

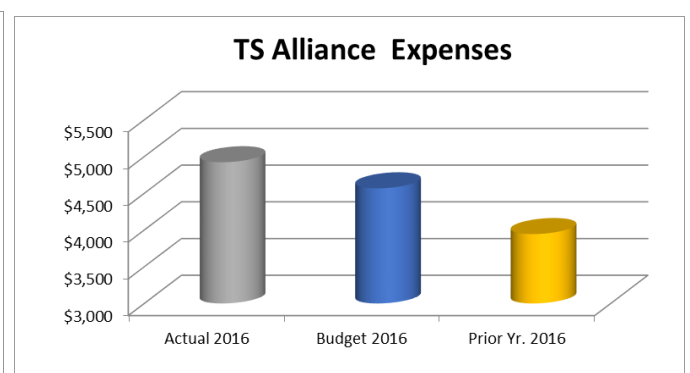
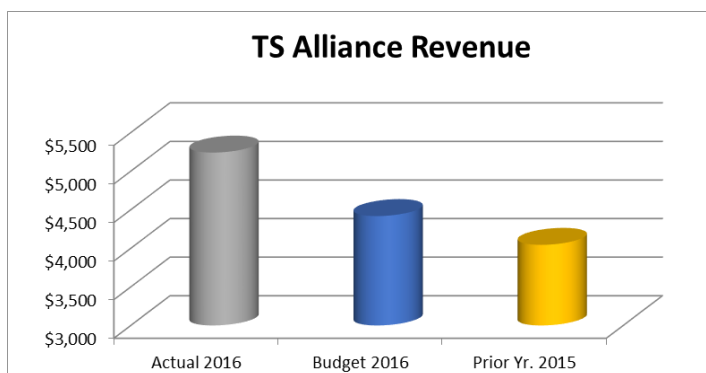
CEO DASHBOARD

December 2016

TSA Financial Dashboard							
REVENUE/EXPENSES	2-Yrs Prior Act.	Prior Actual	Budget	Actual	YTD v. Bud. Variance		Comments
	12/31/14	YTD 12/31/15	12/31/16	12/31/16	\$	%	
Net Special Events Revenue	\$ 1,471	\$ 1,467	\$ 1,527	\$ 1,363	(164)	-10.7%	
Major Donor Contributions	794	551	1,106	786	(320)	-28.9%	
Grants	524	1,015	842	2,195	1,353	160.7%	Includes Engles Family Foundation 3 year grant
Contracts	551	380	418	629	211	50.5%	Includes \$175k of unbudgeted Preclinical Consortium rever
Sponsorships	553	96	-	-	-		
Other General Contributions	296	313	306	251	(55)	-18.0%	
Total General Contributions	\$ 2,718	\$ 2,355	\$ 2,672	\$ 3,861	1,189	44.5%	
Endowment Transfer	97	202	206	-	(206)		No Endowment contribution needed in 2016
Other Revenue	129	21	13	17	4	30.8%	
TOTAL REVENUE	\$ 4,415	\$ 4,045	\$ 4,418	\$ 5,241	823	18.6%	
TOTAL EXPENSES	4,305	3,945	4,568	4,916	348	-7.6%	
Change in Net Assets	110	100	(150)	325	475		
NET ASSETS	\$ 3,559	\$ 3,657	N/A	\$ 3,981			
RATIOS:							
CASH & INVESTMENTS	12/31/14	YTD 12/31/15	12/31/16		Comments		
Cash & Cash Equivalents	\$ 2,223	\$ 2,672	\$ 1,920		Increased reserve to \$700 in Nov 14 From the TS Alliance operating SFP		
Cash Reserve	700	700	700				
TOTAL OPERATING CASH	\$ 2,923	\$ 3,372	\$ 2,620				
ACCOUNTS:							
Citibank	\$ 261	\$ 586	\$ 239		Checking - Lockbox, ACH, Disbursements Opened Oct 2013, Payroll, Deposits, Luminate		
TD Bank	470	128	130				
Xenith Bank - ICS Account (0.40%)	1,439	1,940	1,701		Courage Funds Courage Funds CD matured June 30, 2015		
Xenith Bank - Money Market (1.26%)	-	263	267				
Xenith CD 1 Yr (1.28%)	248	-	-		Opened May 2014, rate increased in March 2015		
Capital One Money Market (1.00%)	342	498	513		Matured Sept. 10, 2015		
Synchrony Bank CD 15 Month (1.14%)	247	-	-		Stock donations- unrestricted		
Morgan Stanley Cash Account	-	1	-				
TOTAL DEPOSITS	\$ 3,007	\$ 3,416	\$ 2,850		* At Dec. 31, 2016 deposit accts. exceeded the FDIC insured limits by \$280k.		
Temp Restricted Net Assets	\$ 1,624	\$ 1,879	\$ 2,993				
Unrestricted Net Assets	\$ 1,828	\$ 1,778	\$ 988				
ENDOWMENT	12/31/14	YTD 12/31/15	12/31/16		Comments		
			PYTD Net	YTD Net			
NET ASSETS (Beginning)	\$ 4,995	\$ 5,062		\$ 4,764		-5.9%	Mutual funds sold and new funds acquired in Oct 2016
Realized Gains (Losses)	-	(16)		58			
Unrealized Gains (Losses)	(191)	(389)		467		-220.1%	
Other	258	109		5		-95.4%	
NET ASSETS (Ending)	\$ 5,062	\$ 4,766	\$ (296)	\$ 5,294	\$ 530	11.1%	
Cash - Citibank	\$ 65	\$ 154		\$ 135			Investments transferred in August 2016
Investments-Morg.Stanley/Wealth Dimensions	\$ 5,082	\$ 4,689	\$ (393)	\$ 5,215	\$ 526	11.2%	
		\$ 5,082		\$ 4,689			

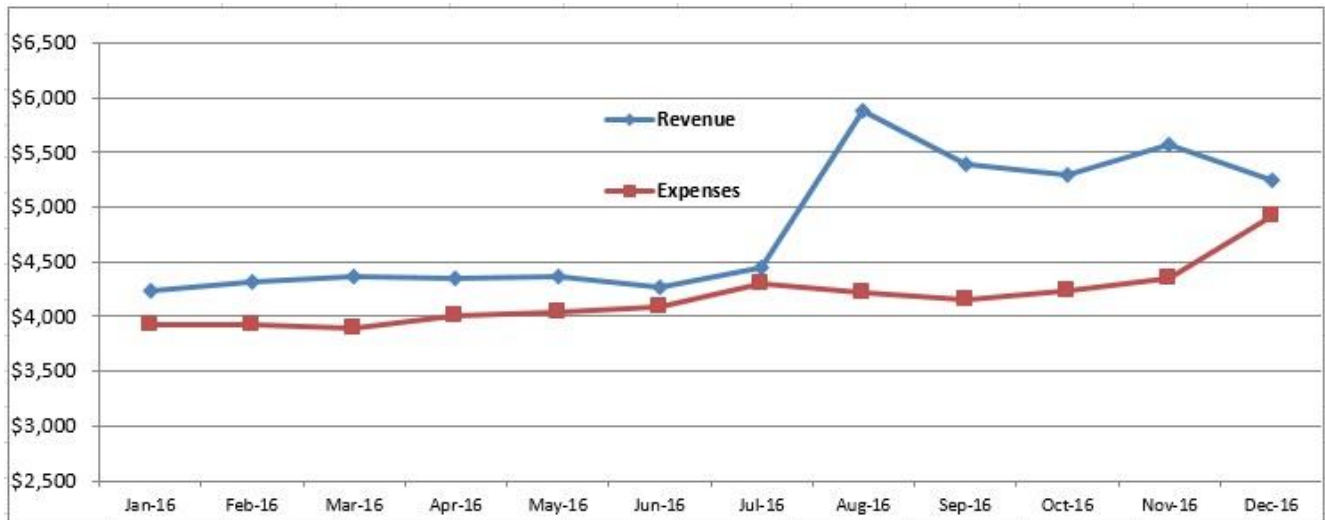
YTD Financials vs. Budget and Prior Year

Source: TS Alliance General Ledger



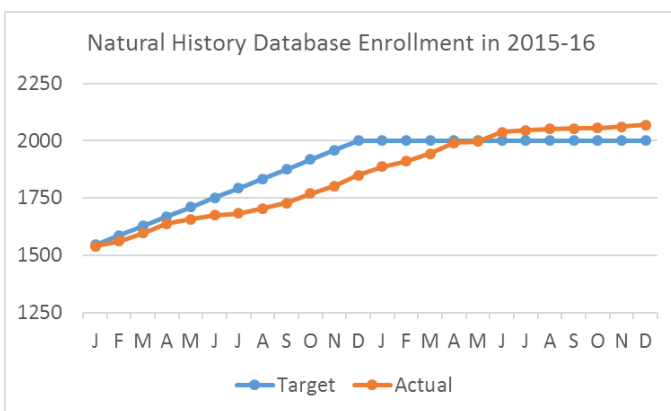
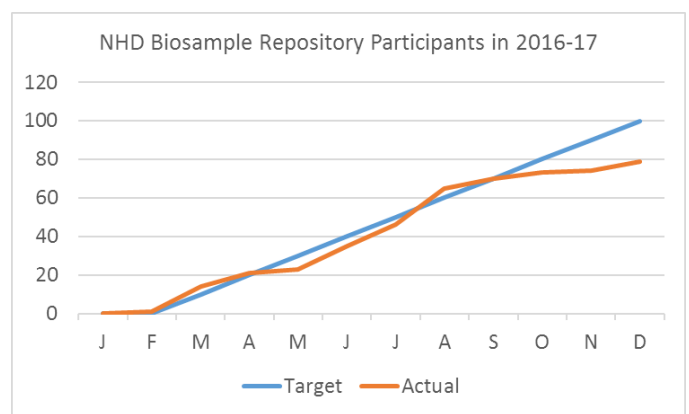
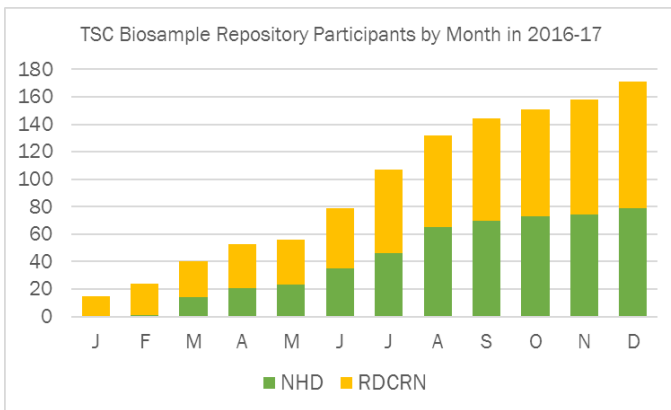
Twelve Month Trailing Totals

Source: TS Alliance General Ledger and Audited Financial Statements



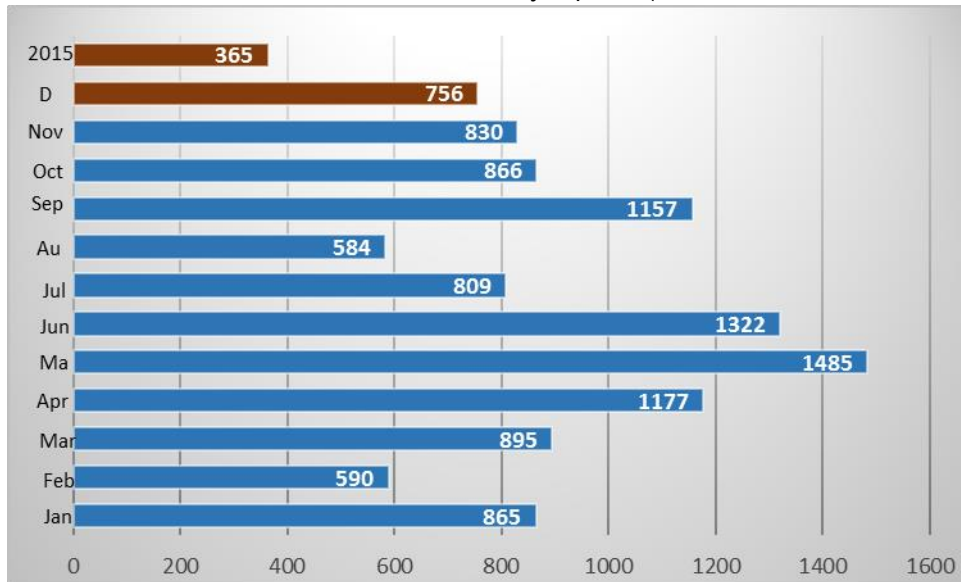
TSC Biosample Repository

Source: Van Andel Research Institute



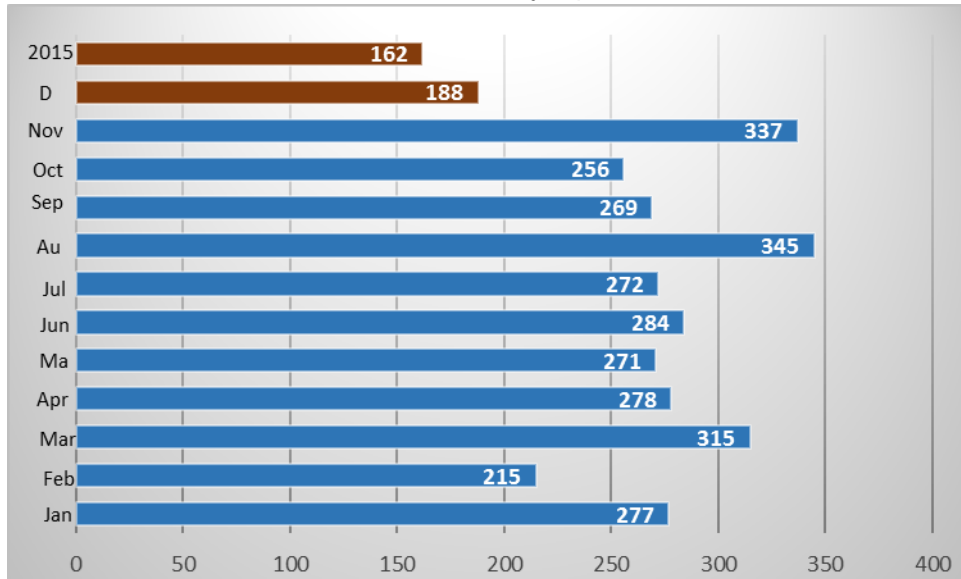
Constituent Support Peer-to-Peer Outreach Programs Contacts

Source: Vice President of Outreach monthly reports (CA, TSCA, ARC, DATRC Programs)



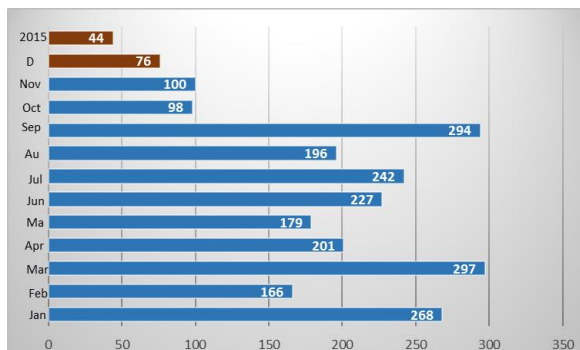
Constituent Support Contacts

Source: Vice President of Outreach monthly reports

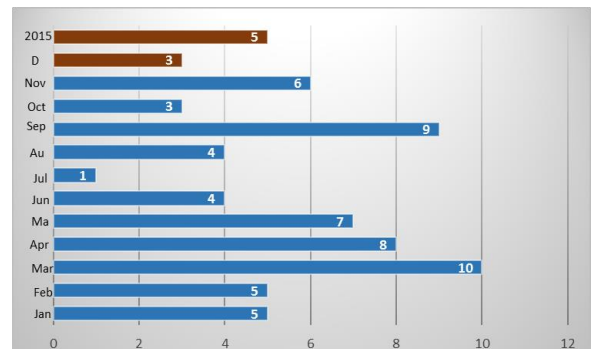


Educational Training Information Provided

Source: Vice President of Outreach monthly reports (from Educational Liaison)

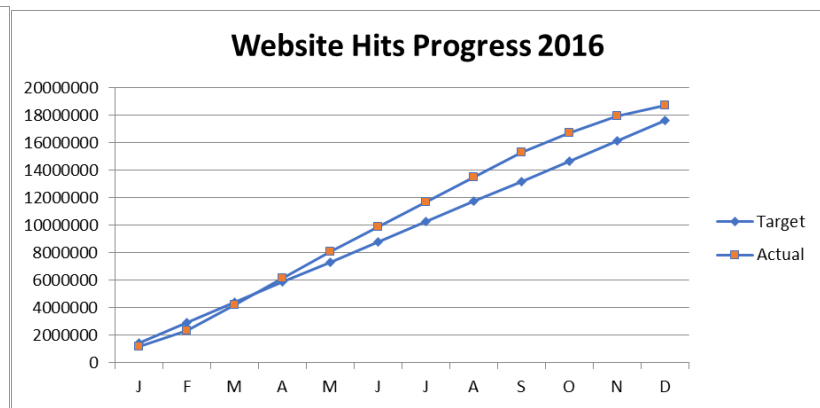
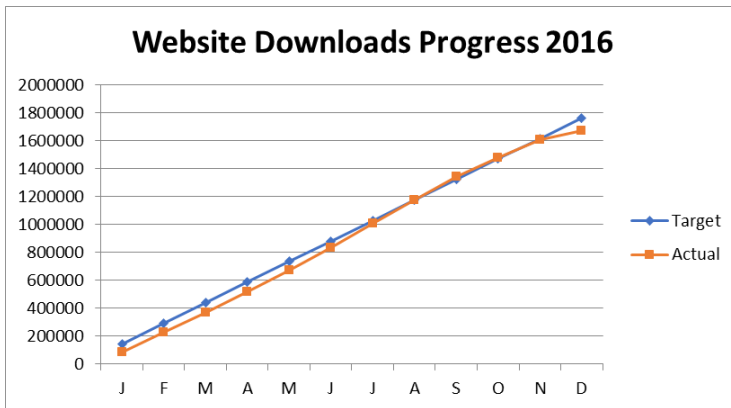


School Meetings



Website Statistics

Sources: Google Analytics and OneTwoThreeLogAnalyzer



CEO WRITTEN REPORT December 2016

Accelerate scientific advancements by funding research, driving the development of tools that support basic, translational and clinical research, and advocating for research funding by partnering with government and industry sponsors and other patient organization.

The CSO participated in the **TSCR Programmatic Panel** vision setting meeting for FY2017 on December 1.

The CEO, CSO, VPCS, SDDR, MRGA, and DCPTCL attended the **American Epilepsy Society (AES)** annual meeting in Houston, December 2 – 6. Events and meetings included:

- Epilepsy Leadership Council meeting of government and non-profit organizations involved in epilepsy care, training, and research on December 2.
- TS Alliance Reception the evening of December 2 was attended by nearly 80 industry, non-profit, and academic partners and featured a call to action for IS Awareness Week, presentation of the IS HOPE Award to Ellen Wehrman, on overview of the PREVeNT Trial by Martina Bebin, information on CBD data and the ongoing trial in TSC by Elizabeth Thiele, and data from the EXIST-3 trial by Darcy Krueger.
- Partnering and/or scientific meetings with industry partners UCB, GW Pharma, Novartis, Upsher-Smith, Mallinckrodt, LivaNova, Sage Therapeutics, Zogenix, and Lundbeck. The CEO and CSO spoke briefly at the Upsher-Smith reception and attended the UCB reception, and the CEO and SDDR attended the Lundbeck reception.
- The TSC Clinic Directors Meeting on December 3 had 28 attendees (including 5 TS Alliance staff) participating in useful discussions on sharing best practices.
- Infantile Spasms Advocacy Forum on December 4 provided the opportunity to meet with current IS Week partners and begin to plan for 2017 activities and expansion into a year-round Action Network.
- The Infantile Spasms Awareness Pavilion on December 5 welcomed more than 100 visitors and featured a poster and presentation by Dr. Martina Bebin on the PREVeNT trial.
- TSC research was featured throughout AES, most visibly in the Presidential Symposium, a session on TSC (understanding and modifying epileptogenesis), and a TSC Special Interest Group.
- The CSO and DCPTCL met with UCLA neurosurgeons, Drs. Gary Mathern and Aria Fallah, and TSC Clinic Director, Dr. Joyce Wu, in Houston on December 3 to discuss the TS Alliance TSC Biosample Repository Project, Dr. Mathern's UCLA Rare Brain Disease Tissue Bank and possible ways to collaborate.

The CEO, CSO, and MRGA had annual visits with senior staff of **NCATS, NIDDK, and NIAMS** during the week of December 12.

On December 14, the staff from **The LAM Foundation** visited the TS Alliance office to make decisions on a number of aspects regarding the 2017 International Research Conference on TSC and LAM. As a result,

the room block was increased and additional meeting space was obtained from the hotel to accommodate more educational sessions for individuals and families affected by TSC and/or LAM.

Professional Advisory Board and Other TSC Advisor Activities - the following PAB members and/or TSC healthcare members provided feedback to questions by individuals with TSC:

- Lia Drees, MD (University Hospital Colorado); Ashley Pounders, RN, BSN, CCRN (LeBonheur Children’s Hospital, Memphis);
- Lisa Henske, MD (Brigham and Women’s, Boston);
- Darcy Krueger, MD, PhD (Cincinnati Children’s);
- Ki Hyeong Lee, MD (Florida Hospital, Orlando);
- Robb Romp, MD (UAB);
- Howard Weiner, MD (Texas Children’s);
- James Wheless, MD (LeBonheur Children’s, Memphis); and
- Mary Zupanc, MD (Children’s Hospital Orange Co, California).

Identify more individuals impacted by TSC and engage them through improved clinical and support services.

There was a decrease in the number **constituent contacts** in December from 337 in the previous month to 188 in December. The percentage of education-related calls decreased from 53% to 51% from the previous month. Out of the 188 contacts, 17% were from adults with TSC (this does not include the support numbers provided by the ARCs). There was a total of 25 face to face supports to families/individuals with TSC (Face to Face numbers includes ARCs, Clinic Ambassadors (on site), Community Alliances, and Vice President of Outreach). There were also 59 one-on-one support contacts provided by Community Alliances.

CDs and **healthcare e-packets** were given to 11 doctors in need of information on TSC diagnosis, treatment, and management in TX, CA, DE, CA, NY, VA, MD, NC, SC, DC, WV.

We added 11 new individuals to our constituent database through the **website popup** in December, of which 55% were parents, 16% were individuals with TSC, 8% relatives, 8% physicians and the remainder sibling, grandparent and other.

In December, the overall **website hits** decreased by 477,447 (38%) hits from November. **Total downloads also** decreased by 51% from November. Some of our stats are only through December 14 when the new site was launched. Since the new site is on a different platform, we are working with the web vendor on how to meaningfully capture analytics. The summary report can be found below.

Website Statistics (Sources: Google Analytics and OneTwoThreeLogAnalyzer)

	December 2016	vs. Previous Month November 2016	vs. Previous Year December 2015
Total Hits	776,943*	1,254,390	1,048,610
Unique Visitors	43,174	39,653	35,897
Only One Visit	16,031*	30,918	28,865
More Than One Visit	5,027*	8,735	7,032
Most Requested Pages	<ol style="list-style-type: none"> 1. Home Page (196,388) 2. What is TSC? (7,379) 3. Types of Seizures (4,771) 4. Community Alliance Listing (1,358) 5. For the Newly Diagnosed (1,204) 	<ol style="list-style-type: none"> 1. Home Page (263,044) 2. What is TSC? (11,982) 3. Skin Features (7,783) 4. Types of Seizures (6,053) 5. TSC Clinic Listing (2,762) 	<ol style="list-style-type: none"> 1. Home Page (198,872) 2. What is TSC? (6,477) 3. Types of Seizures (5,118) 4. Infantile Spasms (1,879) 5. Skin Features (1,414)
Most Downloaded Files*	<ol style="list-style-type: none"> 1. Table of Anti-Epileptic Drugs (2,633) 2. Spanish Intro to TSC (1,674) 3. Perspective Summer 2016 (758) 	<ol style="list-style-type: none"> 1. Spanish Intro to TSC (4,331) 2. Table Anti-Epileptic Drugs (3,844) 3. Perspective Fall 2016 (2,549) 	<ol style="list-style-type: none"> 1. Spanish Intro to TSC (3,328) 2. Table of Anti-Epileptic Drugs (2,495) 3. Perspective Fall 2015 (1,553)

	4. Differential Diagnosis (722)	4. Behavioral Issues and TSC (1,581)	4. Perspective Summer 2015 (1,126)
	5. Perspective Fall 2016 (489)	5. Perspective Summer 2016 (946)	5. Perspective Winter 2014 (890)
Total Downloads	63,097	128,784	78,794
www.IAMTSC.org	1,696 Page Views 937 Unique Visitors	1,299 Page Views 805 Unique Visitors	710 Pageviews 485 Unique Visitors

*Stats through December 14, 2016 on old website only.

Broaden and strengthen the base of financial support for TSC research, TS Alliance and TS Alliance Endowment Fund from both private and public sources.

Through December 31, 2016, **total revenue** for the year is \$5,240,880 compared to budget of \$4,418,335, creating a positive variance of \$822,545. The positive variance is in large part due to the \$1.5 million pledge from the Engles Family Foundation and the Lundbeck Impact Fund grant (\$210,000 of the \$282,500 recognized in 2016), which gives us a positive variance for grants of \$1,354,238 for the year. This variance, along with a \$211,005 positive variance for contract revenue is partially offset by a few factors: (a) major donor contributions came in (\$320,462) under budget since the Engles' pledge came in as a grant rather than the \$250,000 that was budgeted for the Family as a major donation; (b) Net Special Events revenue came in (\$148,476) below budget primarily due to Walk and major event shortfalls; and (c) electing to do without any contribution from the Endowment Fund this year created a (\$206,000) negative variance.

Total expenses for the year ending December 31, 2016 are \$4,923,005 which exceeds budgeted expenses by \$354,725. The main reason for the higher expenses is that we aimed to reach at least 75% program spending for the full year, and prioritized spending in excess of budget levels on research and global outreach grants at year end to reach that goal. Grant spending exceeded budget by \$388,391, which was partially offset by the Preclinical Consortium studies coming in \$139,239 under budget. Overall, spending on research and global outreach grants/contracts was \$1,972,347 for the year, which was \$239,130 over budget. Spending on travel also exceeded budget by \$80,783. We were able to increase the portion of our spending on programs to 76.25% for the year. The Change in Net Assets for 2016 is a positive \$316,750 vs. a budgeted deficit of (\$149,946).

The **TS Alliance Endowment Fund** has \$42,684 in donations in 2016 compared to \$34,656 for 2015. The Fund is showing a \$530,708 positive change in net assets for the year, due to the \$525,868 increase in value of its investments, not needing to pay out any of \$206,000 Endowment contribution to the TS Alliance that was budgeted for 2016, and other expenses being kept to a minimum.

The **Twelve Month Trailing Totals Chart** demonstrates a decrease in revenues and increase in expenses. The decrease in revenue can be accounted for by the decrease in major gifts, in part by a timing issue since some of these gifts were received in January. The increase in expenses due to the additional grants funded at year end in research and global alliances, which allowed us to reach target program expense ratios.

As of December 31, **Major Donor** gifts accounted for \$785,533 versus a budget of \$1,106,495. Some significant budgeted contributions impacting this discrepancy are: \$250,000 gift budgeted to be received by Gregg Engles that was increased to \$1.5 million but was accounted for in Grants; \$50,000 budgeted and not received from Chris and Joy Dinsdale and \$50,00 budgeted to be received by Board Prospects.

Major Donor and Corporate visits were made in December with:

- **UCB**, December 2, December 3, the CEO, CSO and SDDR met with Kim Moran, Matthew Simonian, senior research executives to discuss sponsorship of DC Sound Bites, Comedy for a Cure, Step Forward to Cure TSC Walks, Regional Conferences and Transition Workshops, Research Conference and the 2018 World TSC Conference as well as research updates. As a result, UCB approved a \$15,000 grant at year end to support the Volunteer Leadership Training.
- **Greenwich Biosciences**, December 3, the CEO and SDDR met with Michelle Welborn, Ryan Bovia, Alice Mead, Jennifer Triemstra, Al Marshall and Julian Gangolli to discuss sponsorship of DC Sound Bites, Comedy for a Cure, Step Forward to Cure TSC Walks, Regional Conferences and Transition Workshops, Research Conference, MN Sounds Bites and the 2018 World TSC Conference. Michelle

requested we send all requests by the end of the year which we did. We also discussed how we can help with the rescheduling process for cannabinoids and learned that in the US, GW will now be known as Greenwich Biosciences due the existence of an American company with the GW name.

- **Novartis**, December 3, the CEO and SDDR met with Jane Vesotsky to discuss transition of care, TSC Global Awareness Day and treatment access.
- **Brain Sentinel**, December 3, CEO and SDDR met with Tracy Blitz, Jeff Jung and Mike Girouard to discuss opportunities for partnership including International Research Conference, Regional Conferences and Transition Workshops.
- **Child Neurology Foundation**, December 3, the CEO and SDDR had dinner with Executive Director, Amy Miller.
- **Mallinckrodt**, December 4, the CEO and SDDR met with Cathy Jackson, Molli Salzman, Keith Fry and Sylvia to discuss sponsorship of DC Sound Bites / Advocacy Training, Comedy for a Cure, Step Forward to Cure TSC Walks, Regional Conferences, IS Awareness and the 2018 World TSC Conference.
- **LivaNova**, December 4, the CEO and SDDR met with Jennifer Lively, Kim Cooper and Victoria Driscoll (Nate Minnich joined briefly at the end) to discuss sponsorship of Step Forward to Cure TSC Walks, Regional Conferences and Transition Workshops, Research Conference and the 2018 World TSC Conference.
- **Upsher-Smith**, December 4, the CEO and SDDR me with Dave Stefanoni to discuss sponsorship of DC Sound Bites, Comedy for a Cure, Step Forward to Cure TSC Walks, Regional Conferences and Transition Workshops, Research Conference and the 2018 World TSC Conference. Dave let us know that their budgets for advocacy are being cut by 30% but that he has funds in mind to direct toward the TS Alliance.
- **Lundbeck**, December 4, the CEO and SDDR met with Deena Andreola to talk about IS Awareness.
- **CVS**, December 19, the CEO, CSO, Vice President of Outreach and SDDR met with Calvin Wasdyke, Ross Luke, Andrew Glover, Glen Howell, Joel Helle and Faith Weiner to discuss access to treatment and sponsorship opportunities, particularly Step Forward to Cure TSC walks and Comedy for a Cure.

Grants as of December 31 totaled \$2,194,674 versus a budgeted \$842,100. Included in grants received in December:

- \$5,000 - ARMATURE
- \$1,786 – Licking County Foundation
- \$2,000 – Norgren Family Fund
- \$22,000 – The Winifred M. Gordon Foundation

Honorariums & Memorials as of December 31 totaled \$68,707 versus a budgeted \$103,200. **Appeals** as of December 31 totaled \$97,312 versus a budgeted \$112,500. **Federated Funding** as of November 30 totaled \$36,904 versus a budgeted \$60,000.

Special Events as of December 31, net totaled \$1,363,223 versus a budgeted \$1,526,890.

December Major Gifts (Source: Raiser’s Edge (reported on cash or in-kind gifts received))

Name	Gift Amount	Gift Date	Gift Type	Fund ID
The Winifred M. Gordon Foundation Inc	\$22,000.00	12/31/2016	Cash	Krinsky Resch Fund
Neely, Ned	\$15,000.00	12/31/2016	Cash	Major Donor
Moore, Julianne	\$10,000.00	12/23/2016	Cash	Major Donor
Price, Allan	\$10,000.00	12/6/2016	Cash	Major Donor
Richards, Nancy	\$10,000.00	12/31/2016	Cash	DC Sound Bites SPON FY17
White, Karen	\$10,000.00	12/31/2016	Cash	Major Donor
Armature Solutions Corp	\$5,000.00	12/20/2016	Cash	Website Redesign
Bayless, Nicole	\$5,000.00	12/31/2016	Cash	ULC-Major Donor
Denharder, Cornelius	\$5,000.00	12/15/2016	Cash	Major Donor
Frost, Michael D.	\$5,000.00	12/31/2016	Cash	Major Donor
Frost, Rebecca Jane	\$5,000.00	12/31/2016	Cash	DC Sound Bites SPON FY17
Johnson, Michael	\$5,000.00	12/5/2016	Cash	Major Donor

Marton, Herbert	\$5,000.00	12/6/2016	Cash	IAMTSC Crowd FY16
Mischel, Robert W.	\$5,000.00	12/31/2016	Cash	Major Donor
Ramesh and Kalpana Bhatia Family Foundation	\$5,000.00	12/27/2016	Cash	Major Donor
The Cliff and Deborah White Family Fund	\$5,000.00	12/19/2016	Cash	Major Donor
Ward, William G.	\$5,000.00	12/31/2016	Cash	End Major Donor 2016
Waxlax, Paul	\$5,000.00	12/22/2016	Cash	End Major Donor 2016
Wright, Sarah N.	\$5,000.00	12/31/2016	Cash	Krinsky MD RES FUND
Krinsky, Cathy J.	\$4,000.00	12/31/2016	Cash	ULC-Major Donor
Fox, Judy	\$3,000.00	12/20/2016	Cash	End Major Donor 2016
CSW Industrials, Inc	\$2,500.00	12/31/2016	Cash	Houston Walk FY2016
Marton, Stuart	\$2,500.00	12/31/2016	Cash	ULC-Major Donor
Medtech	\$2,500.00	12/28/2016	Cash	Cleveland Conf Grant 16
Medtech	\$2,500.00	12/28/2016	Cash	Nashville Conf Gran 16
Medtech	\$2,500.00	12/28/2016	Cash	Seattle Conf Gran 16
Russell, Leslie E.	\$2,500.00	12/31/2016	Cash	Major Donor
Blackwood, Alicia	\$2,200.00	12/21/2016	Cash	Major Donor
Burbridge, Pablo	\$2,000.00	12/31/2016	Cash	Major Donor
Flicker, Kasey	\$2,000.00	12/27/2016	Cash	Major Donor, Research
Hall, Andrea	\$2,000.00	12/31/2016	Cash	DC Sound Bites SPON FY17
Hulbert, John C.	\$2,000.00	12/31/2016	Cash	Major Donor
Keiser Family Foundation	\$2,000.00	12/22/2016	Cash	ULC-Major Donor
Mastroianni, Theodore	\$2,000.00	12/15/2016	Cash	DC Sound Bites SPON FY17
Norgren Family Fund	\$2,000.00	12/20/2016	Cash	Rocky Mt. Region CA
Wang, Victor	\$2,000.00	12/7/2016	Cash	ULC-Major Donor
Mistler Family Foundation	\$1,700.00	12/29/2016	Cash	Major Donor
Waccamaw Community Foundation	\$1,664.00	12/29/2016	Cash	CA of Alabama
Hoersch, Jeff S.	\$1,500.00	12/30/2016	Cash	Krinsky MD RES FUND
Home Association	\$1,500.00	12/20/2016	Cash	Major Donor
Joseph, William	\$1,500.00	12/31/2016	Cash	ULC-Major Donor
Leonard, Jean M.	\$1,500.00	12/31/2016	Cash	Major Donor
Marton, Frederic	\$1,500.00	12/31/2016	Cash	Major Donor
Miranda, Joseph M.	\$1,500.00	12/29/2016	Cash	Major Donor
Smith, Michele G.	\$1,500.00	12/31/2016	Cash	Major Donor
Voya Foundation	\$1,500.00	12/29/2016	Cash	Major Donor
Travelers	\$1,120.00	12/29/2016	Cash	Federated Funding Refunds 1200-00-000-
MetLife	\$1,087.37	12/5/2016	Cash	
Lee, William W.	\$1,074.00	12/31/2016	Cash	Major Donor
Yohn, Joseph J.	\$1,074.00	12/31/2016	Cash	Major Donor
Arborscapes, LLC	\$1,000.00	12/29/2016	Cash	Major Donor
Beattie, Thomas W.	\$1,000.00	12/22/2016	Cash	IAMTSC Crowd FY16
BNY Mellon	\$1,000.00	12/20/2016	Cash	Major Donor
Buchsbaum, Elizabeth S.	\$1,000.00	12/31/2016	Cash	Major Donor
Clark, Sue S.	\$1,000.00	12/31/2016	Cash	Major Donor
Duberstein, Nathaniel	\$1,000.00	12/13/2016	Cash	Major Donor
Escobar, Kenneth	\$1,000.00	12/31/2016	Cash	Major Donor
Frieder, Wendy	\$1,000.00	12/31/2016	Cash	Major Donor
Graham, Nancy	\$1,000.00	12/31/2016	Cash	Major Donor
Green, Miriam S.	\$1,000.00	12/21/2016	Cash	Major Donor
Gross, Jennifer	\$1,000.00	12/31/2016	Cash	Major Donor
Groves, Robert W.	\$1,000.00	12/31/2016	Cash	Major Donor

Hoffmann, Jeffrey M.	\$1,000.00	12/31/2016	Cash	Major Donor
Hollingsworth, LLP	\$1,000.00	12/27/2016	Cash	DC Sound Bites DON FY17
Holmes, William	\$1,000.00	12/31/2016	Cash	Major Donor
Insulation Products Corp	\$1,000.00	12/13/2016	Cash	Major Donor
Lembke, Janet	\$1,000.00	12/19/2016	Cash	Major Donor
Leone, Matt	\$1,000.00	12/21/2016	Cash	Major Donor
Morgan, Kay	\$1,000.00	12/29/2016	Cash	Major Donor
Piotrowski, Andrew S.	\$1,000.00	12/31/2016	Cash	Major Donor, Research
Rapaport, Peter	\$1,000.00	12/29/2016	Cash	Major Donor
Scott, Mary Ellen	\$1,000.00	12/6/2016	Cash	Major Donor
Seward, Mary L.	\$1,000.00	12/31/2016	Cash	Major Donor
Smith, Joseph P.	\$1,000.00	12/20/2016	Cash	Major Donor
Spain, Paul	\$1,000.00	12/29/2016	Cash	Major Donor
Staples, Kate A.	\$1,000.00	12/1/2016	Cash	Major Donor
The Winifred M. Gordon Foundation Inc	\$1,000.00	12/31/2016	Cash	DC Sound Bites DON FY17
Wasserman, Ann	\$1,000.00	12/15/2016	Cash	Major Donor
Total	\$229,919.37			

Facilitate more interaction among the national and international TSC community.

In December, there was a total of 241 **volunteer hours** and 46 **volunteer participants**. There were 145 one-on-one support contacts between the Community Outreach Manager and the TSC community. A total of 133 people attended TS Alliance events in Arkansas, Kentucky, Texas, Illinois, Ohio and Georgia.

Throughout December, the **Adult Regional Coordinators (ARCs)** supported 557 adults with TSC through phone, e-mail, Facebook, and face to face. The ARCs had a conference call meeting to discuss and decide the topics and speakers for the Jan, Feb, March Adult Topic Calls.

There were 71 parents/caregivers supported through the **Dependent Adult Transitional Resource Coordinators (DATRCs)** program in December. A new DATRC was added in AZ and Puerto Rico.

We officially added the TS Alliance of Mexico and the TS Alliance ASEAN Foundation (TSAAF) in Thailand as Global Alliances, with signed Global Affiliate and International Grant agreements for seed funding. We will work with both organizations on when to make public announcements about these partnerships in the upcoming year. Mexico is now a legal, registered entity, and Thailand will begin the process of establishing themselves as a legal entity now that they have some funding in place. Nok and Carl Brenden from TSAAF and Ary Agami from the TS Alliance of Mexico are the founders of our newest global partners.

Our membership on **Inspire** grew by 67 to 4,411 from 103 countries. There were 3 journal entries and 510 replies in December. There were 24 new discussions and 82 replies. The top three posts were:

- “Diet for TS” posted from a parent of a newly diagnosed son looking at diets, asking others for their experience and good books detailing different types of diets.
- “Surgery?” posted from a mother of a 10-week-old daughter who has had sub-clinical seizures since birth, considering brain surgery and asking for others experience.
- “14 weeks Pregnant with Tuberous Sclerosis” from a 32-year-old woman with TSC who found out she was pregnant with a girl carrying the same TSC1 mutation and looking for support if others had been in that situation.

For specific data on additional peer to peer support programs, educational advocacy, or social media presence please see the chart below.

Constituent Outreach Statistics (Sources: Vice President of Outreach, Community Outreach Manager, Inspire web statistics, FaceBook, Twitter, Raiser's Edge database)

Mode of Constituent Outreach	December 2016	vs. Previous Month November 2016	vs. Previous Year December 2015
Contact with VP Outreach	188	337	162
Of Contact, % Education Related	51%	53%	62%
Adult Regional Coordinators	557	558	67
Community Outreach Manager Support Contacts with Community Alliances	145	323	241
Community Alliance One on One Support within their Communities	59	139	14
Newly Diagnosed Children	1	3	4
Newly Diagnosed Adults	2	3	1
Information Packets - Email	11	23	30
Information Packets - Hard Copy	1	5	10
Web Pop Up Capture-New to TS Alliance	51	41	31
School Meetings Attended	3 NY, MN, IL	6 from TX, GA (2), NY, TN, NJ	5- FL, KS, WI, MD(2)
Free Educational Trainings Through PTIs	76	100	44
# of Families Touched by Clinic Ambassador Program	69	78	77
Educator Mentor Program Connections	3	6	10
# of Families Touched by Dependent Adult Transition Resource Coordinator	71	55	45
# Attended Community Alliance Meetings	133	273	30
Inspire Membership	4,411 from 103 countries	4,344 from 102 countries	3,415 from 92 countries
FaceBook Group Discussion	7,793	7,742	7194
FaceBook Nonprofit Followers	5,777	5,736	4685
Twitter Followers	1,590	1,583	1409
Instagram Followers	556	548	397
Support to Other Countries	Canada, India, Mexico, Morocco, South Korea, Ukraine	Bosnia, Canada, Egypt, Lebanon, Mexico, Norway, Saudi Arabia, Ukraine	Argentina, Ecuador, Iran, Taiwan, United Arab Emirates
Volunteer Hours	241	479	57
# of Active Volunteer Participants	46	130	32

Increase diversity of Board membership and enhance staff skill sets to ensure execution of the strategic plan and to maintain recognition of TSC as a linchpin disorder.

The TS Alliance participated in **Infantile Spasms Awareness Week** activities December 1-7, specifically leading communications and media efforts. Working with McCabe Messaging a communications toolkit was developed and circulated to 15 partners. The TS Alliance conducted a **media tour** with 16 Radio and TV interviews with 30 placements with 6,083,651 total audience. The CEO, Board Member Dr. Martina Bebin and Hope Award Winner Ellen Wehrman participated.

In terms of social media and paid ads, the following was achieved:

- **Facebook advertising:**
 - **Geo Targeted ad:** 77,762 people reached; 6,481 post clicks; 6,449 link clicks
 - **General ad:** 210,987 people reached; 7,819 post clicks; 7,025 link clicks
 - **IS Quiz:** reaching 671 individuals on Facebook to date
 - Links to **IS specific videos** and messaging with 2,072 views
- **ACEP Now circulation:** 37,249 emergency room physicians
- **AAP News circulation:** 64,805 pediatricians and others interested in pediatric health care

The new **TS Alliance website** launched on December 14 after a year of planning, preparation and work by the entire staff team and led by the Vice President Communications Strategy (VPCS). In addition, the VPCS worked with our vendor Teramark on new email signatures, letterhead/envelope designs, and eBlast email templates for Luminare and NetCommunity

On December 8, David Coit, **prospective board member**, visited the TS Alliance office. Incoming Board Chair Tim Dills and all staff participated in a welcome meeting followed by more detailed presentations by the CEO, CSO and CFO and lunch with Tim Dills and the CEO.

The CEO, SDDR and SMSE conducted nine 1-hour interviews for the **Director of Special Events and Corporate Partnerships**. As a result of interviews by the staff team and search committee, April Cooper was offered the position and began January 3. Additionally, Gail Saunders was promoted to **Associate Director, National Walks and Community Campaigns** and Shelly Meitzler signed a contract to support Step Forward to Cure TSC walks as the **National Walk Coordinator**.

With the help of all staff, the CSO interviewed several individuals for the new **Science Project Coordinator** position and offered the job to Calvin Ho, who agreed to start in January. This position will increase the impact and visibility of the TS Alliance's research programs.