,270
Less: accumulated depreciation and amortization	 (417,309)	_	(347,998)
	\$ 393,961	<u>\$</u>	463,272

Property and equipment consisted of the following at December 31, 2023 and 2022:

## 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 \$188,111 and \$177,382 at December 31, 2023 and 2022, 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 \$90,397 and \$113,451 at December 31, 2023 and 2022, respectively.

## NOTE 7. NET ASSETS

**Without donor restrictions**: Net assets without donor restrictions consisted of the following at December 31, 2023 and 2022:

	2023	2022
Undesignated	<u>\$ 779,859</u>	<u>\$ (158,002</u> )
Board-designated		
Endowment fund	4,866,862	4,634,432
Grant commitments	726,237	674,909
	5,593,099	5,309,341
	<u>\$ 6,372,958</u>	<u>\$ 5,151,339</u>

**With donor restrictions**: Net assets with donor restrictions consisted of the following as of and for the year ended December 31, 2023 and 2022:

		Balance at January 1, 2023		ntributions Investment Return	Net Assets Released from Restrictions			alance at cember 31, 2023
Restricted by program:								
Research	\$	6,197,181	\$	3,487,712	\$	(3,193,184)	\$	6,491,709
Endowment fund		832,058		128,672		(41,603)		919,127
Public education		122,228		113,500		(124,674)		111,054
Family services		98,662		207,500		(203,662)		102,500
TSC International		53,378		-		<u>(53,378</u> )		-
	<u>\$</u>	7,303,507	\$	3,937,384	\$	(3,616,501)	<u>\$</u>	7,624,390
		alance at anuary 1, 2022		ntributions Investment Return	Rel	Net Assets eased from restrictions		alance at cember 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
	\$	5,028,381	\$	4,748,235	\$	(2,473,109)	\$	7,303,507

### 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.

#### NOTE 8. ENDOWMENT FUNDS (CONTINUED)

**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 donorrestricted endowment funds absent explicit donor stipulations to the contrary. As a result of this interpretation, the Alliance classifies as net assets with donor restriction: (a) the original value of gifts donated to the endowment, (b) the original value of subsequent gifts to the endowment, and (c) accumulations to the endowment made in accordance with the direction of the applicable donor gift instrument Endowment funds are appropriated for expenditure by the Alliance in a manner consistent with the standard of prudence prescribed by MUPMIFA.

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

**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 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 \$572,625 and \$238,000 during the years ended December 31, 2023 and 2022, respectively. The actual contributions to TSC Alliance totaled \$572,625 and \$308,000 during the years ended December 31, 2023 and 2022, respectively.

#### NOTE 8. ENDOWMENT FUNDS (CONTINUED)

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, 2023 and 2022. In accordance with the 5% spending policy, the expected appropriations for next year totaled \$239,000. Furthermore, the cumulative authorized but unused transfers (contributions) from the Endowment Fund to TSC Alliance totaled \$334,625 for the years ending December 31, 2023 and 2022.

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, 2023 and 2022.

Endowment funds consisted of the following at December 31, 2023:

		With Donor Restrictions					
	Without	End	owment investm	ents	Other	Total	Total
	Donor	Available for	Held in		Temporary	with Donor	Endowment
	Restrictions	Appropriation	Perpetuity	Total	Net Assets	Restriction	Funds
Board-designated	\$ 4,866,863	\$-	\$-	\$-	\$-	\$-	\$ 4,866,863
Donor-restricted		39,683	879,444	919,127	35,197	954,324	954,324
	<u>\$ 4,866,863</u>	\$ 39,683	<u>\$ 879,444</u>	<u>\$ 919,127</u>	<u>\$ 35,197</u>	<u>\$ 954,324</u>	\$ 5,821,187

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

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

Changes in the endowment funds consisted of the following as of and for the year ended December 31, 2023:

		With Donor Restrictions												
		Without		End	owme	ent investm	ents		Other		Total		Total	
		Donor	Avc	ilable for	ł	leld in			Ten	nporary	wi	th Donor	En	dowment
	R	estrictions	Арр	ropriation	Pe	rpetuity		Total	Ne	t Assets	Re	estriction		Funds
Beginning	\$	4,634,432	\$	(47,386)	\$	879,444	\$	832,058	\$	33,897	\$	865,955	\$	5,500,387
Contributions		109,961		-		-		-		1,300		1,300		111,261
Net investment return		705,918		128,672		-		128,672		-		128,672		834,590
Appropriations and transfers														
Appropriation per spending policy		(572,625)		-		-		-		-		-		(572,625)
Program and supporting services		(10,823)		(41,603)		-		(41,603)		-		(41,603)		(52,426)
Ending	\$	4,866,863	\$	39,683	\$	879,444	\$	919,127	\$	35,197	\$	954,324	\$	5,821,187

## NOTE 8. ENDOWMENT FUNDS (CONTINUED)

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

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

### NOTE 9. 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.

Donated goods and services used for operations or special events are recognized as inkind 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, 2023 and 2022:

	 2023	2022		
Donated services				
Event and advertising services	\$ 4,718	\$	10,000	
Investment management fees	 22,081		23,843	
	\$ 26,799	<u>\$</u>	33,843	

### NOTE 9. CONTRIBUTED NONFINANCIAL ASSETS (CONTINUED)

**Unrecorded amounts**: Many individuals volunteer their time and perform a variety of tasks that assist the Alliance with the administration of its programs. Without these volunteers, the Alliance would struggle to maintain the same level of program services. Although greatly appreciated by the Alliance, U.S. GAAP does not allow such services to be recorded in the consolidated financial statements because the criteria for recording donated services have not been met.

## NOTE 10. ALLOCATION OF JOINT COSTS

The Alliance incurred joint costs relating to the Family services program. This program service activity, specifically the series of Step Forward to Cure TSC Walks, included both program content and appeals for contributions. Therefore, joint costs allocated between program and supporting services totaled \$43,084 and \$36,068 during the years ended December 31, 2023 and 2022, respectively.

Joint costs were allocated to the following activities for the years ended December 31, 2023 and 2022:

		2023		2022
Family services Fundraising	\$	21,542 21,542	\$	18,034 18,034
	<u>\$</u>	43,084	\$	36,068

#### NOTE 11. PROFESSIONAL FEES

Professional fees consisted of the following for the years ended December 31, 2023 and 2022:

	 2023		2022
Professional fundraising consulting	\$ 101,480	\$	122,652
Marketing consulting	26,115		97,000
Government relations consulting	116,364		116,364
Legal fees	24,530		36,436
Website	87,419		24,715
Audit and tax preparation fees	31,000		34,421
Recruiting and payroll fees	6,846		7,138
Other consulting	345		12,781
Events production consulting	 20,000		10,000
	\$ 414,099	\$	461,507

#### NOTE 12. RETIREMENT PLAN

The Alliance maintains a defined contribution 401(k) retirement plan for all employees who have met certain eligibility requirements. The plan requires employer contributions equal to 3% of the participating employees' eligible compensation. The Alliance's contributions to the plan totaled \$72,419 and \$67,217 for the years ended December 31, 2023 and 2022, respectively.

#### NOTE 13. RELATED PARTY TRANSACTIONS

**Board of Directors**: The Alliance has authorized research grants and natural history database charges to institutions at which certain members of the Board of Directors are employed. In accordance with the Alliance's conflict of interest policy, these relationships are disclosed to all persons charged with responsibility for approving the transactions and the director or officer must recuse themselves from participation in discussion, approvals or votes on such transactions. Grants and natural history database charges provided to such institutions totaled \$224,038 and \$163,749 during the years ended December 31, 2023 and 2022, 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 14. 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%.

## NOTE 14. OPERATING LEASES (CONTINUED)

The net present value of operating lease payments totaled \$1,289,751 on April 1, 2020. The weighted average remaining lease term was 8.25 and 9.25 years at December 31, 2023 and 2022, respectively, and the weighted average discount rate was 4.75%. The operating lease right-of-use asset, net of amortization, totaled \$654,282 and \$718,708 at December 31, 2023 and 2022, respectively. The operating lease liability totaled \$1,084,988 and \$1,189,842 at December 31, 2023 and 2022, 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,

2024	\$ 162,859
2025	167,338
2026	171,940
2027	176,668
2028	181,526
Thereafter	 426,401
	1,286,732
Discount to net present value	 (201,744)
	\$ 1,084,988

Rent expense, including operating pass through costs, related to operating leases was \$144,753 and \$132,836 for the years ended December 31, 2023 and 2022 respectively.

#### NOTE 15. COMMITMENTS AND CONTINGENCIES

**Grant commitments**: The Alliance's Board of Directors has authorized research grants totaling \$726,237 and \$674,909 as of December 31, 2023 and 2022, respectively. The research grants extend through 2025 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,

2024	\$ 419,370
2025	 306,867
	\$ 726,237

#### NOTE 15. 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.

**Paycheck Protection Program (PPP) loans**: The Small Business Administration (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 16. SUBSEQUENT EVENTS REVIEW

Subsequent events have been evaluated through April 5, 2024, 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





## CONSOLIDATING STATEMENT OF FINANCIAL POSITION

#### DECEMBER 31, 2023

	TSC Alliance	Endowment	Eliminations	Total
Assets				
Assets				
Cash and cash equivalents	\$ 2,188,360	\$ 116,806	\$-	\$ 2,305,166
Investments	1,752,986	6,145,070	-	7,898,056
Due from affiliate	334,624	694	(335,318)	-
Accounts receivable	350,534	-	-	350,534
Promises to give, net	4,306,013	-	-	4,306,013
Prepaid expenses and other assets	283,821	-	-	283,821
Interest in net assets of affiliate	5,821,187	-	(5,821,187)	-
Operating lease right-of-use asset, net	654,282	-	-	654,282
Property and equipment, net	393,961			393,961
Total assets	<u>\$ 16,085,768</u>	<u>\$ 6,262,570</u>	<u>\$ (6,156,505</u> )	<u>\$ 16,191,833</u>
Liabilities and Net Assets				
Liabilities				
Accounts payable and accrued expenses	\$ 502,801	\$ 16,361	\$ -	\$ 519,162
Due to affiliate	693	334,625	(335,318)	-
Accrued compensation	310,445	-	-	310,445
Deferred revenue	189,493	-	-	189,493
Operating lease liability, net	1,084,988	-	-	1,084,988
Gift annuity obligations, net		90,397		90,397
Total liabilities	2,088,420	441,383	(335,318)	2,194,485
Net assets				
Without donor restrictions				
Undesignated (deficit)	779,859	-	-	779,859
Board designated	5,593,099	4,866,862	(4,866,862)	5,593,099
Total net assets without donor restrictions	6,372,958	4,866,862	(4,866,862)	6,372,958
With donor restrictions	7,624,390	954,325	(954,325)	7,624,390
Total net assets	13,997,348	5,821,187	(5,821,187)	13,997,348
Total liabilities and net assets	<u>\$ 16,085,768</u>	<u>\$ 6,262,570</u>	<u>\$ (6,156,505</u> )	<u>\$ 16,191,833</u>



#### CONSOLIDATING STATEMENT OF ACTIVITIES

### YEAR ENDED DECEMBER 31, 2023

	TSC Alliance			Endowment Fund			Eliminations			Consolidated Totals		
	Without			Without			Without			Without		
	Donor	With Donor		Donor	With Donor		Donor	With Donor		Donor	With Donor	
	Restrictions	Restrictions	Total	Restrictions	Restrictions	Total	Restrictions	Restrictions	Total	Restrictions	Restrictions	Total
Support and revenue												
Special events	\$ 1,308,033	\$ 130,107	\$ 1,438,140	\$ -	\$ -	\$ -	\$ -	\$ -	\$ -	\$ 1,308,033	\$ 130,107	\$ 1,438,140
Cost of direct benefits to donors	(164,132)		(164,132)							(164,132)		(164,132)
Special events, net	1,143,901	130,107	1,274,008	-	-	-	-	-	-	1,143,901	130,107	1,274,008
Contributions												
Individuals, companies and foundations	1,766,706	3,676,704	5,443,410	108,531		108,531	(572,625)	-	(572,625)	1,302,612	3,676,704	4,979,316
Memorials and honorariums	84,392	600	84,992	1,330	1,300	2,630	-	-	-	85,722	1,900	87,622
Federated funding	40,093	-	40,093	8,574	-	8,574	-	-	-	48,667	-	48,667
Contributed nonfinancial assets	14,718	-	14,718	22,081	-	22,081	-	-	-	36,799	-	36,799
Contracts	2,548,976	-	2,548,976	-	-	-	-	-	-	2,548,976	-	2,548,976
Interest and dividends	36,732	-	36,732	143,754	25,622	169,376	-	-	-	180,486	25,622	206,108
Conferences	266,377	-	266,377	-	-	-	-	-	-	266,377	-	266,377
Other revenue	995	-	995	-	-	-	-	-	-	995	-	995
Net assets released from restrictions	3,574,898	(3,574,898)		41,603	(41,603)					3,616,501	(3,616,501)	
Total support and revenue	9,477,788	232,513	9,710,301	325,873	(14,681)	311,192	(572,625)		(572,625)	9,231,036	217,832	9,448,868
Expenses												
Program services												
Research	5,022,281	-	5,022,281	-	-	-	-	-	-	5,022,281	-	5,022,281
Family services	895,227	-	895,227	-	-	-	-	-	-	895,227	-	895,227
Public health education	554,030	-	554,030	-	-	-	-	-	-	554,030	-	554,030
Government relations	188,742	-	188,742	-	-	-	-	-	-	188,742	-	188,742
Professional education	100,161	-	100,161	-	-	-	-	-	-	100,161	-	100,161
Contribution to TSC Alliance				572,625		572,625	(572,625)		(572,625)			
Total program services	6,760,441		6,760,441	572,625		572,625	(572,625)			6,760,441		6,760,441
Supporting services												
Fundraising	1,163,997	-	1,163,997	38,392	-	38,392	-	-	-	1,202,389	-	1,202,389
Management and general	557,928		557,928	22,508		22,508				580,436		580,436
Total supporting services	1,721,925		1,721,925	60,900		60,900				1,782,825		1,782,825
Total expenses	8,482,366		8,482,366	633,525		633,525	(572,625)		<u> </u>	8,543,266		8,543,266
Change in net assets before other item	995,422	232,513	1,227,935	(307,652)	(14,681)	(322,333)	-	-	(572,625)	687,770	217,832	905,602
Realized and unrealized gain (loss) on investments,												
net of fees	(6,233)	-	(6,233)	540,082	103,051	643,133	-	-	-	533,849	103,051	636,900
Change in interest in affiliate	232,430	88,370	320,800				(232,430)	(88,370)	(320,800)			
Change in net assets	1,221,619	320,883	1,542,502	232,430	88,370	320,800	(232,430)	(88,370)	(320,800)	1,221,619	320,883	1,542,502
Net assets												
Beginning 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
End of year	<u>\$ 6,372,958</u>	<u>\$ 7,624,390</u>	<u>\$ 13,997,348</u>	<u>\$ 4,866,862</u>	<u>\$ 954,325</u>	<u>\$ 5,821,187</u>	<u>\$ (4,866,862</u> )	<u>\$ (954,325</u> )	<u>\$ (5,821,187</u> )	\$ 6,372,958	<u>\$ 7,624,390</u>	<u>\$ 13,997,348</u>