THE TS ALLIANCE TSC CLINIC APPLICATION

(Global Version 8.2.2019)

Print name of person applying for TSC Clinic designation:

Print name of person completing this application if different than applicant.

INSTRUCTIONS: Before completing this application, please read the "*TS Alliance & TSC Clinics Scope of Relationship Policy*" and the "*TSC Clinic Guidelines*." The words "You" or "Your" in this application refer to the Director and/or Co-Director of the clinical practice applying for TSC Clinic Designation.

A. **Information about your clinical practice**

1. What is the name of the hospital, university, or institution that your clinic is affiliated with?

1.1 How do you want your clinic to be listed on the TS Alliance website?
Example: TSC Clinic at University of XXXXX. The term, **"TSC Center of Excellence"** may be used only upon achieving standards as as defined in the TS Alliance Clinic Policy.

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2. What is the approximate total number of individuals with TSC evaluated/ managed in the TSC Clinic since the clinic was started at your hospital/institution. (This includes unique newly diagnosed and active patients.)

2.1 If you have been seeing individuals with TSC in your clinic for more than one year, approximately how many have been seen in the past year?

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3. Please indicate the minimum age of NEW patients with TSC your clinic will accept?

3.1 Please indicate maximum age of NEW patients with TSC your clinic will accept?

3.2 What is your clinic's transition plan for pediatric patients who will be transitioning to adult care?

3.3 Are you able to see TSC patients from other countries?

- [ ] Yes
- [ ] No
- [ ] Other

3.3 What languages to you or your clinic colleagues speak fluently?

- [ ] Amharic
- [ ] Arabic
- [ ] Cantonese
- [ ] English
- [ ] Farsi
- [ ] French
- [ ] German
- [ ] Hebrew
- [ ] Hindi
- [ ] Italian
- [ ] Japanese
- [ ] Mandarin
- [ ] Portuguese
- [ ] Russian
- [ ] Spanish
- [ ] Vietnamese
- [ ] Other

4. Are you able to provide inpatient services to the patients you see in your clinic? This means for diagnostic evaluations or surgical procedures or other reasons that require hospitalization.

- [ ] Yes
- [ ] No
- [ ] Other, explain:

5. To date what are the reasons patients are seen in your clinic? (MARK ALL THAT APPLY)

- [ ] To confirm the diagnosis of TSC
- [ ] Surveillance and management of TSC (this includes coordination of recommended testing per consensus guidelines and/or referral to appropriate specialists for evaluation of other TSC-related conditions)
- [ ] Cardiac includes rhabdomyoma, arrhythmias
- [ ] Dermatological manifestations
- [ ] Genetics includes prenatal or family planning consultation
- [ ] Neurological - epilepsy, includes infantile spasms
- [ ] Neurological - SEGA or other brain manifestations
- [ ] Neuropsychiatric - includes autism, behavioral, developmental issues
- [ ] Ophthalmological manifestations
- [ ] Pulmonary - lymphangioleiomyomatosis, cysts
- [ ] Renal - angiomyolipoma, cysts, renal cell carcinoma
- [ ] Other conditions involving bone, gastrointestinal, liver, pancreas, etc.
- [ ] Other, please specify

5.1 Of all the reasons marked in Item #5, which one applies to the majority of the patients seen in your practice? (Choose answer from Drop Down Menu)

5.2 Do you/your colleagues do a complete initial evaluation on a new patient with TSC or suspected TSC? This means a complete screening following the consensus guidelines for diagnosis/ surveillance. Example: If your specialty is neurology/epilepsy, you also review other systems by going through surveillance checklist and/or refer to appropriate specialist for evaluation.

- [ ] Yes
- [ ] No

5.3 How often does your practice utilize the TSC Associated Neuropsychiatric Disorders(TAND) Checklist? (Choose answer from Drop Down menu)

5.4 What is the reason your practice does not utilize the TAND Checklist? (Choose answer from Drop Down Menu)

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6. How often are the TSC surveillance recommendations reviewed with an individual who is seen at your practice?

- [ ] At least annually or at next follow-up visit if seen less frequently.
- [ ] ONLY if patient reports a problem at the clinic visit.
- [ ] Other, please specify:

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7. Does your practice hold a virtual or in person meeting at least annually with your core healthcare providers to review new treatments, research, and clinical trials for individuals with TSC?

- [ ] Yes, GO TO QUESTION 7.1
- [ ] No
- [ ] Other, please specify:

7.1. How many virtual and/or in person meetings did you hold in the past 12 months?

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8. Do the healthcare providers on your referral list update you about a patient you evaluated in the TSC Clinic who needed an evaluation by one of them? The update may be by phone, e-mail, in person, or having access to the patient's medical records.

- [ ] Yes
- [ ] No
- [ ] Other, please specify:

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9. Have you or one or more of your key TSC healthcare providers completed at least one TSC-related continuing medical education course in the past two years? (This means completing an online course or attending a conference for which you receive continuing education credit.)

- [ ] Yes
- [ ] No
- [ ] I don't know
- [ ] Other, please explain: _____

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10. Do you utilize telehealth technology to provide consultation and/or follow-up with a TSC patient? This means you use video conferencing software to conduct a virtual meeting with your patient, especially for those who live far away.

- [ ] Yes
- [ ] No
- [ ] Other, please specify: _____

B. Educational resource

1. Have you/your practice informed your patients about the TS Alliance?

- [ ] Yes
- [ ] No
- [ ] Other, please specify: _____

2. What types of information do you provide to your patients, their families, or to their primary care doctor? CHECK ALL THAT APPLY.

- [ ] We don't provide any materials.
- [ ] TS Alliance print materials.
- [ ] We direct them to the TS Alliance website.
- [ ] We provide them with our own print materials about TSC.
- [ ] We share TSC-related publications authored by the Clinic Director or colleague.
- [ ] Other, please specify: _____

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3. Tell us what kind of TSC-related meeting you or a colleague have held in the past 12 months to update your colleagues in the community or regionally, or individuals with TSC or their families. CHECK ALL THAT APPLY.

- [ ] We haven't had any TSC-related meetings in the past 12 months.
- [ ] We've done an educational meeting and/or Grand Rounds for healthcare providers.
- [ ] We've done a local or regional educational meeting for individuals with TSC and their families, healthcare providers welcome.
- [ ] We've done more than one TSC related meeting in the past 12 months.
- [ ] Other, please specify: _____

4. We've shared a TSC-related publication or other resource materials authored by the Clinic Director or colleague with the TS Alliance and/or other TSC Clinics in the past 12 months.	☐ Yes, GO TO QUESTION #4.1. ☐ No	4.1 List publication and/or resource(s) shared in the past 12 months.	

C. Partnership

1. In addition to the TS Alliance National Office in Silver Spring, MD, USA there are TSC organizations in other countries around the world who are members of Tuberous Sclerosis International (TSCi). Have you contacted the TS Alliance or another TSC organization for information and/or informed your TSC patients about the TS Alliance or TSCi?

- ☐ Yes
- ☐ No
- ☐ Comment: _____

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2. Have you/your colleague(s) collectively participated in at least three TSC related clinical or research events as a speaker or attendee in the past 12 months?

- ☐ Yes, Go to Question 2.1 and indicate activity type(s)
- ☐ No, Skip to Part D

2.1 Indicate TSC-related activities you/ your colleague have participated in the past 12 months. MARK ALL THAT APPLY

- ☐ TS Alliance Clinic Directors Meeting
- ☐ A community alliance educational meeting
- ☐ A national or international TSC research conference
- ☐ An informational webcast
- ☐ Other, please specify _____

D. Clinical trials and basic science research in TSC

1. Do you or a TSC clinic colleague conduct TSC-related research?

- ☐ No, Skip to Section E
- ☐ Yes, go to question 1.1

1.1 How many years have you/your colleague(s) been conducting TSC-related research?

- ☐ less than 1 year
- ☐ at least 1 year but less than 5 years
- ☐ more than 5 years but less than 10 years
- ☐ 10 years or more

1.2 Please tell us about your current TSC research activity (Mark all that apply)

- [ ] I am conducting and/or a TSC clinic colleague is conducting an investigator-initiated clinical trial for individuals with TSC.
- [ ] I am conducting and/or a TSC clinic colleague is conducting an industry-sponsored clinical trial for individuals with TSC.
- [ ] I am participating and/or a TSC clinic colleague is participating in a TS Alliance sponsored project (e.g. TSC Natural History Database, TSC Biosample Repository)
- [ ] I am conducting and/or a TSC clinic colleague is conducting basic science research

1.3 Have you/your colleagues authored any papers that have resulted from your research?

- [ ] Not applicable
- [ ] No
- [ ] Yes

E. Clinic director information

1. Name of director, include credentials (i.e. MD, PhD, etc)

2. Specialty (i.e. neurology, genetics, dermatology, epilepsy, etc.)

3. Medical board certification. This should be in country of clinical practice, if not, explain in Comment section.

- [ ] in specialty listed in #2
- [ ] in another specialty, please specify in Comment
- [ ] Comment

4. e-mail address

5. business mailing address

6. city, state/province, zip code if applicable

7. If not USA - country name

8. office telephone number

9. cell phone number

10. administrative assistant's name

11. administrative's assistant's e-mail address

12. administrative assistant's telephone number

F. Co-clinic director information

Not Applicable ☐

1. Name of director, include credentials (i.e. MD, PhD, etc)

2. Specialty (i.e. neurology, genetics, dermatology, epilepsy, etc.)

3. Medical board certification. This should be in country of clinical practice, if not, explain in Comment section.

- ☐ in specialty listed in #2
- ☐ in another specialty, please specify in Comment
- ☐ Comment

4. e-mail address

5. business mailing address

6. city, state/province, zip code, if applicable

7. if not USA - country name

8. office telephone number

9. cell phone number

10. administrative assistant's name

11. administrative assistant's e-mail address

12. administrative assistant's telephone number

G. Nurse coordinator information

Not applicable ☐

1. name of coordinator include credentials such as RN, BSN, CPNP, ANP-BC, MSN, PNP

2. coordinator experience (provide a brief description of clinical experience and knowledge of TSC)

3. approximately what percentage of time will coordinator spend with TSC clinic related activities?

- ☐ less than 25% time
- ☐ at least 25% but less than 50% time
- ☐ at least 50% time
- ☐ more than 50% but less than full-time
- ☐ full-time
- ☐ Other

4. business mailing address

same as clinic director's: ☐

5. city, state/province, zip code, if applicable

same as clinic director's ☐

6. country (if not USA)

7. e-mail address

8. telephone number (direct line)

9. cell phone number

10. alternate telephone number

H. Point of contact for clinic information and scheduling an appointment in the TSC Clinic

1. name of person to contact for clinic information

1.1 e-mail address

1.2 telephone number

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2. name of person to contact to schedule an appointment in the TSC Clinic

2.1 e-mail address

2.2 telephone number

I. TSC Clinic schedule

1. Please provide clinic schedule/frequency (example: daily, weekly, monthly, every 1st and 3rd week, etc.)

1.1 Is this schedule tentative and subject to change?

- ☐ Yes
- ☐ it's permanent, until further notice
- ☐ Other

J. Clinic healthcare providers

In this section, list the **name**, their **credentials** (i.e. MD, PhD, LCSW, PA-C, etc.) and **e-mail^** for each specialist affiliated with your TSC Clinic who are expected to be knowledgeable about TSC and agree to accept a referral from the TSC Clinic if they do not see TSC patients on the same day in the TSC Clinic.

^e-mail addresses are for TS Alliance communication and to share with other healthcare providers only.

>>>>After each name, add (A) to specify an adult specialist only.
Add (P) to specify a pediatric specialist only. Add (A/P) if specialist sees all ages.<<<

Cardiologist		One or more provider in this specialty sees patients on same day in the TSC Clinic ☐
Dentist		One or more provider in this specialty sees patients on same day in the TSC Clinic ☐ Choic e 1
Dermatologist		One or more provider in this specialty sees patients on same day in the TSC Clinic ☐
Endocrinologist		One or more provider in this specialty sees patients on same day in the TSC Clinic ☐
Epileptologist		One or more provider in this specialty sees patients on same day in the TSC Clinic ☐

Gastroenterologist		One or more provider in this specialty sees patients on same day in the TSC Clinic	☐ Choic e 1
Geneticist		One or more provider in this specialty sees patients on same day in the TSC Clinic	☐
Genetic counselor		One or more provider in this specialty sees patients on same day in the TSC Clinic	☐
Nephrologist		One or more provider in this specialty sees patients on same day in the TSC Clinic	☐
Neurologist		One or more provider in this specialty sees patients on same day in the TSC Clinic	☐
Neuropsychologist		One or more provider in this specialty sees patients on same day in the TSC Clinic	☐
Neuroradiologist			
Neurosurgeon		One or more provider in this specialty sees patients on same day in the TSC Clinic	☐
Nurse practitioner		One or more provider in this specialty sees patients on same day in the TSC Clinic	☐

Ophthalmologist		One or more provider in this specialty sees patients on same day in the TSC Clinic	☐ Choice 1
Physician's assistant		One or more provider in this specialty sees patients on same day in the TSC Clinic	☐
Psychologist		One or more provider in this specialty sees patients on same day in the TSC Clinic	☐
Psychiatrist		One or more provider in this specialty sees patients on same day in the TSC Clinic	☐
Pulmonologist		One or more provider in this specialty sees patients on same day in the TSC Clinic	☐
Radiologist, interventional			
Social worker		One or more provider in this specialty sees patients on same day in the TSC Clinic	☐
Urologist		One or more provider in this specialty sees patients on same day in the TSC Clinic	☐

Other, specify specialty:		Which of theses providers see patients on same day in the TSC Clinic?	

K. Applicant's statement: Tell us what your clinic provides for people affected by TSC that is different or unique than other centers in your region.

STATEMENT:

L. Applicant's acknowledgement

1. I/we certify the information submitted in this application is accurate and complete to the best of my/our knowledge.
2. I/we have read the TS Alliance "Scope of Relationship Policy" and agree to abide by it.
3. I/we agree not to solicit the Community Alliance leadership team to raise funds for my/our TSC Clinic.
4. I/we understand that TS Alliance may publicize information from this application on its website at www.tsalliance.org or in TS Alliance publications. **EXCLUDES** clinic director/co-director's e-mail and direct office phone & mobile numbers, which will not be shared without your authorization.

Mark this box to acknowledge the above four statements. ☐

L-1. TSC Clinic Director with one or more co-director

Not Applicable ☐

The Director is board-certified in their country of clinical practice in a specialty related to one or more aspect of TSC.

- ☐ Yes, board-certified
- ☐ Board-eligible
- ☐ No, not board-certified

Co-Director named in Section F.

- ☐ Yes, board-certified
- ☐ Board-eligible
- ☐ No, not board-certified

A COPY OF DIRECTOR'S AND CO-DIRECTOR'S (if applicable) CURRICULUM VITAE AND PHOTO ARE SUBMITTED WITH THIS APPLICATION ☐

Please submit your completed application, CV and a photo (jpeg format) by email to Jo Anne Nakagawa at jnakagawa@tsalliance.org
If questions, email or call (240) 638-4654

Applicant's digital or typed signature

Date