



# STATE OF THE TSC COMMUNITIES REPORT

FY 2018 (JANUARY 1–DECEMBER 31, 2018)



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## FOREWORD

This *State of the TSC Communities Report* was compiled to provide information on the multiple ways the [Tuberous Sclerosis Alliance](#) (TS Alliance) impacts communities, states and other countries. This report provides a benchmark of “where things stand” and helps identify areas where the TS Alliance can strengthen identification of individuals with tuberous sclerosis complex (TSC) as well as areas that need greater support and information.

The report analyzes all organizational activities on a state-by-state and international basis. Each state listing overlays the following major areas (if applicable in the given state):

- Approximate population with TSC (based on 2010 Census Bureau population estimates)
- Number of Identified TSC Individuals in the State (i.e., individuals with TSC and/or parents with children who have TSC) in the TS Alliance database
- One-on-one constituent support
- Educational Liaison Program (an educational liaison provides educational support for families of school-age children by providing information on free trainings on Educational Advocacy by collaborating with the state Parent Training and Information Center)
- IEPs and school meetings attended through conference calls and/or SKYPE
- TS Alliance Clinic Ambassador Program (Clinic Ambassadors provide one on one support for families/individuals at a TSC Clinic)
- Adult Resource Coordinator peer to peer support
- Dependent Adult Transition Resource Coordinator peer to peer support
- Number of identified constituents in a Community Alliance (CA) (i.e., individuals with TSC, parents/caregivers, adult siblings, grandparents, extended family and other designated supporters)
- Community Alliance activities
- Congressional advocacy efforts
- TSC research activities and funding
- TSC clinic locations, clinical trials, and TSC Natural History Database participation
- TS Alliance Board and Advisory Boards participation

ACTIVITY COMPARISON CHART							
	2018	2017	2016	2015	2014	2013	2012
Constituents Provided One-on-One Support	4,083	3,547	3,307	2,905	2,519	2,272	2,108
Constituents Added Via Web Sign up Form	389	574	428	377	374	940	711
Educational Training Sessions Posted on Inspire/Facebook	4,473	3,005	2,344	1,885	1,766	1,072	1,341
School Meetings (IEP, 504, ERT, TS Training) Attended via Conference Calls/SKYPE	83	74	65	39	34	26	18
Education Parent Mentor Support Contacts	802	N/A	N/A	N/A	N/A	N/A	N/A
Constituents Contacted via Clinic Ambassador Program	2,573	2,014	1,515	648	503	238	153
Constituents Contacted via Adult Regional Coordinators	15,664	13,806	8,135	3,766	1,508	1,077	N/A
Constituents Contacted via Dependent Adult Transition Resource Coordinators	1,134	745	597	695	N/A	N/A	N/A
Community Alliance Meetings	39	62	85	76	59	52	34
Participants in Community Alliance (CA) Meeting/ CA Peer to Peer Contacts (e-mail, phone, text, face to face)	4,679	3,681	2,147	2,304	2,174	2,418	N/A
Participants in TSC Natural History Database	2,179	2,122	2,070	1,849	1,504	1,305	1,175
Number of TS Alliance-Funded Research Grants	6	8	15	11	12	17	19
Total TS Alliance-Funded Research Expenditures	\$451,689	\$548,349	\$2,469,977	\$1,706,806	\$1,508,138	\$2,037,048	\$1,046,940

Results from this report's analysis are used to:

- Provide information on identified TSC individuals to help create and measure outreach strategies
- Develop business plans to address demonstrated success and needs community by community and state by state
- Provide data for Community Alliances to share with local event sponsors for impact in their local communities

The following two graphs illustrate that the vast majority of TSC research funding is awarded by the National Institutes of Health (NIH) and the Tuberous Sclerosis Complex Research Program (TSCRP) at the Department of Defense. Importantly, the second graph shows that researchers funded by the TS Alliance subsequently receive more than ten times additional funding from federal sources. TS Alliance grant awards are peer reviewed to ensure the organization funds projects in line with priorities and in the strategic plan set by the board's Science and Medical Committee.

## Annual Investments in Research Grants

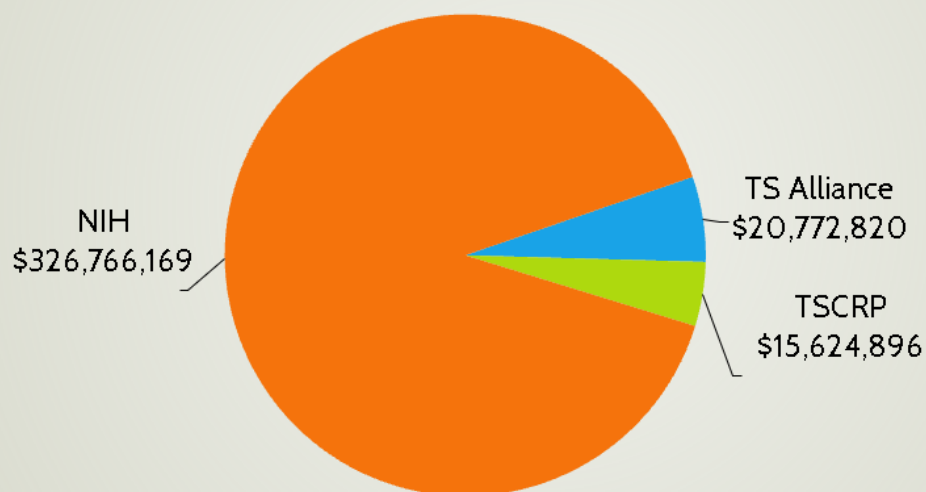
*TS Alliance, NIH, and DoD TSCRP*

### TSC Research Grant Dollars by Funder, 2002-2018



## NIH and TSCRP Funding

*Obtained by Researchers After Receiving Their First TS Alliance Grants, 1984-2018*





## ALABAMA

Number Estimated with TSC in 2010 by State (Census / 6,000):	796
Number Identified Constituents in Entire State:	1,948
VP Support Services Provided One-on-One Support:	142
School Meetings Attended (virtually and in person):	6
TSC Community Supported via TS Alliance Clinic Ambassador Program:	30
TSC Community Supported via Adult Support Contacts Program:	154
TSC Community Support Provided to School Districts via Educator Mentor Program:	6
TSC Community Supported via Education Parent Mentor:	28
The Community Alliance in this state includes:	Alabama
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	330
Number of Community Alliance Meetings Held in 2018:	NA
Step Forward to Cure TSC Walk (Y/N):	Y
Other Community Campaigns:	Krewe for a Cure
Total Gross Dollars Raised:	\$27,452
Number of House Supporters (FY18):	4
House Dear Colleague Signers:	Bradley Byrne R-AL-1 Mike Rogers R-AL-3 Gary Palmer R-AL-6 Terri A. Sewell D-AL-7
National Institutes of Health (FY2018) Funded Research Information:	1
Project Title:	Preventing Epilepsy Using Vigabatrin in Infants with Tuberous Sclerosis Complex
Principal Investigator:	Martina Bebin, MD, MPA
Institute:	University of Alabama at Birmingham
Congressional District:	7
Award Amount:	\$1,496,413
Number of TSC Natural History Database Sites:	1
TSC Natural History Database Sites:	University of Alabama at Birmingham
Amount Funded in FY18:	\$11,495
Number of Clinic Trials:	5
Clinical Trial 1:	Longitudinal study to identify early biomarkers of autism spectrum disorder (ASD) in infants with tuberous sclerosis complex (TSC)
Name of Participating Institution:	University of Alabama at Birmingham
Clinical Trial 2:	Potential EEG biomarkers and antiepileptogenic strategies for epilepsy in TSC
Name of Participating Institution:	University of Alabama at Birmingham
Clinical Trial 3:	Preventing Epilepsy Using Vigabatrin in Infants with Tuberous Sclerosis Complex (PREVeNT Trial) A Randomized, Double-blind, Placebo-controlled Seizure Prevention Clinical Trial for Infants With TSC.
Name of Participating Institution:	University of Alabama at Birmingham

Clinical Trial 4: Name of Participating Institution:	Autism spectrum disorder (ASD) and intellectual disability (ID) determinants in tuberous sclerosis complex (TSC) University of Alabama at Birmingham
Clinical Trial 5: Name of Participating Institution:	A Double-blind, Randomized, Placebo-controlled Study to Investigate the Efficacy and Safety of Cannabidiol (GWP42003-P, CBD) as Add-on Therapy in Patients With Tuberous Sclerosis Complex Who Experience Inadequately-controlled Seizures University of Alabama at Birmingham
Number of TSC Clinics & Locations:	1
TSC Clinic Location (1): City:	University of Alabama at Birmingham Birmingham
Number of Biosample Repository Site Locations:	1
Biosample Repository Site Location: Biosample Repository Funding:	University of Alabama Birmingham \$0
Number of TS Alliance Professional Advisory Board Members:	3
Professional: Institution: City:	E. Martina Begin, MD, MPA University of Alabama at Birmingham Birmingham
Professional: Institution: City:	Bruce Korf, MD, PhD University of Alabama at Birmingham Birmingham
Professional: Institution: City:	Robb Romp, MD University of Alabama at Birmingham Birmingham
TS Alliance Operating Board Members:	2
Current Board Member: City:	Martina Bebin, MD, MPA Athens
Current Board Member: City:	Margaret Cox Vestavia



## ALASKA

Number Estimated with TSC in 2010 by State (Census / 6,000):	118
Number Identified Constituents in Entire State:	147
VP Support Services Provided One-on-One Support:	68
Educational Training Sessions Posted on Social Media:	283
TSC Community Supported via Adult Support Contacts Program:	400
TSC Community Supported via Dependent Adult Transition Resource Coordinator Program:	12
TSC Community Supported via Education Parent Mentor:	17
The Community Alliance in this state includes:	Alaska
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	53
Number of Community Alliance Meetings Held in 2018:	1
Community Alliance Provided One-on-One Support in 2018:	117
Step Forward to Cure TSC Walk (Y/N):	Y
Total Gross Dollars Raised:	\$1,738
Number of House Supporters (FY18):	1
House Dear Colleague Signers:	Donald Young R-AK
Number of Senate Supporters (FY18):	1
Senate Dear Colleague Signers:	Daniel Sullivan R-AK

## ARIZONA

Number Estimated with TSC in 2010 by State (Census / 6,000):	1,065
Number Identified Constituents in Entire State:	1,900
VP Support Services Provided One-on-One Support:	73
Educational Training Sessions Posted on Social Media:	36
TSC Community Supported via Adult Support Contacts Program:	639
TSC Community Supported via Dependent Adult Transition Resource Coordinator Program:	2
The Community Alliance in this state includes:	Arizona
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	468
Community Alliance Provided One-on-One Support in 2018:	150
Step Forward to Cure TSC Walk (Y/N):	Y
Total Gross Dollars Raised:	\$17,490
Number of House Supporters (FY18):	4
House Dear Colleague Signers:	Tom O'Halleran D-AZ-1 Raul Grijalva D-AZ-3 Ruben Gallego D-AZ-7 Krysten Sinema D-AZ-9
Number of Clinic Trials:	1
Clinical Trial 1: Name of Participating Institution:	Phenotypic variability in TSC Arizona Pediatric Neurology & Neurogenetics Associates and Translational Genomics Research Institute
Number of TSC Clinics & Locations:	1
TSC Clinic Location (1): City:	Children's Rehabilitative Services (CRS) Tuberous Sclerosis Clinic for CRS-eligible children and Arizona Pediatric Neurology & Neurogenetics Associates (for adults and non-CRS pediatric patients) Phoenix
TS Alliance Corporate Advisory Board Members:	1
Professional: City:	Alan Marshall Scottsdale
Number of TS Alliance Professional Advisory Board Members:	2
Professional: Institution: City:	Vinodh Narayanan, MD Arizona Pediatric Neurology & Neurogenetics Associates Phoenix
Professional: Institution: City:	Rahmin Rabenou, MD Southern Arizona VA Healthcare System and University of Arizona School of Medicine Tucson

## ARKANSAS

Number Estimated with TSC in 2010 by State (Census / 6,000):	486
Number Identified Constituents in Entire State:	400
VP Support Services Provided One-on-One Support:	40
Educational Training Sessions Posted on Social Media:	126
TSC Community Supported via Adult Support Contacts Program:	288
The Community Alliance in this state includes:	Arkansas
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	141
Number of House Supporters (FY18):	1
House Dear Colleague Signers:	Eric. A Crawford AR-R-1
Number of Clinic Trials:	1
Clinical Trial 1:	A Double-blind, Randomized, Placebo-controlled Study to Investigate the Efficacy and Safety of Cannabidiol (GWP42003-P, CBD) as Add-on Therapy in Patients with Tuberous Sclerosis Complex Who Experience Inadequately-controlled Seizures
Name of Participating Institution:	Arkansas Children's
Number of TSC Clinics & Locations:	1
TSC Clinic Location (1):	Arkansas Children's
City:	Little Rock
Number of TS Alliance Professional Advisory Board Members:	2
Professional:	Stephen Kahler, MD
Institution:	Arkansas Children's
City:	Little Rock
Professional:	Debopam Samanta, MD
Institution:	Arkansas Children's
City:	Little Rock

## CALIFORNIA (NORTH)

Number Estimated with TSC in 2010 by State (Census / 6,000):	6,209
Number Identified Constituents in Entire State:	15,543
VP Support Services Provided One-on-One Support:	214
Educational Training Sessions Posted on Social Media:	197
School Meetings Attended (virtually and in person):	3
TSC Community Supported via Adult Support Contacts Program:	642
TSC Community Supported via Dependent Adult Transition Resource Coordinator Program:	2
The Community Alliance in this state includes:	Northern California
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	2,085
Number of Community Alliance Meetings Held in 2018:	1
Community Alliance Provided One-on-One Support in 2018:	684
Step Forward to Cure TSC Walk (Y/N):	Y
Total Gross Dollars Raised:	\$30,327
Number of House Supporters (FY18):	15
House Dear Colleague Signers:	John Garamendi D-CA-3 Doris Matsui D-CA-6 Arni Bera D-CA-7 Paul Cook R-CA-8 Jerry McNerney D-CA-9 Mark DeSaulnier D-CA-11 Barbara Lee D-CA-13 Jackie Speier D-CA-14 Eric Swalwell D-CA-15 Ro Khanna D-CA-17 Anna Eshoo D-CA-18 Zoe Lofgen D-CA-19 Jimmy Panetta D-CA-20 Julia Brownley D-CA-26 Judy Chu D-CA-27
Number of Senate Supporters (FY18):	1
Senate Dear Colleague Signers:	Dianne Feinstein D-CA
National Institutes of Health (FY2018) Funded Research Information:	1
Project Title:	Elucidating the neuropathophysiology of TSC using genetically engineered human neurons
Principal Investigator:	Helen Bateup
Institute:	University of California, Berkeley
Congressional District:	13
Award Amount:	\$324,707
Number of TSC Natural History Database Sites:	1
TSC Natural History Database Sites:	UCSF Benioff Children's Hospital Oakland
Amount Funded in FY18:	\$6,360
Number of Clinic Trials:	2
Clinical Trial 1:	Frontotemporal Dementia: Genes, Images and Emotions6
Name of Participating Institution:	University of California San Francisco

Clinical Trial 2: Name of Participating Institution:	Preventing Epilepsy Using Vigabatrin in Infants with Tuberous Sclerosis Complex (PREVeNT Trial) A Randomized, Double-blind, Placebo-controlled Seizure Prevention Clinical Trial for Infants With TSC1 Stanford University
Number of TSC Clinics & Locations:	2
TSC Clinic Location (1): City:	Lucille Packard Children's Hospital and Stanford Hospital and Clinics Palo Alto
TSC Clinic Location (2): City:	UCSF Benioff Children's Hospital Oakland Oakland
Number of TS Alliance Professional Advisory Board Members:	6
Professional: Institution: City:	Bryan King, MD, MBA University of California San Francisco Weill Institute for Neurosciences San Francisco
Professional: Institution: City:	Carrie Krupitsky, RN, FNP UCSF Benioff Children's Hospital Oakland
Professional: Institution: City:	Rachel Kuperman, MD UCSF Benioff Children's Hospital Oakland
Professional: Institution: City:	Scheherazade Le, MD Stanford Hospital and Clinics Palo Alto
Professional: Institution: City:	Brenda Porter, MD, PhD Lucille Packard Children's Hospital Stanford Palo Alto
Professional: Institution: City:	Joyce Teng, MD, PhD Stanford Hospital and Clinics Palo Alto
TS Alliance Operating Board Members:	1
Current Board Member: City:	Cassandra Carroll, Secretary Oakland
TS Alliance Endowment Board Members:	1
Current Endowment Board Member: City:	Mark Carroll Saratoga

## CALIFORNIA (SOUTH)

Number Estimated with TSC in 2010 by State (Census / 6,000):	6,209
Number Identified Constituents in Entire State:	15,543
VP Support Services Provided One-on-One Support:	213
Educational Training Sessions Posted on Social Media:	197
School Meetings Attended (virtually and in person):	4
TSC Community Supported via TS Alliance Clinic Ambassador Program:	20
TSC Community Supported via Adult Support Contacts Program:	642
TSC Community Supported via Dependent Adult Transition Resource Coordinator Program:	2
TSC Community Supported via Education Parent Mentor:	326
The Community Alliance in this state includes:	Southern California
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	1,682
Number of Community Alliance Meetings Held in 2018:	2
Community Alliance Provided One-on-One Support in 2018:	334
Step Forward to Cure TSC Walk (Y/N):	Y
Major Events:	Comedy for a Cure
Total Gross Dollars Raised:	\$280,891
Number of House Supporters (FY18):	14
House Dear Colleague Signers:	Adam Schiff D-CA-28 Grace Napolitano D-CA-32 Ted Liu D-CA-33 Jimmy Gomez D-CA-34 Raul Ruiz D-CA-36 Linda Sanchez D-CA-38 Lucille Roybal-Allard D-CA-40 Mark Takano D-CA-41 Nanette Barragan D-CA-44 Alan Lowenthal D-CA-47 Duncan Hunter R-CA-50 Juan Varggas D-CA-51 Scott Peters D-CA-52 Susan Davis D-CA-53
National Institutes of Health (FY2018) Funded Research Information:	4
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Mechanisms of change with early intervention in Tuberous Sclerosis Complex Shafali Jeste University of California, Los Angeles 33 \$524,169
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Beyond Baby Siblings: Early Developmental Trajectories and Biomarkers of Risk for ASD Jeste, Shafali University of California, Los Angeles 33 \$209,831



Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Beyond Baby Siblings: Early Developmental Trajectories and Biomarkers of Risk for ASD Jeste, Shafali University of California, Los Angeles 33 \$21,496
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Beyond Baby Siblings: Early Developmental Trajectories and Biomarkers of Risk for ASD Jeste, Shafali University of California, Los Angeles 33 \$47,441
Number of TSC Natural History Database Sites:	2
TSC Natural History Database Sites:	University of California Los Angeles (UCLA) Loma Linda University Medical Center
Amount Funded in FY18:	\$25,345
Number of Clinic Trials:	5
Clinical Trial 1: Name of Participating Institution:	Autism spectrum disorder (ASD) and intellectual disability (ID) determinants in tuberous sclerosis complex (TSC) University of California Los Angeles
Clinical Trial 2: Name of Participating Institution:	Longitudinal study to identify early biomarkers of autism spectrum disorder (ASD) in infants with tuberous sclerosis complex (TSC) University of California Los Angeles
Clinical Trial 3: Name of Participating Institution:	Potential EEG biomarkers and antiepileptogenic strategies for epilepsy in TSC University of California Los Angeles
Clinical Trial 4: Name of Participating Institution:	JASPER Early Intervention for Tuberous Sclerosis (JETS) University of California Los Angeles
Clinical Trial 5: Name of Participating Institution:	Preventing Epilepsy Using Vigabatrin in Infants with Tuberous Sclerosis Complex (PREVeNT Trial) A Randomized, Double-blind, Placebo-controlled Seizure Prevention Clinical Trial for Infants With TSC1 University of California Los Angeles
Number of TSC Clinics & Locations:	5
TSC Clinic Location (1): City:	University of California Los Angeles Los Angeles
TSC Clinic Location (2): City:	Loma Linda University Medical Center Loma Linda
TSC Clinic Location (3): City:	Children's Hospital Los Angeles Los Angeles
TSC Clinic Location (4): City:	Children's Hospital Orange County Orange
TSC Clinic Location (5): City:	Rady Children's Hospital of San Diego San Diego
Number of Biosample Repository Site Locations:	1
Biosample Repository Site Location: Biosample Repository Funding:	UCLA \$10,235
TS Alliance Corporate Advisory Board Members:	2
Professional: City:	Will Cooper, Sr, Honorary Chair Newport Beach
Professional:	Henry Shapiro

City:	Santa Monica
<b>Number of TS Alliance Professional Advisory Board Members:</b>	<b>9</b>
Professional: Institution: City:	Stephen Ashwal, MD Loma Linda University Medical Center Loma Linda
Professional: Institution: City:	Shafali Jeste, MD UCLA Los Angeles
Professional: Institution: City:	Joyce Wu, MD UCLA Los Angeles
Professional: Institution: City:	W. Donald Shields, MD UCLA Los Angeles
Professional: Institution: City:	Tena Rosser, MD Children's Hospital Los Angeles Los Angeles
Professional: Institution: City:	Lily Hoang Tran, MD Children's Hospital Orange Co. Orange
Professional: Institution: City:	Mary Zupanc, MD Children's Hospital Orange Co. Orange
Professional: Institution: City:	Doris Trauner, MD Rady Children's Hospital at University of California San Diego
Professional: Institution: City:	Donald J. Phillips, MD, MPH Children's Hospital Orange Co. Orange
<b>TS Alliance Operating Board Members:</b>	<b>2</b>
Current Board Member: City:	Rob Grandia Riverside
Current Board Member: City:	Jim Maginn, Treasurer Manhattan Beach
<b>TS Alliance Endowment Board Members:</b>	<b>1</b>
Current Endowment Board Member: City:	Michael Augustine, Secretary San Gabriel

## COLORADO

Number Estimated with TSC in 2010 by State (Census / 6,000):	838
Number Identified Constituents in Entire State:	2,818
VP Support Services Provided One-on-One Support:	129
Educational Training Sessions Posted on Social Media:	120
School Meetings Attended (virtually and in person):	3
TSC Community Supported via TS Alliance Clinic Ambassador Program:	529
TSC Community Supported via Adult Support Contacts Program:	233
TSC Community Supported via Dependent Adult Transition Resource Coordinator Program:	60
TSC Community Support Provided to School Districts via Educator Mentor Program:	5
The Community Alliance in this state includes:	Rocky Mountain (Colorado, New Mexico and Wyoming)
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	705
Number of Community Alliance Meetings Held in 2018:	2
Other Community Campaigns:	Bill & Nancy Youmans BBQ Fighting for Xander & Sophie
Total Gross Dollars Raised:	\$10,778
Number of House Supporters (FY18):	3
House Dear Colleague Signers:	Diana Degette D-CO-1 Jared Polis D-CO-2 Ed Perlmutter D-CO-7
Number of TSC Natural History Database Sites:	1
TSC Natural History Database Sites:	Children's Hospital Colorado
Amount Funded in FY18:	\$9,120
Number of Clinic Trials:	1
Clinical Trial 1:	A Randomized Controlled Trial of Cannabidiol (GWP42003-P, CBD) for Seizures in Tuberous Sclerosis Complex (GWPCARE6)
Name of Participating Institution:	Children's Hospital Colorado
Number of TSC Clinics & Locations:	1
TSC Clinic Location (1): City:	Children's Hospital Colorado & University Hospital Aurora
Number of TS Alliance Professional Advisory Board Members:	3
Professional: Institution: City:	Cornelia Drees, MD University Hospital Colorado Aurora
Professional: Institution: City:	Charuta Joshi, MBBS Children's Hospital Colorado Aurora
Professional: Institution: City:	Susan Koh, MD Children's Hospital Colorado Aurora
TS Alliance Operating Board Members:	1
Current Board Member: City:	Dana Holinka Northglenn

## CONNECTICUT

Number Estimated with TSC in 2010 by State (Census / 6,000):	596
Number Identified Constituents in Entire State:	2,853
VP Support Services Provided One-on-One Support:	34
Educational Training Sessions Posted on Social Media:	40
School Meetings Attended (virtually and in person):	4
TSC Community Supported via Adult Support Contacts Program:	196
TSC Community Support Provided to School Districts via Educator Mentor Program:	3
The Community Alliance in this state includes:	Connecticut and Rhode Island
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	414
Number of Community Alliance Meetings Held in 2018:	1
Step Forward to Cure TSC Walk (Y/N):	Y
Other Community Campaigns:	Bonnie Gould Rothberg Fund for Clinical Excellence
Total Gross Dollars Raised:	\$23,988
Number of House Supporters (FY18):	5
House Dear Colleague Signers:	John Larson D-CT-1 Joe Courtney D-CT-2 Rosa DeLauro D-CT-3 Jim Himes D-CT-4 Elizabeth Esy D-CT-5
Number of Senate Supporters (FY18):	2
Senate Dear Colleague Signers:	Richard Blumenthal D-CT Christopher Murphy D-CT
National Institutes of Health (FY2018) Funded Research Information:	1
Project Title:	Filamin A in TSC
Principal Investigator:	Angelique Bordey
Institute:	Yale University
Congressional District:	3
Award Amount:	\$366,406
TS Alliance Funded Research:	1
Project Title:	Non-cell autonomous effects in TSC brain malformations
Principal Investigator:	Bordey, Angélique
Institute:	Yale University
Congressional District:	3
FY:	18
Award Amount:	\$148,768.26
Number of TSC Clinics & Locations:	2
TSC Clinic Location (1):	Connecticut Children's Medical Center
City:	Farmington
TSC Clinic Location (2):	Associated Neurologists of Southern Connecticut
City:	Fairfield
Number of TS Alliance Professional Advisory Board Members:	3
Professional:	Nicholas Blondin, MD
Institution:	Associated Neurologists of Southern Connecticut
City:	Fairfield
Professional:	Francis J. DiMario, Jr. MD
Institution:	Connecticut Children's Medical Center
City:	Farmington

Professional:	Miguel A. Materin, MD
Institution:	Yale School of Medicine
City:	Fairfield

## DELAWARE

Number Estimated with TSC in 2010 by State (Census / 6,000):	149
Number Identified Constituents in Entire State:	439
VP Support Services Provided One-on-One Support:	37
TSC Community Supported via Adult Support Contacts Program:	185
TSC Community Support Provided to School Districts via Educator Mentor Program:	1
The Community Alliance in this state includes:	Delaware and East Pennsylvania
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	808
Step Forward to Cure TSC Walk (Y/N):	Y
Total Gross Dollars Raised:	\$25,511
Number of House Supporters (FY18):	1
House Dear Colleague Signers:	Lisa Rochester D-DE
Number of Senate Supporters (FY18):	2
Senate Dear Colleague Signers:	Thomas Carper D-DE Christopher Coons D-DE
Number of TSC Clinics & Locations:	1
TSC Clinic Location (1): City:	Nemours/Al duPont Children's Hospital Wilmington
Number of TS Alliance Professional Advisory Board Members:	1
Professional: Institution: City:	Harry T. Chugani, MD Nemours/Al duPont Hospital for Children Wilmington



## DISTRICT OF COLUMBIA

Number Estimated with TSC in 2010 by State (Census / 6,000):	100
Number Identified Constituents in Entire State:	562
VP Support Services Provided One-on-One Support:	62
Educational Training Sessions Posted on Social Media:	385
School Meetings Attended (virtually and in person):	2
TSC Community Supported via Adult Support Contacts Program:	215
TSC Community Support Provided to School Districts via Educator Mentor Program:	2
The Community Alliance in this state includes:	Washington, DC and Virginia
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	602
Number of Community Alliance Meetings Held in 2018:	NA
Community Alliance Provided One-on-One Support in 2018:	3
Step Forward to Cure TSC Walk (Y/N):	Y
Other Community Campaigns:	43rd Annual Marine Corps Marathon
Total Gross Dollars Raised:	\$66,448
National Institutes of Health (FY2018) Funded Research Information:	2
Project Title:	Characterization of the Pathogenesis of Lymphangi leiomyomatosis (LAM)
Principal Investigator:	Joel Moss
Institute:	NIH
Congressional District:	8
Award Amount:	\$3,551,929
Project Title:	Dysregulation of Protein Synthesis in Fragile X Syndrome and Other Developmental Disorders
Principal Investigator:	BEEBE, CAROLYN
Institute:	NIH
Congressional District:	8
Award Amount:	\$1,582,883
Number of TSC Natural History Database Sites:	1
TSC Natural History Database Sites:	Children's National Medical Center
Amount Funded in FY18:	<i>See Virginia</i>
TS Alliance Corporate Advisory Board Members:	1
Professional:	Ted Mastroianni
City:	Washington, DC
Number of TS Alliance Professional Advisory Board Members:	2
Professional:	Nancy J. Elling, RN, BSN, CPN
Institution:	Children's National Medical Center
City:	Washington, DC
Professional:	William McClintock, MD
Institution:	Children's National Medical Center
City:	Washington, DC
TS Alliance Operating Board Members:	1
Current Board Member:	Sara Chieffo
City:	Washington, DC

## FLORIDA

Number Estimated with TSC in 2010 by State (Census / 6,000):	3,133
Number Identified Constituents in Entire State:	4,617
VP Support Services Provided One-on-One Support:	40
School Meetings Attended (virtually and in person):	3
TSC Community Supported via TS Alliance Clinic Ambassador Program:	5
TSC Community Supported via Adult Support Contacts Program:	161
TSC Community Support Provided to School Districts via Educator Mentor Program:	4
The Community Alliance in this state includes:	Florida
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	1,013
Community Alliance Provided One-on-One Support in 2018:	59
Step Forward to Cure TSC Walk (Y/N):	Y
Total Gross Dollars Raised:	\$53,342
Number of House Supporters (FY18):	8
House Dear Colleague Signers:	Al Lawson D-FL-5 Darren Soto D-FL-9 Kathy Castor D-FL-14 Dennis Ross R-FL-15 Alcee Hastings D-FL-20 Theodore Deutch D-FL-22 Carlos Curbelo R-FL-26 Ileana Ros-Lehtinen R-FL-27
National Institutes of Health (FY2018) Funded Research Information:	1
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Multicenter Interventional Lymphangioma myomatosis Early Disease Trial (MILED) - DCC Jeffrey Krischer University of Southern Florida 14 \$301,440
Number of TSC Natural History Database Sites:	1
TSC Natural History Database Sites:	Nicklaus Children's Hospital Miami
Amount Funded in FY18:	\$2,603
Number of Clinic Trials:	1
Clinical Trial 1: Name of Participating Institution:	A Randomized Controlled Trial of Cannabidiol (GWP42003-P, CBD) for Seizures in Tuberous Sclerosis Complex (GWPCARE6) Nicklaus Children's Hospital
Number of TSC Clinics & Locations:	1
TSC Clinic Location (1): City:	Nicklaus Children's Hospital Miami
Number of Biosample Repository Site Locations:	1
Biosample Repository Site Location: Biosample Repository Funding:	Nicklaus Children's Hospital \$6,275
Number of TS Alliance Professional Advisory Board Members:	9
Professional: Institution:	Melissa Crenshaw, MD Johns Hopkins All Children's Hospital

	City:	St. Petersburg
	Professional:	Ki Hyeong Lee, MD
	Institution:	Florida Hospital for Children
	City:	Orlando
	Professional:	Sepideh Mokhtari, MD
	Institution:	Lee Moffitt Cancer Center
	City:	Tampa
	Professional:	Xia Wang, MD
	Institution:	Lee Moffitt Cancer Center
	City:	Tampa
	Professional:	Joo Hee Seo, MD, MSc
	Institution:	Florida Hospital for Children
	City:	Orlando
	Professional:	Stacie Stapleton, MD
	Institution:	Johns Hopkins All Children's Hospital
	City:	St. Petersburg
	Professional:	Vikram Prakash, MD
	Institution:	Arnold Palmer Hospital for Children
	City:	Orlando
	Professional:	Michael Duchowny, MD
	Institution:	Nicklaus Children's Hospital
	City:	Miami
	Professional:	Ian Miller, MD
	Institution:	Nicklaus Children's Hospital
	City:	Miami
TS Alliance Operating Board Members:		1
	Current Board Member:	Tom Gwinn
	City:	Parkland

## GEORGIA

Number Estimated with TSC in 2010 by State (Census / 6,000):	1,615
Number Identified Constituents in Entire State:	3,396
VP Support Services Provided One-on-One Support:	118
Educational Training Sessions Posted on Social Media:	269
School Meetings Attended (virtually and in person):	5
TSC Community Supported via TS Alliance Clinic Ambassador Program:	65
TSC Community Supported via Adult Support Contacts Program:	154
TSC Community Supported via Dependent Adult Transition Resource Coordinator Program:	6
TSC Community Support Provided to School Districts via Educator Mentor Program:	2
The Community Alliance in this state includes:	Georgia
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	605
Number of Community Alliance Meetings Held in 2018:	NA
Step Forward to Cure TSC Walk (Y/N):	Y
Other Community Campaigns:	Alex Donato - 19th Birthday Fundraiser
Total Gross Dollars Raised:	\$11,805
Number of House Supporters (FY18):	1
House Dear Colleague Signers:	David Scott D-GA-13
Number of Senate Supporters (FY18):	1
Senate Dear Colleague Signers:	Johnny Isakson R-GA
National Institutes of Health (FY2018) Funded Research Information:	1
Project Title:	The Role of Polyamines in the Neuropathology of Tuberous Sclerosis Complex
Principal Investigator:	Michael Gambello
Institute:	Emory University
Congressional District:	5
Award Amount:	\$195,000
Number of TSC Clinics & Locations:	1
TSC Clinic Location (1):	Children's Healthcare of Atlanta
City:	Atlanta
Number of TS Alliance Professional Advisory Board Members:	3
Professional:	J. Robert Flamini, MD
Institution:	PANDA Neurology
City:	Atlanta
Professional:	David S. Wolf, MD, PhD
Institution:	Children's Healthcare of Atlanta/Emory University
City:	Atlanta
Professional:	Suzanne M. Strickland, MD
Institution:	Georgia Regents University
City:	Augusta

## HAWAII

Number Estimated with TSC in 2010 by State (Census / 6,000):	226
Number Identified Constituents in Entire State:	144
VP Support Services Provided One-on-One Support:	27
TSC Community Supported via Adult Support Contacts Program:	412
The Community Alliance in this state includes:	Hawaii
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	52
Number of House Supporters (FY18):	2
House Dear Colleague Signers:	Colleen Hanabusa D-HI-1 Tulsi Gabbard D-HI-2

## IDAHO

Number Estimated with TSC in 2010 by State (Census / 6,000):	261
Number Identified Constituents in Entire State:	222
VP Support Services Provided One-on-One Support:	25
TSC Community Supported via Adult Support Contacts Program:	423
The Community Alliance in this state includes:	Intermountain West (Idaho, Montana and Utah)
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	411



## ILLINOIS

Number Estimated with TSC in 2010 by State (Census / 6,000):	2,138
Number Identified Constituents in Entire State:	6,807
VP Support Services Provided One-on-One Support:	137
Educational Training Sessions Posted on Social Media:	49
School Meetings Attended (virtually and in person):	4
TSC Community Supported via Adult Support Contacts Program:	369
TSC Community Supported via Dependent Adult Transition Resource Coordinator Program:	32
TSC Community Support Provided to School Districts via Educator Mentor Program:	5
TSC Community Supported via Education Parent Mentor:	65
The Community Alliance in this state includes:	Illinois
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	4,892
Number of Community Alliance Meetings Held in 2018:	3
Community Alliance Provided One-on-One Support in 2018:	181
Step Forward to Cure TSC Walk (Y/N):	Y
Other Community Campaigns:	Brad Rubeck - Birthday Celebration
Total Gross Dollars Raised:	\$88,093
Number of House Supporters (FY18):	12
House Dear Colleague Signers:	Bobby Rush D-IL-1 Robin Kelly D-IL-2 Daniel Lipinski D-IL-3 Luis Gutierrez D-IL-4 Peter Roskam R-IL-6 Danny Davis D-IL-7 Raja Krishamoorthi D-IL-8 Janis Schakowski D-IL-9 Brad Schneider D-IL-10 Bill Foster D-IL-11 Rodney Davis R-IL-13 Adam Kinzinger R-IL-16
Number of Senate Supporters (FY18):	1
Senate Dear Colleague Signers:	Tammy Duckworth D-IL
National Institutes of Health (FY2018) Funded Research Information:	1
Project Title:	Progesterone/Progesterone Receptor Axis in Lymphangiomiomatosis
Principal Investigator:	Lucia Schuger
Institute:	University of Chicago
Congressional District:	4
Award Amount:	\$399,048
Number of TSC Natural History Database Sites:	1
TSC Natural History Database Sites:	University of Chicago
Amount Funded in FY18:	\$11,060
Number of Clinic Trials:	1
Clinical Trial 1:	A Randomized Controlled Trial of Cannabidiol (GWP42003-P, CBD) for Seizures in Tuberous Sclerosis Complex (GWPCARE6)
Name of Participating Institution:	Lurie Children's Hospital

Number of TSC Clinics & Locations:	3
TSC Clinic Location (1): City:	University of Chicago Comer Children's Hospital Chicago
TSC Clinic Location (2): City:	Ann & Robert H. Lurie Children's Hospital of Chicago Chicago
TSC Clinic Location (3): City:	University of Illinois Chicago
Number of Biosample Repository Site Locations:	1
Biosample Repository Site Location: Biosample Repository Funding:	University of Chicago \$3,000
TS Alliance Corporate Advisory Board Members:	1
Professional: City:	Sean C. Nolan Libertyville
Number of TS Alliance Professional Advisory Board Members:	5
Professional: Institution: City:	Saba Ahmad, MD University of Illinois Chicago Chicago
Professional: Institution: City:	Anna Jeong, MD AbbVie North Chicago
Professional: Institution: City:	James Tonsgard, MD University of Chicago Chicago
Professional: Institution: City:	Patricia Ogden, APN, MSN University of Chicago Chicago
Professional: Institution: City:	Akira Yoshii, MD, PhD University of Illinois Chicago
TS Alliance Operating Board Members:	1
Current Board Member: City:	Beth Dean, Chair Grayslake
TS Alliance Endowment Board Members:	1
Current Endowment Board Member: City:	James Achterhof Palos Park

## INDIANA

Number Estimated with TSC in 2010 by State (Census / 6,000):	1,080
Number Identified Constituents in Entire State:	2,443
VP Support Services Provided One-on-One Support:	35
Educational Training Sessions Posted on Social Media:	240
TSC Community Supported via Adult Support Contacts Program:	374
The Community Alliance in this state includes:	Indiana
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	472
Community Alliance Provided One-on-One Support in 2018:	163
Step Forward to Cure TSC Walk (Y/N):	Y
Other Community Campaigns:	IN Golf Tournament Polo @ Sunset
Total Gross Dollars Raised:	\$17,269
Number of House Supporters (FY18):	2
House Dear Colleague Signers:	Luke Messer R-IN-6 Andre Carson D-IN-7
Number of Senate Supporters (FY18):	1
Senate Dear Colleague Signers:	Joe Donnelly D-IN
National Institutes of Health (FY2018) Funded Research Information:	1
Project Title:	Enhancing Anti-Neoplastic Activity of Metformin in Prostate Cancer
Principal Investigator:	Xiaoqi Liu
Institute:	Purdue University
Congressional District:	4
Award Amount:	\$357,717
TS Alliance Corporate Advisory Board Members:	1
Professional:	Ken Kocher
City:	Indianapolis
Number of TS Alliance Professional Advisory Board Members:	1
Professional:	David W. Dunn, MD
Institution:	Riley Hospital for Children
City:	Indianapolis

## IOWA

Number Estimated with TSC in 2010 by State (Census / 6,000):	508
Number Identified Constituents in Entire State:	1,105
VP Support Services Provided One-on-One Support:	37
School Meetings Attended (virtually and in person):	1
TSC Community Supported via Adult Support Contacts Program:	185
The Community Alliance in this state includes:	Heartland (Iowa and Nebraska)
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	395
Other Community Campaigns:	99 Counties (Beth Adams)
Total Gross Dollars Raised:	\$2,236
Number of House Supporters (FY18):	2
House Dear Colleague Signers:	David Loeb sack D-IA-2 Steve King R-IA-4

## KANSAS

Number Estimated with TSC in 2010 by State (Census / 6,000):	476
Number Identified Constituents in Entire State:	1,597
VP Support Services Provided One-on-One Support:	36
School Meetings Attended (virtually and in person):	1
TSC Community Supported via Adult Support Contacts Program:	258
The Community Alliance in this state includes:	Kansas
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	254
Number of Community Alliance Meetings Held in 2018:	2
Community Alliance Provided One-on-One Support in 2018:	50
Other Community Campaigns:	Kick TSC to the Curb Kickball Tournament
Total Gross Dollars Raised:	\$7,964
Number of House Supporters (FY18):	1
House Dear Colleague Signers:	Lynn Jenkins R-KS-2

## KENTUCKY

Number Estimated with TSC in 2010 by State (Census / 6,000):	723
Number Identified Constituents in Entire State:	1,074
VP Support Services Provided One-on-One Support:	67
School Meetings Attended (virtually and in person):	2
TSC Community Supported via Adult Support Contacts Program:	144
TSC Community Supported via Dependent Adult Transition Resource Coordinator Program:	2
The Community Alliance in this state includes:	Kentucky and West Virginia
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	398
Number of Community Alliance Meetings Held in 2018:	NA
Community Alliance Provided One-on-One Support in 2018:	12
Step Forward to Cure TSC Walk (Y/N):	Y
Total Gross Dollars Raised:	\$4,406
Number of House Supporters (FY18):	1
House Dear Colleague Signers:	John Yarmuth D-KY-3
Number of TSC Clinics & Locations:	1
TSC Clinic Location (1): City:	Norton Children's Hospital Louisville
Number of TS Alliance Professional Advisory Board Members:	2
Professional: Institution: City:	Arpita Lahkotia, MD Norton Children's Hospital Louisville
Professional: Institution: City:	Sushil Gupta, MD Norton Children's Hospital Louisville



## LOUISIANA

Number Estimated with TSC in 2010 by State (Census / 6,000):	756
Number Identified Constituents in Entire State:	1,149
VP Support Services Provided One-on-One Support:	100
Educational Training Sessions Posted on Social Media:	40
School Meetings Attended (virtually and in person):	2
TSC Community Supported via Adult Support Contacts Program:	288
TSC Community Supported via Dependent Adult Transition Resource Coordinator Program:	27
The Community Alliance in this state includes:	Delta Region (Louisiana and Mississippi)
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	340
Number of Community Alliance Meetings Held in 2018:	3
Community Alliance Provided One-on-One Support in 2018:	158
Step Forward to Cure TSC Walk (Y/N):	Y
Other Community Campaigns:	Temple Poche' Annual Fundraiser
Total Gross Dollars Raised:	\$23,183
Number of House Supporters (FY18):	3
House Dear Colleague Signers:	Cedric Richmond D-LA-2 Ralph Abraham R-LA-5 Garrett Graves R-LA-6

## MAINE

Number Estimated with TSC in 2010 by State (Census / 6,000):	221
Number Identified Constituents in Entire State:	340
VP Support Services Provided One-on-One Support:	26
Educational Training Sessions Posted on Social Media:	54
TSC Community Supported via Adult Support Contacts Program:	197
The Community Alliance in this state includes:	New England (New Hampshire, Maine, Massachusetts and Vermont)
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	732
Number of House Supporters (FY18):	2
House Dear Colleague Signers:	Chellie Pingree D-ME-1 Bruce Poliquin R-ME-2
Number of Senate Supporters (FY18):	1
Senate Dear Colleague Signers:	Susan Collins R-ME
TS Alliance Operating Board Members:	1
Current Board Member:	David Coit
City:	Cape Eliz

## MARYLAND

Number Estimated with TSC in 2010 by State (Census / 6,000):	962
Number Identified Constituents in Entire State:	3,116
VP Support Services Provided One-on-One Support:	56
School Meetings Attended (virtually and in person):	2
TSC Community Supported via TS Alliance Clinic Ambassador Program:	398
TSC Community Supported via Adult Support Contacts Program:	190
The Community Alliance in this state includes:	Maryland
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	489
Number of Community Alliance Meetings Held in 2018:	3
Community Alliance Provided One-on-One Support in 2018:	100
Step Forward to Cure TSC Walk (Y/N):	See Washington, DC
Other Community Campaigns:	Dance for Austin Cornmaze for a Cause
Total Gross Dollars Raised:	\$7,309
Number of House Supporters (FY18):	3
House Dear Colleague Signers:	Dutch Ruppersberger D-MD-2 John Delaney D-MD-6 Jamie Raskin D-MD-8
Number of Senate Supporters (FY18):	2
Senate Dear Colleague Signers:	Benjamin Cardin D-MD Chris Van Hollen D-MD
National Institutes of Health (FY2018) Funded Research Information:	1
Project Title:	Role of Tuberlin S1365 Phosphorylation in mTORC1 Regulation
Principal Investigator:	Brittany Dunkerly-Eyring
Institute:	Johns Hopkins University
Congressional District:	7
Award Amount:	\$44,524
Number of Clinic Trials:	1
Clinical Trial 1:	Cutaneous Tumorigenesis In Patients With Tuberous Sclerosis
Name of Participating Institution:	United States Uniformed Health Service
Number of TSC Clinics & Locations:	2
TSC Clinic Location (1):	Kennedy Krieger Institute
City:	Baltimore
TSC Clinic Location (2):	University of Maryland Medical Center
City:	Baltimore
TS Alliance International Scientific Advisory Board Members:	1
International Scientific Advisor Name:	Peter Crino, MD, PhD
Institution:	University of Maryland, School of Medicine
City, Country:	Baltimore, MD, USA
Number of TS Alliance Professional Advisory Board Members:	3
Professional:	Peter Crino, MD, PhD
Institution:	University of Maryland Medical Center
City:	Baltimore
Professional:	Jacqueline Harris, MD, MS
Institution:	Kennedy Krieger Institute
City:	Baltimore

Professional:	Joel Moss, MD, PhD
Institution:	NIH/NHLBI
City:	Bethesda
TS Alliance Operating Board Members:	2
Current Board Member:	Bonnie Hogue Duffy
City:	Chevy Chase
Current Board Member:	Rebecca Anhang Price
City:	Chevy Chase

## MASSACHUSETTS

Number Estimated with TSC in 2010 by State (Census / 6,000):	1,091
Number Identified Constituents in Entire State:	4,218
VP Support Services Provided One-on-One Support:	82
Educational Training Sessions Posted on Social Media:	10
School Meetings Attended (virtually and in person):	2
TSC Community Supported via Adult Support Contacts Program:	209
TSC Community Supported via Dependent Adult Transition Resource Coordinator Program:	332
The Community Alliance in this state includes:	New England (New Hampshire, Maine, Massachusetts and Vermont)
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	732
Number of Community Alliance Meetings Held in 2018:	2
Step Forward to Cure TSC Walk (Y/N):	Y
Total Gross Dollars Raised:	\$32,272
Number of House Supporters (FY18):	7
House Dear Colleague Signers:	James McGovern D-MA-2 Niki Tsongas D-MA-3 Joseph Kennedy D-MA-4 Seth Moulton D-MA-6 Michael Capuano D-MA-7 Stephen Lynch D-MA-8 Willima Keating D-MA-9
Number of Senate Supporters (FY18):	2
Senate Dear Colleague Signers:	Edward Markey D-MA Elizabeth Warren D-MA
National Institutes of Health (FY2018) Funded Research Information:	30
Project Title:	Targeting Choline Phospholipid Metabolism in Lymphangiomyomatosis
Principal Investigator:	Carmen Priolo
Institute:	Brigham and Women's Hospital
Congressional District:	7
Award Amount:	\$436,000
Project Title:	Synaptic Pathophysiology of the 16p11.2 Microdeletion Mouse Model
Principal Investigator:	Mark Bear
Institute:	Massachusetts Institute of Technology
Congressional District:	7
Award Amount:	\$531,026
Project Title:	Developmental Synaptopaties Associated with TSC, PTEN and SHANK3 Mutations
Principal Investigator:	Mustafa Sahin
Institute:	Boston Children's Hospital
Congressional District:	7
Award Amount:	\$74,694

Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Developmental Synaptopaties Associated with TSC, PTEN and SHANK3 Mutations Mustafa Sahin Boston Children's Hospital 7 \$47,917
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Developmental Synaptopaties Associated with TSC, PTEN and SHANK3 Mutations Mustafa Sahin Boston Children's Hospital 7 \$104,723
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Developmental Synaptopaties Associated with TSC, PTEN and SHANK3 Mutations Mustafa Sahin Boston Children's Hospital 7 \$73,079
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Developmental Synaptopaties Associated with TSC, PTEN and SHANK3 Mutations Mustafa Sahin Boston Children's Hospital 7 \$51,454
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Developmental Synaptopaties Associated with TSC, PTEN and SHANK3 Mutations Mustafa Sahin Boston Children's Hospital 7 \$33,008
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Developmental Synaptopaties Associated with TSC, PTEN and SHANK3 Mutations Mustafa Sahin Boston Children's Hospital 7 \$72,140
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Developmental Synaptopaties Associated with TSC, Pten And Shank3 Mutations Mustafa Sahin Boston Children's Hospital 7 \$50,341
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Developmental Synaptopaties Associated with TSC, Pten And Shank3 Mutations Mustafa Sahin Boston Children's Hospital 7 \$46,577
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Developmental Synaptopaties Associated with TSC, PTEN and SHANK3 Mutations Mustafa Sahin Boston Children's Hospital 7 \$29,880

Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Developmental Synaptopaties Associated with TSC, PTEN and SHANK3 Mutations Mustafa Sahin Boston Children's Hospital 7 \$65,303
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Developmental Synaptopaties Associated with TSC, PTEN and SHANK3 Mutations Mustafa Sahin Boston Children's Hospital 7 \$45,571
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Developmental Synaptopaties Associated with TSC, PTEN and SHANK3 Mutations Mustafa Sahin Boston Children's Hospital 7 \$78,544
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Developmental Synaptopaties Associated with TSC, PTEN and SHANK3 Mutations Mustafa Sahin Boston Children's Hospital 7 \$50,387
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Developmental Synaptopaties Associated with TSC, PTEN and SHANK3 Mutations Mustafa Sahin Boston Children's Hospital 7 \$110,121
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Developmental Synaptopaties Associated with TSC, PTEN and SHANK3 Mutations Mustafa Sahin Boston Children's Hospital 7 \$76,846
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Developmental Synaptopaties Associated with TSC, PTEN and SHANK3 Mutations Mustafa Sahin Boston Children's Hospital 7 \$17,168
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Developmental Synaptopaties Associated with TSC, PTEN and SHANK3 Mutations Mustafa Sahin Boston Children's Hospital 7 \$11,013
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Developmental Synaptopaties Associated with TSC, PTEN and SHANK3 Mutations Mustafa Sahin Boston Children's Hospital 7 \$24,070

Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Developmental Synaptopaties Associated with TSC, PTEN and SHANK3 Mutations Mustafa Sahin Boston Children's Hospital 7 \$16,797
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Decoding and targeting the PI3K-mTOR signaling network in cancer Brendan Manning Harvard School of Public Health 7 \$924,904
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Induction of Oncogenic mircoRNA by rapamycin: Role in TSC Therapy Elizabeth Henske Brigham and Women's Hospital 7 \$383,333
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	The Molecular and Genetic Pathogenesis of LAM Elizabeth Henske Brigham and Women's Hospital 7 \$686,741
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Mechanisms of Synapse Remodeling in TSC Beth Stevens Boston Children's Hospital 7 \$126,066
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Project 3: Identifying Transcriptional Driver Genes And Targeting Transcription in TSC David Kwiatkowski Brigham and Women's Hospital 7 \$530,163
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Core B: Mass Spectrometry, Proteomics, Metabolomics and Lipidomics John Asara Beth Israel Deaconess Medical Center 7 \$193,824
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Impact of Mitochondrial Dynamics on the Development of Renal Cysts in Tuberous Sclerosis Complex (TSC) Hilaire Lam Brigham and Women's Hospital 7 \$157,459
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Developmental Synaptopathies Associated with TSC, PTEN and SHANK3 Mutations Mustafa Sahin Boston Children's Hospital 7 \$62,698



Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Early Biomarkers of Autism Spectrum Disorders in infants with Tuberous Sclerosis Mustafa Sahin Boston Children's Hospital 7 \$500,000
<b>TSCRP Funded Research Information:</b>	<b>1</b>
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Dissecting Mechanisms of Immune Suppression in Tuberous Sclerosis Complex (TSC) by Integrative Single Cell Profiling of Tumor-Microenvironment Interaction Tang, Yan Brigham and Women's Hospital, Inc 7 \$179,000
<b>TS Alliance Funded Research:</b>	<b>1</b>
Project Title: Principal Investigator: Institute: Congressional District: FY: Award Amount:	Mitochondrial DNA Heteroplasmy in the Pathogenesis and Therapy of TSC Hilaire C. Lam Brigham and Women's Hospital 7 18 \$20,000
<b>Number of TSC Natural History Database Sites:</b>	<b>2</b>
<b>TSC Natural History Database Sites:</b>	Herscot Center for TSC at Massachusetts General Hospital Boston Children's Hospital
<b>Amount Funded in FY18:</b>	<b>\$23,040</b>
<b>Number of Clinic Trials:</b>	<b>8</b>
Clinical Trial 1: Name of Participating Institution:	Biospecimen collection for LAM/TSC research Dana-Farber Cancer Center
Clinical Trial 2: Name of Participating Institution:	Longitudinal study to identify early biomarkers of autism spectrum disorder (ASD) in infants with tuberous sclerosis complex (TSC) Boston Children's Hospital
Clinical Trial 3: Name of Participating Institution:	Potential EEG biomarkers and antiepileptogenic strategies for epilepsy in TSC Boston Children's Hospital
Clinical Trial 4: Name of Participating Institution:	Autism spectrum disorder (ASD) and intellectual disability (ID) determinants in tuberous sclerosis complex Boston Children's Hospital
Clinical Trial 5: Name of Participating Institution:	A Double-blind, Randomized, Placebo-controlled Study to Investigate the Efficacy and Safety of Cannabidiol (GWP42003-P, CBD) as Add-on Therapy in Patients With Tuberous Sclerosis Complex Who Experience Inadequately-controlled Seizures Herscot Center for TSC at Massachusetts General Hospital
Clinical Trial 6: Name of Participating Institution:	Preventing Epilepsy Using Vigabatrin in Infants with Tuberous Sclerosis Complex (PREVeNT Trial) A Randomized, Double-blind, Placebo-controlled Seizure Prevention Clinical Trial for Infants With TSC Boston Children's Hospital

Professional:	Elizabeth A. Thiele, MD, PhD
Institution:	Herscot Center for TSC at MGH
City:	Boston
Professional:	Elahna Paul, MD, PhD
Institution:	Massachusetts General Hospital
City:	Boston
TS Alliance Operating Board Members:	
1	
Current Board Member:	Brendan D. Manning, PhD
City:	Boston

## MICHIGAN

Number Estimated with TSC in 2010 by State (Census / 6,000):	1,647
Number Identified Constituents in Entire State:	4,508
VP Support Services Provided One-on-One Support:	72
School Meetings Attended (virtually and in person):	2
TSC Community Supported via TS Alliance Clinic Ambassador Program:	226
TSC Community Supported via Adult Support Contacts Program:	331
TSC Community Supported via Dependent Adult Transition Resource Coordinator Program:	8
TSC Community Support Provided to School Districts via Educator Mentor Program:	8
The Community Alliance in this state includes:	Michigan
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	803
Number of Community Alliance Meetings Held in 2018:	1
Community Alliance Provided One-on-One Support in 2018:	87
Step Forward to Cure TSC Walk (Y/N):	Y
Total Gross Dollars Raised:	\$12,782
Number of House Supporters (FY18):	5
House Dear Colleague Signers:	Daniel Kildee D-MI-5 Sander Levin D-MI-9 Dave Trott R-MI-11 Debbie Dingel D-MI-12 Brenda Lawrence D-MI-14
Number of Senate Supporters (FY18):	2
Senate Dear Colleague Signers:	Gary Peters D-MI Debbie Stabenow D-MI
TS Alliance Funded Research:	1
Project Title:	The Role of Exosomes in Epilepsy of TSC
Principal Investigator:	Dombkowski, Alan
Institute:	Wayne State University
Congressional District:	12
FY:	18
Award Amount:	\$50,000
Number of TSC Clinics & Locations:	3
TSC Clinic Location (1):	Children's Hospital of Michigan
City:	Detroit
TSC Clinic Location (2):	Beaumont Health System
City:	Royal Oak
TSC Clinic Location (3):	Helen deVos Children's Hospital
City:	Grand Rapids
Number of TS Alliance Professional Advisory Board Members:	5
Professional:	Steven DeRoos, MD
Institution:	Helen DeVos Children's Hospital
City:	Grand Rapids
Professional:	Aimee Luat, MD
Institution:	Children's Hospital Michigan
City:	Detroit
Professional:	Anne Marie Michon, MSN, RN, CPNP-PC
Institution:	Beaumont Children's Hospital
City:	Royal Oak

Clinical Trial 7: Name of Participating Institution:	JASPER Early Intervention for Tuberous Sclerosis (JETS) Boston Children's Hospital
Clinical Trial 8: Name of Participating Institution:	An Open-label Extension Trial of Cannabidiol (GWP42003-P, CBD) for Seizures in Tuberous Sclerosis Complex (GWPCARE6) Herscot Center for TSC at MGH
Number of TSC Clinics & Locations:	2
TSC Clinic Location (1): City:	Boston Children's Hospital Boston
TSC Clinic Location (2): City:	Herscot Center for TSC at Massachusetts General Hospital Boston
Number of Biosample Repository Site Locations:	1
Biosample Repository Site Location: Biosample Repository Funding:	Herscot Center for TSC at Massachusetts General Hospital \$13,320
TS Alliance International Scientific Advisory Board Members:	4
International Scientific Advisor Name: Institution: City, Country:	Brendan Manning, PhD Department of Genetics and Complex Disease, Harvard School of Public Health Boston, MA, USA
International Scientific Advisor Name: Institution: City, Country:	Elizabeth Petri Henske, MD Brigham and Women's Hospital, Harvard Medical School Boston, MA, USA
International Scientific Advisor Name: Institution: City, Country:	David Kwiatkowski, MD, PhD Brigham and Women's Hospital, Harvard Medical School Boston, MA, USA
International Scientific Advisor Name: Institution: City, Country:	Mustafa Sahin, MD, PhD Children's Hospital and Harvard University Boston, MA, USA
Number of TS Alliance Professional Advisory Board Members:	9
Professional: Institution: City:	Mary Elizabeth Aronow, MD Massachusetts Eye & Ear Infirmary Boston
Professional: Institution: City:	Kira A. Dies, ScM, CGC Boston Children's Hospital Boston
Professional: Institution: City:	Souheil El-Chemaly, MD, MPH Brigham and Women's Hospital Boston
Professional: Institution: City:	Cristina R. Ferrone, MD Massachusetts General Hospital Boston
Professional: Institution: City:	Joannes (Joop) Grevelink, MD, PhD Boston Dermatology & Laser Center Boston
Professional: Institution: City:	Elizabeth P. Henske, MD Brigham and Women's Hospital Boston
Professional: Institution: City:	David Kwiatkowski, MD, PhD Brigham and Women's Hospital Boston

Professional:	Danielle Nolan, MD
Institution:	Beaumont Children's Hospital
City:	Royal Oak

Professional:	Melissa Gregory, MD
Institution:	Children's Hospital Michigan
City:	Detroit

## MINNESOTA

Number Estimated with TSC in 2010 by State (Census / 6,000):	884
Number Identified Constituents in Entire State:	4,838
VP Support Services Provided One-on-One Support:	87
Educational Training Sessions Posted on Social Media:	594
TSC Community Supported via TS Alliance Clinic Ambassador Program:	215
TSC Community Supported via Adult Support Contacts Program:	186
TSC Community Supported via Dependent Adult Transition Resource Coordinator Program:	8
TSC Community Support Provided to School Districts via Educator Mentor Program:	2
The Community Alliance in this state includes:	Upper Midwest (North Dakota, Minnesota, South Dakota)
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	765
Community Alliance Provided One-on-One Support in 2018:	341
Step Forward to Cure TSC Walk (Y/N):	Y
Total Gross Dollars Raised:	\$22,265
Number of House Supporters (FY18):	4
House Dear Colleague Signers:	Timothy Walz D-MN-1 Keith Ellison D-MN-5 Collin Peterson D-MN-7 Richard Nolan D-MN-8
TSCRP Funded Research Information:	1
Project Title:	Role of the Immunoproteasome in TSC Pathogenesis and Therapeutics
Principal Investigator:	Kim, Do-Hyung
Institute:	Minnesota University of, Twin Cities
Congressional District:	5
Award Amount:	\$693,000
Number of TSC Natural History Database Sites:	1
TSC Natural History Database Sites:	Minnesota Epilepsy Group in St. Paul
Amount Funded in FY18:	\$19,265
Number of Clinic Trials:	2
Clinical Trial 1:	A Double-blind, Randomized, Placebo-controlled Study to Investigate the Efficacy and Safety of Cannabidiol (GWP42003-P, CBD) as Add-on Therapy in Patients With Tuberous Sclerosis Complex Who Experience Inadequately-controlled Seizures
Name of Participating Institution:	Minnesota Epilepsy Group
Clinical Trial 2:	Preventing Epilepsy Using Vigabatrin in Infants with Tuberous Sclerosis Complex (PREVeNT Trial) A Randomized, Double-blind, Placebo-controlled Seizure Prevention Clinical Trial for Infants With TSC
Name of Participating Institution:	Minnesota Epilepsy Group
Number of TSC Clinics & Locations:	1
TSC Clinic Location (1):	Minnesota Epilepsy Group
City:	Saint Paul
Number of Biosample Repository Site Locations:	1

Biosample Repository Site Location:	Minnesota Epilepsy Group
Biosample Repository Funding:	\$8,425
TS Alliance Corporate Advisory Board Members:	1
Professional:	Judy Shoulak
City:	Corcoran
Number of TS Alliance Professional Advisory Board Members:	2
Professional:	Michael D. Frost, MD
Institution:	The Minnesota Epilepsy Group, PA
City:	Saint Paul
Professional:	John Hulbert, MD
Institution:	Urologic Physicians PA
City:	Edina
TS Alliance Operating Board Members:	1
Current Board Member:	Darren Miles
City:	Edina
TS Alliance Endowment Board Members:	1
Current Endowment Board Member:	Hal Tearse
City:	Maple Plain

## MISSISSIPPI

Number Estimated with TSC in 2010 by State (Census / 6,000):	495
Number Identified Constituents in Entire State:	510
VP Support Services Provided One-on-One Support:	17
School Meetings Attended (virtually and in person):	1
TSC Community Supported via Adult Support Contacts Program:	164
The Community Alliance in this state includes:	Delta Region (Louisiana and Mississippi)
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	340
Number of Community Alliance Meetings Held in 2018:	See LA
Step Forward to Cure TSC Walk (Y/N):	See LA
Other Community Campaigns:	Brewing for a Cure
Total Gross Dollars Raised:	\$37,881
Number of House Supporters (FY18):	3
House Dear Colleague Signers:	Trent Kelly R-MS-1 Bennie Thompson D-MS-2 Gregg Harper R-MS03



## MISSOURI

Number Estimated with TSC in 2010 by State (Census / 6,000):	998
Number Identified Constituents in Entire State:	3,291
VP Support Services Provided One-on-One Support:	150
Educational Training Sessions Posted on Social Media:	333
School Meetings Attended (virtually and in person):	3
TSC Community Supported via TS Alliance Clinic Ambassador Program:	227
TSC Community Supported via Adult Support Contacts Program:	281
TSC Community Support Provided to School Districts via Educator Mentor Program:	36
TSC Community Supported via Education Parent Mentor:	66
The Community Alliance in this state includes:	Missouri and Southern Illinois
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	2,081
Step Forward to Cure TSC Walk (Y/N):	Y
Total Gross Dollars Raised:	\$7,040
Number of House Supporters (FY18):	4
House Dear Colleague Signers:	William "Lacy" Clay Jr. D-MO-1 Vicky Hartzler R-MO-4 Emanuel Cleaver D-MO-5 Sam Graves R-MO-6
Number of Senate Supporters (FY18):	1
Senate Dear Colleague Signers:	Claire McCaskill D-MO
National Institutes of Health (FY2018) Funded Research Information:	3
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Mechanisms of Brain Dysfunction in Tuberous Sclerosis Michael Wong Washington University 1 \$333,594
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	A Mouse Model of Sleep Disorders in Tuberous Sclerosis Complex Michael Wong Washington University 1 \$233,250
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	A Mouse Model of Infantile Spasms in Tuberous Sclerosis Complex Michael Wong Washington University 1 \$228,750
Number of TSC Natural History Database Sites:	1
TSC Natural History Database Sites:	Washington University St. Louis
Amount Funded in FY18:	\$12,860

<b>Number of Clinic Trials:</b>	<b>1</b>
<b>Clinical Trial 1:</b>	A Randomized Controlled Trial of Cannabidiol (GWP42003-P, CBD) for Seizures in Tuberous Sclerosis Complex (GWPCARE6)
<b>Name of Participating Institution:</b>	Washington University St. Louis
<b>Number of TSC Clinics &amp; Locations:</b>	<b>2</b>
<b>TSC Clinic Location (1):</b>	Washington University St. Louis
<b>City:</b>	St. Louis
<b>TSC Clinic Location (2):</b>	Children's Mercy Hospital
<b>City:</b>	Kansas City
<b>Number of Biosample Repository Site Locations:</b>	<b>1</b>
<b>Biosample Repository Site Location:</b>	Washington University St. Louis
<b>Biosample Repository Funding:</b>	\$17,900
<b>TS Alliance International Scientific Advisory Board Members:</b>	<b>1</b>
<b>International Scientific Advisor Name:</b>	Michael Wong, MD, PhD
<b>Institution:</b>	Dept. of Neurology, Washington University School of Medicine
<b>City, Country:</b>	St. Louis, MO, USA
<b>Number of TS Alliance Professional Advisory Board Members:</b>	<b>6</b>
<b>Professional:</b>	L. Richard Feldenberg, MD
<b>Institution:</b>	Cardinal Glennon Children's Hospital
<b>City:</b>	St. Louis
<b>Professional:</b>	Bryce Heese, MD
<b>Institution:</b>	Children's Mercy Hospital
<b>City:</b>	Kansas City
<b>Professional:</b>	Mohammed Ilyas, MD
<b>Institution:</b>	Children's Mercy Hospital
<b>City:</b>	Kansas City
<b>Professional:</b>	Laura A. Jansen, MD, PhD
<b>Institution:</b>	Washington University
<b>City:</b>	St. Louis
<b>Professional:</b>	Michael Wong, MD, PhD
<b>Institution:</b>	Washington University
<b>City:</b>	St. Louis
<b>Professional:</b>	Vikram Prakash, MD (until 7.31.2018)
<b>Institution:</b>	Children's Mercy Hospital
<b>City:</b>	Kansas City

## MONTANA

Number Estimated with TSC in 2010 by State (Census / 6,000):	165
Number Identified Constituents in Entire State:	130
VP Support Services Provided One-on-One Support:	13
School Meetings Attended (virtually and in person):	1
TSC Community Supported via TS Alliance Clinic Ambassador Program:	227
TSC Community Supported via Adult Support Contacts Program:	283
The Community Alliance in this state includes:	Intermountain West (Idaho, Montana and Utah)
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	411
Number of House Supporters (FY18):	1
House Dear Colleague Signers:	Gregg Gianforte R-MT

## NEBRASKA

Number Estimated with TSC in 2010 by State (Census / 6,000):	304
Number Identified Constituents in Entire State:	481
VP Support Services Provided One-on-One Support:	39
TSC Community Supported via Adult Support Contacts Program:	185
The Community Alliance in this state includes:	Heartland (Iowa and Nebraska)
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	395

## NEVADA

Number Estimated with TSC in 2010 by State (Census / 6,000):	450
Number Identified Constituents in Entire State:	681
VP Support Services Provided One-on-One Support:	131
School Meetings Attended (virtually and in person):	4
TSC Community Supported via Adult Support Contacts Program:	426
TSC Community Supported via Dependent Adult Transition Resource Coordinator Program:	108
TSC Community Support Provided to School Districts via Educator Mentor Program:	10
TSC Community Supported via Education Parent Mentor:	145
The Community Alliance in this state includes:	Nevada
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	129
Number of Community Alliance Meetings Held in 2018:	1
Community Alliance Provided One-on-One Support in 2018:	490
Step Forward to Cure TSC Walk (Y/N):	Y
Total Gross Dollars Raised:	\$5,799
Number of House Supporters (FY18):	2
House Dear Colleague Signers:	Jakcy Rosen D-NV-3 Ruben Kihuen D-NV-4
Number of Senate Supporters (FY18):	1
Senate Dear Colleague Signers:	Catherine Cortez-Masto D-NV
TS Alliance Operating Board Members:	1
Current Board Member:	Tara Zimmerman
City:	Sparks

## NEW HAMPSHIRE

Number Estimated with TSC in 2010 by State (Census / 6,000):	219
Number Identified Constituents in Entire State:	690
VP Support Services Provided One-on-One Support:	29
Educational Training Sessions Posted on Social Media:	70
TSC Community Supported via Adult Support Contacts Program:	192
The Community Alliance in this state includes:	New England (New Hampshire, Maine, Massachusetts and Vermont)
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	732
Number of House Supporters (FY18):	2
House Dear Colleague Signers:	Carol Shea-Porter D-NH-1 Ann Marie Kuster D-NH-2
Number of Senate Supporters (FY18):	1
Senate Dear Colleague Signers:	Jeanne Shaheen D-NH

## NEW JERSEY

Number Estimated with TSC in 2010 by State (Census / 6,000):	1,465
Number Identified Constituents in Entire State:	4,543
VP Support Services Provided One-on-One Support:	44
TSC Community Supported via Adult Support Contacts Program:	202
The Community Alliance in this state includes:	New York and New Jersey
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	1,744
Number of Community Alliance Meetings Held in 2018:	1
Community Alliance Provided One-on-One Support in 2018:	57
Step Forward to Cure TSC Walk (Y/N):	Y
Total Gross Dollars Raised:	\$15,586
Number of House Supporters (FY18):	10
House Dear Colleague Signers:	Donald Norcross D-NJ-1 Frank LoBiondo R-NJ-2 Tom MacArthur R-NJ-3 Chris Smith R-NJ-4 Josh Gottheimer D-NJ-5 Leonard Lance R-NJ-7 Albio Sires D-NJ-8 Bill Pascrell Jr. D-NJ-9 Donald Payne D-NJ-10 Bonnie Watson Coleman D-NJ-12
Number of Senate Supporters (FY18):	2
Senate Dear Colleague Signers:	Cory Booker D-NJ Robert Menendez D-NJ
Number of TSC Clinics & Locations:	2
TSC Clinic Location (1): City:	Northeast Regional Epilepsy Group Hackensack
TSC Clinic Location (2): City:	St. Barnabas Medical Center Livingston
TS Alliance Corporate Advisory Board Members:	1
Professional: City:	James S. Richter Chester
Number of TS Alliance Professional Advisory Board Members:	2
Professional: Institution: City:	Eric B. J. Ségal, MD Northeast Regional Epilepsy Group Hackensack
Professional: Institution: City:	Rajeshwari Mahalingham, MD and Puja Joshi, MD St. Barnabas Medical Center Livingston
TS Alliance Operating Board Members:	2
Current Board Member: City:	Peter Crino, MD, PhD Moorestown
Current Board Member: City:	David Fitzmaurice Wyckoff

## NEW MEXICO

Number Estimated with TSC in 2010 by State (Census / 6,000):	343
Number Identified Constituents in Entire State:	292
VP Support Services Provided One-on-One Support:	23
TSC Community Supported via Adult Support Contacts Program:	418
The Community Alliance in this state includes:	Rocky Mountain (Colorado, New Mexico and Wyoming)
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	705
Number of House Supporters (FY18):	2
House Dear Colleague Signers:	Michelle Lujan Grisham D-NM-1 Ben Lujan D-NM-3
Number of Senate Supporters (FY18):	1
Senate Dear Colleague Signers:	Martin Heinrich D-NM



## NEW YORK

Number Estimated with TSC in 2010 by State (Census / 6,000):	3,230
Number Identified Constituents in Entire State:	8,132
VP Support Services Provided One-on-One Support:	160
School Meetings Attended (virtually and in person):	5
TSC Community Supported via Adult Support Contacts Program:	328
TSC Community Support Provided to School Districts via Educator Mentor Program:	12
TSC Community Supported via Education Parent Mentor:	92
The Community Alliance in this state includes:	New York and New Jersey
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	1,744
Number of Community Alliance Meetings Held in 2018:	2
Community Alliance Provided One-on-One Support in 2018:	272
Step Forward to Cure TSC Walk (Y/N):	Y
Other Community Campaigns:	Strike Out for TSC Rollin' For a Cure Team TSC – NYC Rabobank Dinner & Auction Help Jesenia Destroy TSC
Total Gross Dollars Raised:	\$152,771
Number of House Supporters (FY18):	18
House Dear Colleague Signers:	Lee Zeldin R-NY-1 Pete King R-NY-2 Thomas Suozzi D-NY-3 Kathleen Rice D-NY-4 Gregory Meeks D-NY-5 Grace Meng D-NY-6 Nydia Velazquez D-NY-7 Yvette Clarke D-NY-9 Jerrold Nadler D-NY-10 Carolyn Maloney D-NY-12 Adriano Espaillat D-NY-13 Joseph Crowley D-NY-14 Eliot Engel D-NY-16 Sean Maloney D-NY-18 John Faso R-NY-19 Paul Tonko D-NY-20 John Katko R-NY-24 Louise Slaughter D-NY-25
Number of Senate Supporters (FY18):	1
Senate Dear Colleague Signers:	Kirsten Gillibrand D-NY
National Institutes of Health (FY2018) Funded Research Information:	3
Project Title:	Estrogen Signaling in a Mouse Model for Lymphangioliomyomatosis
Principal Investigator:	Stephen Hammes
Institute:	University of Rochester
Congressional District:	25
Award Amount:	\$352,275

Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Defining the Temporal Sequence of PI3K Pathway Mutations in Bladder Cancer David Solit Sloan-Kettering Inst Can Research 12 \$368,728
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Comprehensive Motion-Robust Pediatric MR Imaging Using Radial Acquisitions Kai Tobias Block New York University School of Medicine 12 \$380,639
Number of TSC Natural History Database Sites:	1
TSC Natural History Database Sites:	NYU Langone Medical Center
Amount Funded in FY18:	\$11,040
Number of Clinic Trials:	2
Clinical Trial 1: Name of Participating Institution:	A pilot study to evaluate the effects of everolimus on brain mTOR activity and cortical hyperexcitability in TSC and FCD NYU Langone Medical Center
Clinical Trial 2: Name of Participating Institution:	A Randomized Controlled Trial of Cannabidiol (GWP42003-P, CBD) for Seizures in Tuberous Sclerosis Complex (GWPCARE6 NYU Langone Medical Center
Number of TSC Clinics & Locations:	4
TSC Clinic Location (1): City:	NYU Langone Medical Center New York City
TSC Clinic Location (2): City:	Mount Sinai Health System New York City
TSC Clinic Location (3): City:	Children's Hospital Montefiore Bronx
TSC Clinic Location (4): City:	Presbyterian/Columbia University Center New York City
Number of Biosample Repository Site Locations:	1
Biosample Repository Site Location: Biosample Repository Funding:	NYU Langone Medical Center \$3,000
TS Alliance Corporate Advisory Board Members:	4
Professional: City:	Julianne Moore New York City
Professional: City:	Orrin Devinsky, MD New York City
Professional: City:	Gail Gershon New York City
Professional: City:	Marc Shapses Plainview
TS Alliance International Scientific Advisory Board Members:	1
International Scientific Advisor Name: Institution: City:	John Blenis, PhD Department of Pharmacology, Weill Cornell Medical College New York

Number of TS Alliance Professional Advisory Board Members:		9
	Professional:	Orrin Devinsky, MD
	Institution:	NYU Langone University Medical Center
	City:	New York City
	Professional:	Patricia McGoldrick, PNP, MPA
	Institution:	Mt. Sinai Health System
	City:	New York City
	Professional:	Kimberly Parker Menzer, ANP-BC, GNP-BC
	Institution:	NYU Langone University Medical Center
	City:	New York City
	Professional:	Steven Wolf, MD
	Institution:	Mt. Sinai Health System
	City:	New York City
	Professional:	Jules Beal, MD
	Institution:	Children's Hospital at Montefiore
	City:	Bronx
	Professional:	Cigdem Akman, MD
	Institution:	New York Presbyterian/ Columbia University Medical Center
	City:	New York City
	Professional:	Elena Gonzalez, MSN, RNC, CPNP
	Institution:	New York Presbyterian/ Columbia University Medical Center
	City:	New York City
	Professional:	Josiane Lajoie, MD
	Institution:	NYU Langone University Medical Center
	City:	New York City
	Professional:	Srishti Nangia, MD
	Institution:	New York Presbyterian/Weil Cornell Medical Center
	City:	New York City
TS Alliance Endowment Board Members:		1
	Current Endowment Board Member:	Rita DiDomenico, Treasurer
	City:	Staten Island

## NORTH CAROLINA

Number Estimated with TSC in 2010 by State (Census / 6,000):	1,589
Number Identified Constituents in Entire State:	1,871
VP Support Services Provided One-on-One Support:	85
School Meetings Attended (virtually and in person):	3
TSC Community Supported via TS Alliance Clinic Ambassador Program:	367
TSC Community Supported via Adult Support Contacts Program:	185
TSC Community Supported via Dependent Adult Transition Resource Coordinator Program:	44
The Community Alliance in this state includes:	North Carolina
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	510
Community Alliance Provided One-on-One Support in 2018:	51
Total Gross Dollars Raised:	\$12,391
Number of House Supporters (FY18):	3
House Dear Colleague Signers:	G.K. Butterfield D-NC-1 Walter Jones R-NC-3 Alma Adams D-NC-12
National Institutes of Health (FY2018) Funded Research Information:	1
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Molecular Mechanism of Hippocampal network excitability in a novel, in vivo model of Tuberous Sclerosis Complex Kimberly Raab-Graham Wake Forest University Health Sciences 4 \$335,999
Number of Clinic Trials:	1
Clinical Trial 1:	A Randomized Controlled Trial of Cannabidiol (GWP42003-P, CBD) for Seizures in Tuberous Sclerosis Complex (GWPCARE6)
Name of Participating Institution:	Wake Forest Baptist Medical Center
Number of TSC Clinics & Locations:	3
TSC Clinic Location (1): City:	Wake Forest Baptist Medical Center Winston-Salem
TSC Clinic Location (2): City:	Duke University Durham
TSC Clinic Location (3): City:	Levine Children's Hospital Charlotte
Number of TS Alliance Professional Advisory Board Members:	9
Professional: Institution: City:	Patricia A. Gibson, MSSW DHL ACSW Wake Forest University School of Medicine Baptist Medical Center Winston-Salem
Professional: Institution: City:	Chad Jacobsen, MD Levine Children's Hospital Charlotte
Professional: Institution: City:	Miguel Materin, MD Duke Eye Center Durham

	Professional: Institution: City:	Katherine Van Poppel, MD Levine Children's Hospital Charlotte
	Professional: Institution: City:	Klaus Georg Werner, MD, PhD Duke University Durham
	Professional: Institution: City:	David Van Mater, MD, PhD Duke University Durham
	Professional: Institution: City:	Mary Silvia, MD Wake Forest University School of Medicine Baptist Medical Center Winston-Salem
	Professional: Institution: City:	Matthew Wong, MD Wake Forest University School of Medicine Baptist Medical Center Winston-Salem
	Professional: Institution: City:	William Ward, MD Novant Health Orthopedics & Sports Medicine Winston-Salem

## NORTH DAKOTA

Number Estimated with TSC in 2010 by State (Census / 6,000):	112
Number Identified Constituents in Entire State:	197
VP Support Services Provided One-on-One Support:	19
TSC Community Supported via Adult Support Contacts Program:	185
The Community Alliance in this state includes:	Upper Midwest (North Dakota, Minnesota, South Dakota)
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	765
Number of House Supporters (FY18):	1
House Dear Colleague Signers:	Kevin Cramer R-ND

## OHIO

Number Estimated with TSC in 2010 by State (Census / 6,000):	1,923
Number Identified Constituents in Entire State:	3,631
VP Support Services Provided One-on-One Support:	158
Educational Training Sessions Posted on Social Media:	264
School Meetings Attended (virtually and in person):	2
TSC Community Supported via TS Alliance Clinic Ambassador Program:	254
TSC Community Supported via Adult Support Contacts Program:	470
TSC Community Supported via Dependent Adult Transition Resource Coordinator Program:	32
The Community Alliance in this state includes:	Ohio
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	805
Number of Community Alliance Meetings Held in 2018:	4
Community Alliance Provided One-on-One Support in 2018:	166
Step Forward to Cure TSC Walk (Y/N):	Y
Total Gross Dollars Raised:	\$23,146
Number of Senate Supporters (FY18):	1
Senate Dear Colleague Signers:	Sherrod Brown D-OH
National Institutes of Health (FY2018) Funded Research Information:	8
Project Title:	2017 LAM Foundation International Lymphangioleiomyomatosis Research Conference
Principal Investigator:	Francis McCormack
Institute:	University of Cincinnati
Congressional District:	1
Award Amount:	\$5,000
Project Title:	2017 LAM Foundation International Lymphangioleiomyomatosis Research Conference
Principal Investigator:	Francis McCormack
Institute:	University of Cincinnati
Congressional District:	1
Award Amount:	\$20,000
Project Title:	Resveratrol and Sirolimus in LAM Trial (RESULT)
Principal Investigator:	Gupta Nishant
Institute:	University of Cincinnati
Congressional District:	1
Award Amount:	\$229,320
Project Title:	Multicenter Interventional Lymphangioleiomyomatosis Early Disease Trial (MILED)-CCC
Principal Investigator:	Francis McCormack
Institute:	University of Cincinnati
Congressional District:	1
Award Amount:	\$870,308
Project Title:	Targeting prostaglandin biosynthesis and action in lymphangioleiomyomatosis
Principal Investigator:	Yu, Jane
Institute:	University of Cincinnati
Congressional District:	1
Award Amount:	\$601,109

Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Lymphangioliomyomatosis Bruce Trapnell Cincinnati Children's Hospital Medical Center 1 \$45,334
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Lymphangioliomyomatosis Bruce Trapnell Cincinnati Children's Hospital Medical Center 1 \$45,334
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Regulation of lipid catabolism by autophagy in neural stem cell of tuberous sclerosis complex Chenran Wang University of Cincinnati 1 \$350,000
TS Alliance Funded Research:	1
Project Title: Principal Investigator: Institute: Congressional District: FY: Award Amount:	Quantification of plasma levels of sphingolipids and ceramides in patients with TSC Yu, Jane University of Cincinnati 1 18 \$20,000
Number of TSC Natural History Database Sites:	2
TSC Natural History Database Sites:	Cleveland Clinic Cincinnati Children's Hospital Medical Center
Amount Funded in FY18:	\$9,400
Number of Clinic Trials:	4
Clinical Trial 1: Name of Participating Institution:	Longitudinal study to identify early biomarkers of autism spectrum disorder (ASD) in infants with tuberous sclerosis complex (TSC) Cincinnati Children's Medical Center
Clinical Trial 2: Name of Participating Institution:	Potential EEG biomarkers and antiepileptogenic strategies for epilepsy in TSC1 Cincinnati Children's Hospital Medical Center
Clinical Trial 3: Name of Participating Institution:	Autism spectrum disorder (ASD) and intellectual disability (ID) determinants in tuberous sclerosis complex Cincinnati Children's Hospital Medical Center
Clinical Trial 4: Name of Participating Institution:	Preventing Epilepsy Using Vigabatrin in Infants with Tuberous Sclerosis Complex (PREVeNT Trial) A Randomized, Double-blind, Placebo-controlled Seizure Prevention Clinical Trial for Infants With TSC Cincinnati Children's Hospital Medical Center
Number of TSC Clinics & Locations:	4
TSC Clinic Location (1): City:	Cincinnati Children's Hospital Medical Center Cincinnati
TSC Clinic Location (2): City:	Cleveland Clinic Cleveland
TSC Clinic Location (3): City:	Nationwide Children's Hospital Columbus
TSC Clinic Location (4): City:	Akron Children's Hospital Akron



<b>Number of Biosample Repository Site Locations:</b>	<b>1</b>
Biosample Repository Site Location:	Cincinnati Children's Medical Center
Biosample Repository Funding:	\$7,105
<b>Number of TS Alliance Professional Advisory Board Members:</b>	<b>11</b>
Professional:	Poonam Bhatia, MD
Institution:	Akron Children's Hospital
City:	Akron
Professional:	Anna Byars, PhD
Institution:	Cincinnati Children's Hospital Medical Center
City:	Cincinnati
Professional:	David Neal Franz, MD
Institution:	Cincinnati Children's Hospital Medical Center
City:	Cincinnati
Professional:	Deborah Rukin Gold, MD
Institution:	Rainbow Babies and Children's Hospital
City:	Cleveland
Professional:	Elizabeth Gosnell, DMD, MS
Institution:	Cincinnati Children's Hospital Medical Center
City:	Cincinnati
Professional:	Ajay Gupta, MD
Institution:	Cleveland Clinic
City:	Cleveland
Professional:	Monica P. Islam, MD
Institution:	Nationwide Children's Hospital
City:	Columbus
Professional:	Michael Kohrman, MD
Institution:	Akron Children's Hospital
City:	Akron
Professional:	E. Steve Roach, MD (until May 2018)
Institution:	Nationwide Children's Hospital
City:	Columbus
Professional:	Frank McCormack, MD
Institution:	University of Cincinnati
City:	Cincinnati
Professional:	Asim Shahid, MD
Institution:	Rainbow Babies and Children's Hospital
City:	Cleveland
<b>TS Alliance Endowment Board Members:</b>	<b>1</b>
Current Endowment Board Member:	Douglas P. Loftus, CFP, AIF, Chair
City:	Cincinnati

## OKLAHOMA

Number Estimated with TSC in 2010 by State (Census / 6,000):	625
Number Identified Constituents in Entire State:	612
VP Support Services Provided One-on-One Support:	25
School Meetings Attended (virtually and in person):	1
TSC Community Supported via Adult Support Contacts Program:	264
The Community Alliance in this state includes:	Oklahoma
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	254
Number of Community Alliance Meetings Held in 2018:	1
Step Forward to Cure TSC Walk (Y/N):	Y
Total Gross Dollars Raised:	\$13,824
Number of House Supporters (FY18):	3
House Dear Colleague Signers:	Markwayne Mullin R-OK-2 Frank Lucas R-OK-3 Steve Russel R-OK-5

## OREGON

Number Estimated with TSC in 2010 by State (Census / 6,000):	639
Number Identified Constituents in Entire State:	939
VP Support Services Provided One-on-One Support:	89
Educational Training Sessions Posted on Social Media:	26
TSC Community Supported via Adult Support Contacts Program:	421
TSC Community Supported via Dependent Adult Transition Resource Coordinator Program:	302
The Community Alliance in this state includes:	Pacific Northwest (Oregon and Washington)
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	676
Number of House Supporters (FY18):	4
House Dear Colleague Signers:	Suzanne Bonamici D-OR-1 Earl Blumenauer D-OR-3 Peter DeFazio D-OR-4 Kurt Schrader D-OR-5
Number of Senate Supporters (FY18):	2
Senate Dear Colleague Signers:	Jeff Merkley D-OR Ron Wyden D-OR
Number of Clinic Trials:	1
Clinical Trial 1:	A Double-blind, Randomized, Placebo-controlled Study to Investigate the Efficacy and Safety of Cannabidiol (GWP42003-P, CBD) as Add-on Therapy in Patients With Tuberous Sclerosis Complex Who Experience Inadequately-controlled Seizures
Name of Participating Institution:	Oregon Health & Science University

## PENNSYLVANIA (WEST)

Number Estimated with TSC in 2010 by State (Census / 6,000):	2,117
Number Identified Constituents in Entire State:	6,551
VP Support Services Provided One-on-One Support:	209
Educational Training Sessions Posted on Social Media:	3
School Meetings Attended (virtually and in person):	4
TSC Community Supported via Adult Support Contacts Program:	421
TSC Community Support Provided to School Districts via Educator Mentor Program:	14
TSC Community Supported via Education Parent Mentor:	51
The Community Alliance in this state includes:	West Pennsylvania
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	345
Number of Community Alliance Meetings Held in 2018:	1
Community Alliance Provided One-on-One Support in 2018:	12
Step Forward to Cure TSC Walk (Y/N):	Y
Other Community Campaigns:	2nd Annual Team Lyons Pride Roaring to Cure TSC 10th Annual Tournament for TSC Champions- Western PA
Total Gross Dollars Raised:	\$47,268
Number of House Supporters (FY18):	9
House Dear Colleague Signers:	Robert Brady D-PA-1 Dwight Evans D-PA-2 Glenn Thompson R-PA-5 Ryan Costello R-PA-6 Patrick Meehan R-PA-7 Brian Fitzpatrick R-PA-8 Tom Marino R-PA-10 Brendan Boyle D-PA-13 Mike Doyle D-PA-14
National Institutes of Health (FY2018) Funded Research Information:	1
Project Title:	TSC2 signaling in Pulmonary Arterial Hypertension
Principal Investigator:	Elena Goncharova
Institute:	University of Pittsburgh at Pittsburgh
Congressional District:	18
Award Amount:	\$409,071
Number of TSC Natural History Database Sites:	1
TSC Natural History Database Sites:	University of Pennsylvania
Amount Funded in FY18:	\$720
Number of TSC Clinics & Locations:	1
TSC Clinic Location (1):	Children's Hospital Pittsburgh
City:	Pittsburgh
Number of TS Alliance Professional Advisory Board Members:	1
Professional:	Shelly Williams, MD
Institution:	Children's Hospital Pittsburgh
City:	Pittsburgh

## PENNSYLVANIA (EAST)

Number Estimated with TSC in 2010 by State (Census / 6,000):	2,117
Number Identified Constituents in Entire State:	6,551
VP Support Services Provided One-on-One Support:	209
Educational Training Sessions Posted on Social Media:	3
School Meetings Attended (virtually and in person):	4
TSC Community Supported via Adult Support Contacts Program:	421
TSC Community Support Provided to School Districts via Educator Mentor Program:	14
TSC Community Supported via Education Parent Mentor:	51
The Community Alliance in this state includes:	East Pennsylvania and Delaware
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	808
Number of Community Alliance Meetings Held in 2018:	1
Community Alliance Provided One-on-One Support in 2018:	12
Step Forward to Cure TSC Walk (Y/N):	Y
Other Community Campaigns:	2nd Annual Team Lyons Pride Roaring to Cure TSC 10th Annual Tournament for TSC Champions- Western PA
Total Gross Dollars Raised:	\$47,268
Number of House Supporters (FY18):	9
House Dear Colleague Signers:	Robert Brady D-PA-1 Dwight Evans D-PA-2 Glenn Thompson R-PA-5 Ryan Costello R-PA-6 Patrick Meehan R-PA-7 Brian Fitzpatrick R-PA-8 Tom Marino R-PA-10 Brendan Boyle D-PA-13 Mike Doyle D-PA-14
National Institutes of Health (FY2018) Funded Research Information:	1
Project Title:	Lymphangiogenesis in Pulmonary
Principal Investigator:	Lymphangioleiomyomatosis (LAM)
Institute:	Vera Krymskaya
Congressional District:	University of Pennsylvania
Award Amount:	3
Number of TSC Clinics & Locations:	\$633,911
TSC Clinic Location (1):	1
City:	University of Pennsylvania and Children's Hospital Philadelphia Philadelphia
Number of TS Alliance Professional Advisory Board Members:	2
Professional:	Katherine Nathanson, MD
Institution:	University of Pennsylvania
City:	Philadelphia
Professional:	Katherine Taub, MD
Institution:	Children's Hospital Philadelphia
City:	Philadelphia
TS Alliance Operating Board Members:	1
Current Board Member:	Laura S. Lubbers, PhD
City:	Perkasie

## RHODE ISLAND

Number Estimated with TSC in 2010 by State (Census / 6,000):	175
Number Identified Constituents in Entire State:	343
VP Support Services Provided One-on-One Support:	14
TSC Community Supported via Adult Support Contacts Program:	195
The Community Alliance in this state includes:	Conneticut and Rhode Island
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	414
Number of House Supporters (FY18):	2
House Dear Colleague Signers:	David Cicilline D-RI-1 Jim Langevin D-RI-2
Number of Senate Supporters (FY18):	2
Senate Dear Colleague Signers:	Jack Reed D-RI Sheldon Whitehouse D-RI

## SOUTH CAROLINA

Number Estimated with TSC in 2010 by State (Census / 6,000):	771
Number Identified Constituents in Entire State:	1,275
VP Support Services Provided One-on-One Support:	36
Educational Training Sessions Posted on Social Media:	131
School Meetings Attended (virtually and in person):	1
TSC Community Supported via Adult Support Contacts Program:	215
The Community Alliance in this state includes:	South Carolina
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	268
Number of Community Alliance Meetings Held in 2018:	2
Community Alliance Provided One-on-One Support in 2018:	98
Step Forward to Cure TSC Walk (Y/N):	Y
Number of House Supporters (FY18):	1
House Dear Colleague Signers:	Joe Wilson R-SC-2

## SOUTH DAKOTA

Number Estimated with TSC in 2010 by State (Census / 6,000):	136
Number Identified Constituents in Entire State:	239
VP Support Services Provided One-on-One Support:	8
School Meetings Attended (virtually and in person):	1
TSC Community Supported via Adult Support Contacts Program:	186
The Community Alliance in this state includes:	Upper Midwest (North Dakota, Minnesota, South Dakota)
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	765



## TENNESSEE

Number Estimated with TSC in 2010 by State (Census / 6,000):	1,058
Number Identified Constituents in Entire State:	1,668
VP Support Services Provided One-on-One Support:	168
Educational Training Sessions Posted on Social Media:	126
School Meetings Attended (virtually and in person):	1
TSC Community Supported via TS Alliance Clinic Ambassador Program:	211
TSC Community Supported via Adult Support Contacts Program:	203
TSC Community Supported via Dependent Adult Transition Resource Coordinator Program:	12
The Community Alliance in this state includes:	Tennessee
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	372
Step Forward to Cure TSC Walk (Y/N):	Y
Total Gross Dollars Raised:	\$17,474
Number of House Supporters (FY18):	1
House Dear Colleague Signers:	Steve Cohen D-TN-9
National Institutes of Health (FY2018) Funded Research Information:	6
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Drug development for tuberous sclerosis complex and other pediatric epileptogenic diseases using neurovascular and cardiac microphysiological models John Wikswo Vanderbilt University 1 \$296,419
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Drug development for tuberous sclerosis complex and other pediatric epileptogenic diseases using neurovascular and cardiac microphysiological models John Wikswo Vanderbilt University 1 \$250,000
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Drug development for tuberous sclerosis complex and other pediatric epileptogenic diseases using neurovascular and cardiac microphysiological models John Wikswo Vanderbilt University 1 \$500,000
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Drug development for tuberous sclerosis complex and other pediatric epileptogenic diseases using neurovascular and cardiac microphysiological models John Wikswo Vanderbilt University 1 \$261,603

Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Investigating the Effects of Stem Cell Positional Identity on Brain Tumor Development Gabrielle Rushing Vanderbilt University 1 \$29,188
Project Title: Principal Investigator: Institute: Congressional District: Award Amount:	Quantifying Differences in mTOR Activity and Tumor Development Between Neural Stem Cell Microdomains Rebecca Ihrle Vanderbilt University 1 \$335,669
Number of TSC Clinics & Locations:	2
TSC Clinic Location (1): City:	LeBonheur Children's Hospital Memphis
TSC Clinic Location (2): City:	Monroe Carell, Jr. Children's Hospital Vanderbilt Nashville
Number of TS Alliance Professional Advisory Board Members:	5
Professional: Institution: City:	John Bissler, MD St. Jude Pediatrics Research Hospital and University of Tennessee Health Science Center, Le Bonheur Children's Memphis
Professional: Institution: City:	Kevin C. Ess, MD, PhD Vanderbilt University Nashville
Professional: Institution: City:	Tanjala Gipson, MD LeBonheur Children's Hospital Memphis
Professional: Institution: City:	James Wheless, MD LeBonheur Children's Hospital Memphis
Professional: Institution: City:	Lisa R. Young, MD Vanderbilt University Nashville
TS Alliance Operating Board Members:	1
Current Board Member: City:	John Bissler, MD Memphis

## TEXAS (DALLAS)

Number Estimated with TSC in 2010 by State (Census / 6,000):	4,191
Number Identified Constituents in Entire State:	7,527
VP Support Services Provided One-on-One Support:	118
Educational Training Sessions Posted on Social Media:	55
School Meetings Attended (virtually and in person):	1
TSC Community Supported via TS Alliance Clinic Ambassador Program:	448
TSC Community Supported via Adult Support Contacts Program:	317
TSC Community Supported via Dependent Adult Transition Resource Coordinator Program:	36
The Community Alliance in this state includes:	Greater Dallas with North and West Texas
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	3,060
Number of Community Alliance Meetings Held in 2018:	1
Step Forward to Cure TSC Walk (Y/N):	Y
Major Events:	Art for a Cure
Other Community Campaigns:	Adolfo Orvie: Birthday Celebration (in honor of Emma)
Total Gross Dollars Raised:	\$83,675
Number of House Supporters (FY18):	3
House Dear Colleague Signers:	Al Green D-TX-9 Vicente Gonzalez D-TX-15 Bill Flores R-TX-17
TS Alliance Funded Research:	1
Project Title:	Neural Circuits Underlying Autism-Related Behaviors in Tuberous Sclerosis
Principal Investigator:	Ochoa Escamilla, Christine
Institute:	University of Texas Southwestern Medical Center
Congressional District:	30
FY:	18
Award Amount:	\$150,000
Number of TSC Natural History Database Sites:	1
TSC Natural History Database Sites:	Texas Scottish Rite Hospital for Children
Amount Funded in FY18:	\$3,220
Number of Clinic Trials:	1
Clinical Trial 1:	A Double-blind, Randomized, Placebo-controlled Study to Investigate the Efficacy and Safety of Cannabidiol (GWP42003-P, CBD) as Add-on Therapy in Patients With Tuberous Sclerosis Complex Who Experience Inadequately-controlled Seizures
Name of Participating Institution:	Texas Scottish Rite Hospital for Children
Number of TSC Clinics & Locations:	3
TSC Clinic Location (1):	Texas Scottish Rite Hospital for Children
City:	Dallas
TSC Clinic Location (2):	Cook Children's Hospital
City:	Fort Worth
TSC Clinic Location (3):	Dell Children's Medical Center
City:	Austin

Number of Biosample Repository Site Locations:		1
Biosample Repository Site Location:		Texas Scottish Rite Hospital for Children
Biosample Repository Funding:		\$1,645
Number of TS Alliance Professional Advisory Board Members:		6
	Professional:	David H. Ewalt, MD
	Institution:	Urology Clinic of North Texas
	City:	Dallas
	Professional:	Steven Sparagana, MD
	Institution:	Texas Scottish Rite Hospital for Children
	City:	Dallas
	Professional:	M. Scott Perry, MD
	Institution:	Cook Children's Medical Center
	City:	Fort Worth
	Professional:	Karen Keough, MD
	Institution:	Dell Children's Medical Center
	City:	Austin
	Professional:	Deborah Briggs, MD
	Institution:	Seton Brain and Spine Institute/Dell Children's
	City:	Austin
	Professional:	Colin Hovinga, PharmD, MS, FCCP
	Institution:	Dell Children's Medical Center
	City:	Austin
TS Alliance Operating Board Members:		2
	Current Board Member:	Adolfo Orrive
	City:	Dallas
	Current Board Member:	Chris Russell, Vice Chair
	City:	Dallas

## TEXAS (HOUSTON)

Number Estimated with TSC in 2010 by State (Census / 6,000):	4,191
Number Identified Constituents in Entire State:	7,527
VP Support Services Provided One-on-One Support:	117
Educational Training Sessions Posted on Social Media:	54
TSC Community Supported via TS Alliance Clinic Ambassador Program:	1,293
TSC Community Supported via Adult Support Contacts Program:	317
TSC Community Supported via Dependent Adult Transition Resource Coordinator Program:	37
The Community Alliance in this state includes:	Greater Houston with South and West Texas
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	3,293
Number of Community Alliance Meetings Held in 2018:	1
Community Alliance Provided One-on-One Support in 2018:	100
Step Forward to Cure TSC Walk (Y/N):	Y
Total Gross Dollars Raised:	\$21,759
Number of House Supporters (FY18):	9
House Dear Colleague Signers:	Joaquin Castro D-TX-20 Beto O'Rourke D-TX-22 Roger Williams R-TX-25 Blake Farenthold R-TX-2 Eddie Bernice Johnson D-TX-30 Pete Sessions R-TX-32 Marc Veasey D-TX-33 Filemon Vela D-TX-34 Lloyd Doggett D-TX-35
National Institutes of Health (FY2018) Funded Research Information:	2
Project Title:	Tumor Suppressor Localization and Function at the Peroxisome
Principal Investigator:	Cheryl Walker
Institute:	Baylor College of Medicine
Congressional District:	9
Award Amount:	\$356,625
Project Title:	mTORC1-TFEB pathway in degeneration of the RPE
Principal Investigator:	Yan Chen
Institute:	University of Texas Medical Branch Galveston
Congressional District:	14
Award Amount:	\$383,572
TSCRP Funded Research Information:	1
Project Title:	Deciphering Circuit-Level Mechanisms Underlying Intrinsic Epileptogenicity of Cortical Tubers in TSC
Principal Investigator:	Jiang, Xiaolong
Institute:	Baylor College of Medicine
Congressional District:	7
Award Amount:	\$160,072

<b>TS Alliance Funded Research:</b>	<b>1</b>
Project Title:	Developing a Genetic Risk Prediction Model for Epilepsy in Patients with TSC
Principal Investigator:	Farach, Laura S.
Institute:	University of Texas Health Science Center at Houston
Congressional District:	9
FY:	18
Award Amount:	\$20,000
<b>Number of TSC Natural History Database Sites:</b>	<b>1</b>
TSC Natural History Database Sites:	University of Texas Health Science Center
Amount Funded in FY18:	\$17,985
<b>Number of Clinic Trials:</b>	<b>3</b>
Clinical Trial 1:	Preventing Epilepsy Using Vigabatrin in Infants with Tuberous Sclerosis Complex (PREVeNT Trial) A Randomized, Double-blind, Placebo-controlled Seizure Prevention Clinical Trial for Infants With TSC
Name of Participating Institution:	University of Texas Health Science Center Houston
Clinical Trial 2:	Longitudinal study to identify early biomarkers of autism spectrum disorder (ASD) in infants with tuberous sclerosis complex (TSC)
Name of Participating Institution:	University of Texas Health Science Center Houston
Clinical Trial 3:	Autism spectrum disorder (ASD) and intellectual disability (ID) determinants in tuberous sclerosis complex (TSC)
Name of Participating Institution:	University of Texas Health Science Center Houston
<b>Number of TSC Clinics &amp; Locations:</b>	<b>2</b>
TSC Clinic Location (1):	University of Texas Health Science Center Houston
City:	Houston
TSC Clinic Location (2):	Texas Children's Hospital
City:	Houston
<b>Number of Biosample Repository Site Locations:</b>	<b>1</b>
Biosample Repository Site Location:	Texas Health Science Center at Houston
Biosample Repository Funding:	\$3,000
<b>TS Alliance Corporate Advisory Board Members:</b>	<b>1</b>
Professional:	MaryJane Mudd
City:	Houston
<b>TS Alliance International Scientific Advisory Board Members:</b>	<b>1</b>
International Scientific Advisor Name:	Hope Northrup, MD
Institution:	Division of Medical Genetics, University of Texas – Houston
City, Country:	Houston, TX, USA
<b>Number of TS Alliance Professional Advisory Board Members:</b>	<b>9</b>
Professional:	Mary Kay Koenig, MD
Institution:	University of Texas Health Science Center
City:	Houston
Professional:	Rohini Coorg, MD
Institution:	Texas Children's Hospital
City:	Houston
Professional:	Daniel Curry, MD
Institution:	Texas Children's Hospital
City:	Houston
Professional:	Hope Northrup, MD
Institution:	University of Texas Health Science Center
City:	Houston

	Professional: Institution: City:	Howard Weiner, MD Texas Children's Hospital Houston
	Professional: Institution: City:	Surya Prasad Rao Rednam, MD, MS Texas Children's Hospital Houston
	Professional: Institution: City:	Karen Keough, MD Dell Children's Medical Center Austin
	Professional: Institution: City:	Mary Kay Koenig, MD University of Texas Health Science Center Houston
	Professional: Institution: City:	Faterma Malbari, MD Texas Children's Hospital Houston
TS Alliance Operating Board Members:		1
	Current Board Member: City:	Matthew Simonian Humble

## UTAH

Number Estimated with TSC in 2010 by State (Census / 6,000):	461
Number Identified Constituents in Entire State:	962
VP Support Services Provided One-on-One Support:	17
Educational Training Sessions Posted on Social Media:	218
TSC Community Supported via Adult Support Contacts Program:	328
The Community Alliance in this state includes:	Intermountain West (Idaho, Montana & Utah)
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	411
Step Forward to Cure TSC Walk (Y/N):	Y
Total Gross Dollars Raised:	\$18,060
Number of Clinic Trials:	1
Clinical Trial 1: Name of Participating Institution:	A Randomized Controlled Trial of Cannabidiol (GWP42003-P, CBD) for Seizures in Tuberous Sclerosis Complex (GWPCARE6) Primary Children's Hospital
Number of TSC Clinics & Locations:	1
TSC Clinic Location (1): City:	Primary Children's Hospital Salt Lake City
Number of TS Alliance Professional Advisory Board Members:	2
Professional: Institution: City:	Francis M. Filloux, MD Primary Children's Hospital Salt Lake City
Professional: Institution: City:	David Viskochil, MD, PhD Primary Children's Hospital Salt Lake City



## VERMONT

Number Estimated with TSC in 2010 by State (Census / 6,000):	104
Number Identified Constituents in Entire State:	201
VP Support Services Provided One-on-One Support:	9
Educational Training Sessions Posted on Social Media:	64
TSC Community Supported via Adult Support Contacts Program:	196
The Community Alliance in this state includes:	New England (New Hampshire, Maine, Massachusetts and Vermont)
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	732
Number of House Supporters (FY18):	1
House Dear Colleague Signers:	Peter Welch D-VT
TS Alliance International Scientific Advisory Board Members:	1
International Scientific Advisor Name:	Gregory Holmes, MD
Institution:	Department of Neurological Sciences, University of Vermont School of Medicine
City, Country:	Burlington, VT, USA

## VIRGINIA

Number Estimated with TSC in 2010 by State (Census / 6,000):	1,334
Number Identified Constituents in Entire State:	2,464
VP Support Services Provided One-on-One Support:	155
Educational Training Sessions Posted on Social Media:	391
School Meetings Attended (virtually and in person):	7
TSC Community Supported via Adult Support Contacts Program:	260
TSC Community Supported via Education Parent Mentor:	12
The Community Alliance in this state includes:	Washington, DC and Virginia
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	602
Number of House Supporters (FY18):	5
House Dear Colleague Signers:	Robert Scott D-VA-3 Donald McEachin D-VA-4 Donald Beyer D-VA-8 Barbara Comstock R-VA-10 Gerald Connolly D-VA-11
TSC Natural History Database Sites:	See District of Columbia
Amount Funded in FY18:	\$4,680
Number of TSC Clinics & Locations:	3
TSC Clinic Location (1): City:	Children's Regional Outpatient Center of Children's National Medical Center DC Fairfax
TSC Clinic Location (2): City:	University of Virginia Charlottesville
TSC Clinic Location (3): City:	Virginia Commonwealth University Richmond
TS Alliance Corporate Advisory Board Members:	1
Professional: City:	John Thorpe Richards, Jr. Alexandria
TS Alliance International Scientific Advisory Board Members:	1
International Scientific Advisor Name: Institution: City:	Howard Goodkin, MD, PhD Department of Neurology, University of Virginia Charlottesville
Number of TS Alliance Professional Advisory Board Members:	8
Professional: Institution: City:	Howard Goodkin, MD, PhD University of Virginia Charlottesville
Professional: Institution: City:	Soundarya Gowda, MD Virginia Commonwealth University Health System Richmond
Professional: Institution: City:	Julie A. Matsumoto, MD University of Virginia Charlottesville
Professional: Institution: City:	Laura Jansen, MD, PhD University of Virginia Charlottesville
Professional: Institution: City:	Lawrence D. Morton, MD Virginia Commonwealth University Health System Richmond

	Professional: Institution: City:	Nancy J. Elling, BSN, RN, CPN Children's National Fairfax
	Professional: Institution: City:	Erika Axeen, MD University of Virginia Charlottesville
	Professional: Institution: City:	Derek Bauer, MD University of Virginia Charlottesville
TS Alliance Operating Board Members:		2
	Current Board Member: City:	Michael Caggiano McLean
	Current Board Member: City:	Tim Dills, Immediate Past Chair Great Falls

## WASHINGTON

Number Estimated with TSC in 2010 by State (Census / 6,000):	1,121
Number Identified Constituents in Entire State:	2,684
VP Support Services Provided One-on-One Support:	105
School Meetings Attended (virtually and in person):	1
TSC Community Supported via Adult Support Contacts Program:	813
TSC Community Supported via Dependent Adult Transition Resource Coordinator Program:	63
The Community Alliance in this state includes:	Pacific Northwest (Oregon and Washington)
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	676
Number of Community Alliance Meetings Held in 2018:	2
Community Alliance Provided One-on-One Support in 2018:	234
Total Gross Dollars Raised:	\$31,456
Number of House Supporters (FY18):	5
House Dear Colleague Signers:	Suzan Delene D-WA-1 Rick Larsen D-WA-2 Pramila Jayapal D-WA-7 David Reichert R-WA-8 Denny Heck D-WA-10
Number of Clinic Trials:	1
Clinical Trial 1: Name of Participating Institution:	A Randomized Controlled Trial of Cannabidiol (GWP42003-P, CBD) for Seizures in Tuberous Sclerosis Complex (GWPCARE6) Seattle Children's Hospital
Number of TSC Clinics & Locations:	2
TSC Clinic Location (1): City:	Seattle Children's Hospital Seattle
TSC Clinic Location (2): City:	Swedish Neuroscience Institute Seattle
TS Alliance International Scientific Advisory Board Members:	1
International Scientific Advisor Name: Institution: City, Country:	Raymond Yeung, MD Department of Surgery, University of Washington Seattle, WA, USA
Number of TS Alliance Professional Advisory Board Members:	4
Professional: Institution: City:	Sarah Kiel, ARNP Seattle Children's Hospital Seattle
Professional: Institution: City:	Stephanie Randle, MD Seattle Children's Hospital Seattle
Professional: Institution: City:	Marcio A. Sotero de Menezes, MD Swedish Neuroscience Institute Seattle
Professional: Institution: City:	Michael Doherty, MD Swedish Neuroscience Institute Seattle

## WEST VIRGINIA

Number Estimated with TSC in 2010 by State (Census / 6,000):	309
Number Identified Constituents in Entire State:	309
VP Support Services Provided One-on-One Support:	30
TSC Community Supported via Adult Support Contacts Program:	190
The Community Alliance in this state includes:	Kentucky and West Virginia
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	398
Number of Community Alliance Meetings Held in 2018:	1
Step Forward to Cure TSC Walk (Y/N):	See Kentucky

## WISCONSIN

Number Estimated with TSC in 2010 by State (Census / 6,000):	948
Number Identified Constituents in Entire State:	2,800
VP Support Services Provided One-on-One Support:	43
Educational Training Sessions Posted on Social Media:	98
School Meetings Attended (virtually and in person):	1
TSC Community Supported via Adult Support Contacts Program:	192
TSC Community Supported via Dependent Adult Transition Resource Coordinator Program:	5
The Community Alliance in this state includes:	Wisconsin
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	534
Step Forward to Cure TSC Walk (Y/N):	Y
Other Community Campaigns:	Heather Joy Golf Tournament Cookin' Up a Cure
Total Gross Dollars Raised:	\$21,605
Number of House Supporters (FY18):	3
House Dear Colleague Signers:	Ron Kind D-WI-3 James Sensenbrenner R-WI-5 Mike Gallagher R-WI-8
Number of Senate Supporters (FY18):	1
Senate Dear Colleague Signers:	Tammy Baldwin D-WI
Number of TSC Clinics & Locations:	2
TSC Clinic Location (1): City:	American Family Children's Hospital Madison
TSC Clinic Location (2): City:	Children's Hospital of Wisconsin Milwaukee
Number of TS Alliance Professional Advisory Board Members:	3
Professional: Institution: City:	Donald Basel, MD Children's Hospital of Wisconsin Milwaukee
Professional: Institution: City:	Dawn Siegel, MD Children's Hospital of Wisconsin Milwaukee
Professional: Institution: City:	Neha Patel, MD American Family Children's Hospital Madison

## WYOMING

Number Estimated with TSC in 2010 by State (Census / 6,000):	94
Number Identified Constituents in Entire State:	193
VP Support Services Provided One-on-One Support:	16
TSC Community Supported via Adult Support Contacts Program:	352
The Community Alliance in this state includes:	Rocky Mountain (Colorado, New Mexico and Wyoming)
Number of Identified Constituents with a Direct-TSC connection in the Community Alliance:	705

## PUERTO RICO

Number Identified Constituents in Entire State:	57
VP Support Services Provided One-on-One Support:	59
TSC Community Supported via Dependent Adult Transition Resource Coordinator Program:	2
Number of House Supporters (FY18):	1
House Dear Colleague Signers:	Jennifer Gonzalez Colon R-PR



## INTERNATIONAL OUTREACH

### Global Alliance Program

Officially launched in 2014 with the TS Alliance of Israel, the Global Alliance Program was created as a way to address unmet needs within the global TSC community at the country level. This program provides the opportunity for the TS Alliance to share experiences and assist in the start-up or support of TSC-related organizations in other countries. As of 2018, the TS Alliance has global partnerships with TS Alliance of Israel, Tuberous Sclerosis Canada Sclérose Tubéreuse, TS Alliance of Mexico, TS Alliance Foundation (Thailand), the Hungarian Foundation for Tuberous Sclerosis and the TS Alliance of India.

### TS Alliance of Israel

In 2014, the [TS Alliance of Israel](#) became the first Global Alliance and formal partner of the TS Alliance.

Number of TSC Clinics & Locations		3
TSC Clinic Location (1):	City:	Hadassah Medical Center Jerusalem, Israel
TSC Clinic Location (2):	City:	Safra Children's Hospital, Sheba Medical Center Tel Hashomer, Israel
TSC Clinic Location (3):	City:	Soroka Medical Center affiliated with Ben Gurion University of the Negev Be'er Sheva, Israel

Number of TS Alliance Professional Advisory Board Members		5
Professional:	Institution:	Iris Fried, MD Hadassah Medical Center Jerusalem, Israel
Professional:	Institution:	Tal Gilboa, MD Hadassah Medical Center Jerusalem, Israel
Professional:	Institution:	Oded Volovelsky, MD, PhD Hadassah Medical Center Jerusalem, Israel
Professional:	Institution:	Michal Tzadok, MD Safra Children's Hospital, Sheba Medical Center Tel Hashomer, Israel

Professional:	Iris Noyman, MD
Institution:	Soroka Medical Center affiliated with Ben Gurion University of the Negev
City:	Be'er Sheva, Israel

## Tuberous Sclerosis Canada Sclérose Tubéreuse

In 2016, [Tuberous Sclerosis Canada Sclérose Tubéreuse](#) (TS Canada ST) became a Global Alliance of the TS Alliance.

Number of TSC Clinics & Locations	2
TSC Clinic Location (1): City:	CHU Sainte Justine Montreal
TSC Clinic Location (2): City:	The Hospital for Sick Children Toronto

Number of TS Alliance Professional Advisory Board Members	4
Professional: Institution: City:	Philippe Major, MD CHU Sainte Justine Montreal
Professional: Institution: City:	Bláthnaid McCoy, MD The Hospital for Sick Children Toronto
Professional: Institution: City:	Robyn Whitney, MD, FRCPC The Hospital for Sick Children Toronto
Professional: Institution: City:	Maria Zak, MN, NP The Hospital for Sick Children Toronto

TS Alliance Operating Board Members	1
Current Board Member: City:	Andrew Duffy, Ex-officio Toronto

## Tuberous Sclerosis Alliance of Mexico

The [Tuberous Sclerosis Alliance of Mexico](#) became a Global Alliance in December 2016.

Number of TSC Clinics & Locations:	2
TSC Clinic Location (1): City:	Neural Clinic Merida, Yucatan, Mexico
TSC Clinic Location (2): City:	Hospital Universitario Nuevo León

	Monterrey, Nuevo León, Mexico
<b>Number of TS Alliance Professional Advisory Board Members</b>	<b>3</b>
Professional: Institution: City, Country:	Joao Garcia, MD Neural Clinic Merida, Yucatan, Mexico
Professional: Institution: City, Country:	Ana Beatriz Hinojosa-Amaya, MD Hospital Universitario “José Eleuterio González” Universidad Autónoma de Nuevo León Monterrey, Nuevo León, Mexico
Professional: Institution: City, Country:	Marisol Ibarra-Ramirez, MD Hospital Universitario “José Eleuterio González” Universidad Autónoma de Nuevo León Monterrey, Nuevo León, Mexico

## Tuberous Sclerosis Foundation (Thailand)

In 2016 the [TS Alliance Foundation](#) became a Global Alliance. The TS Alliance Foundation finalized their status as a legal entity in Thailand in November 2017.

## Hungarian Foundation for Tuberous Sclerosis

The [Hungarian Foundation for Tuberous Sclerosis](#) became a Global Alliance in December 2017.

## Tuberous Sclerosis Alliance of India

In 2018, the [TS Alliance of India](#) became a Global Alliance of the TS Alliance.

<b>Number of TSC Clinics &amp; Locations:</b>	<b>1</b>
TSC Clinic Location (1): City, Country:	Kokilaben Dhirubhai Ambani Hospital and Medical Research Institute Mumbai, Maharashtra, India
<b>Number of TS Alliance Professional Advisory Board: Members</b>	<b>1</b>
Professional: Institution: City, Country:	Pradnya Gadgil, MBBS, MRCPCH Kokilaben Dhirubhai Ambani Hospital and Medical Research Institute Mumbai, Maharashtra, India

## TSC International (TSCi)

The TS Alliance also collaborates with Tuberous Sclerosis Complex International (TSCi), a world-wide consortium of existing TSC associations, established to support those affected by TSC around the world, including individuals, families, caregivers, educators and health care providers. TSCi currently consists of 38 countries from 6 continents.

TSCi currently supports the following programs: organizing a TSCi workshop on Improving Care held in conjunction with significant international TSC meetings, maintaining the TSCi website ([www.tscinternational.org](http://www.tscinternational.org)); sponsoring TSC Global Awareness Day each May 15; fostering additional TSC associations throughout the world; and sharing and distributing the TSC Clinical Consensus recommendations, the gold standard of internationally accepted diagnostic criteria, surveillance and treatment guidelines for individuals with TSC.

## Other International

TS Alliance Funded Research:		Portugal
<b>TS Alliance Funded Research</b> <b>Project Title:</b> <b>Principal Investigator:</b> <b>Institute:</b> <b>Award Amount:</b>		Epigenetic and transcriptional analysis of TSC2 in leukocyte DNA from tuberous sclerosis patients Marques, Cristiana Joana University of Porto - Faculty of Medicine \$19,000
		United Kingdom
<b>TS Alliance Funded Research</b> <b>Project Title:</b> <b>Principal Investigator:</b> <b>Institute:</b> <b>Award Amount:</b>		The TSC1 and TSC2 Variation Database Mark Thomas, PhD and Rosemary Ekong, PhD University College London \$ 44,105
TS Alliance International Scientific Advisory Board Members:		7
<b>International Scientific Advisor Name:</b> <b>Institution:</b>  <b>City, Country:</b>		Hongbing Zhang, MD, PhD Institute of Basic Medical Sciences, Chinese Academy of Medical Sciences, Peking Union Medical College Beijing, China

International Scientific Advisor Name: Institution: City, Country:	Andrew Tee, PhD Institute of Medical Genetics, Wales College of Medicine, Cardiff University Cardiff, Wales, UK
International Scientific Advisor Name: Institution: City, Country:	Julian Sampson, DM, FRCP, FMedSci Institute of Medical Genetics, Wales College of Medicine, Cardiff University Cardiff, Wales, UK
International Scientific Advisor Name: Institution: City, Country:	David Mowat, MBBS, MRCP, DRACOG, FRACP Sydney Children's Hospital Sydney, Australia
International Scientific Advisor Name: Institution: City, Country:	Chris Kingswood, MD Brighton & Sussex University Hospitals Trust Renal Unit Brighton, UK
International Scientific Advisor Name: Institution: City, Country:	Luciana Amaral Haddad, MD, PhD Departamento de Genética e Biologia Evolutiva, Universidade de São Paulo São Paulo, Brazil
International Scientific Advisor Name: Institution: City, Country:	Petrus J. de Vries, MBChB, MRCPsych, PhD University of Cape Town Rondebosch, Cape Town, South Africa

Number of TS Alliance Professional Advisory Board Members	3
Professional: Institution: City:	Pei-Lung Chen, MD, PhD National Taiwan University Hospital Taipei City, Taiwan
Professional: Institution: City, Country:	Petrus J. de Vries, MBChB, MRCPsych, PhD University of Cape Town Rondebosch, Cape Town, South Africa
Professional: Institution: City, Country:	Kai-Feng Xu, MD Peking Union Medical College Hospital Beijing, China

## TSC Global Awareness Day

On May 15, 2018, countries around the world recognized TSC Global Awareness Day through social media outreach, community events, walks and meetings among other activities. In honor of TSC Global Awareness Day, a social media campaign of “15 Facts About TSC” were posted daily during the countdown from May 1 to May 15 and translated by TSCi member organizations. The countdown daily posts had over 2,706 shares and reached more than 133,000 people. In some countries, major City: landmarks were lit blue in honor of May 15.

The TSC Global Awareness Day Facebook page ([www.facebook.com/TSCglobalday/](http://www.facebook.com/TSCglobalday/)) has more than 1,000 followers. A Facebook profile picture frame tool was created and shared on social media. Facebook stats show 2,535-plus people used the Facebook picture frame. Finally, a TSC Global Awareness Day news release had 224 total pickups/potential audience of 15.7 million readers.

One-on-One Support Provided Through E-mail and Phone Contacts:	
Country:	36 Argentina, Australia, Benin, Brazil, Bulgaria, Canada, Chile, China, Colombia, Croatia, Cyprus, Dominican Republic, Ecuador, France, Hong Kong, India, Indonesia, Iraq, Ireland, Israel, Japan, Kenya, Libya, Malaysia, Mexico, Nepal, Netherlands, Nigeria, Pakistan, Philippines, Romania, Russia, Spain, United Arab Emirates United Kingdom, Ukraine