TSC care begins with you

1. The better prepared you are, the more you will get out of the doctor visit. Based on your most recent medical tests, check the signs and symptoms you or your loved one has now. Tell your doctor about these at your visit. There is space to write details under each medical concern. The more information you provide, the better your doctor can assess your health.

- ☐ Seizures (Note if these have become more frequent or more severe. If you are taking antiepileptic drugs, or AEDs, note if they are working as well as you think they should.)

- ☐ Brain tumors (You may not know you have a tumor until it is large and causes problems. Note if you are experiencing any signs like headaches, nausea, or vomiting.)

- ☐ Kidney tumors (Note if you have had any pain in your side or your back. Also note if you have had any blood in your urine.)

- ☐ TAND, or TSC-associated neuropsychiatric disorders (This includes any big or small behavior, psychiatric, and intellectual problems; difficulty in school; and social concerns. Examples can include anxiety, depression, trouble concentrating, and aggression.)

- ☐ Facial bumps

- ☐ Bumps on lower back

- ☐ Light-colored spots on skin

- ☐ Skin tags or growths

- ☐ Shortness of breath

- ☐ Wheezing

- ☐ Frequent cough

- ☐ Chest pain

- ☐ Sleep problems

- ☐ Indents in your teeth or bumps on gums

- ☐ Problems with your vision

- ☐ Other
2. **Ask your doctor:** “What changes in my treatment do you recommend based on my signs and symptoms?”

3. It is important to get body areas scanned and monitored often in case new tumors begin to form. The larger tumors grow, the more complications they can cause—especially those in the brain and in the kidneys. **Ask your doctor:** “When should I have scans done?”

4. Because TSC affects different parts of the body, you may have to see different doctors, called specialists. **Ask your doctor:** “How often should I see other specialists?”

   Check the doctors you should see, and then fill in the blank with the date of your visit.

- [ ] Neurologist (brain doctor)
- [ ] Neurosurgeon (brain surgeon)
- [ ] Nephrologist (kidney doctor)
- [ ] Dermatologist (skin doctor)
- [ ] Pulmonologist (lung doctor)
- [ ] Pediatric cardiologist (heart doctor for children)
- [ ] Ophthalmologist (eye doctor)
- [ ] Dentist
- [ ] Geneticist (gene specialist)
- [ ] Primary care physician

5. **Ask your doctor:** “Can you refer me to the other specialists I should be seeing?”

    | Specialist’s name | Phone number | Will monitor my |
    |-------------------|--------------|----------------|
    |                   |              |                |
    |                   |              |                |
    |                   |              |                |

   Notes: __________________________

   **Remember, taking charge of your TSC health means asking questions, learning about TSC, and seeing the right specialists based on your signs and symptoms.**

   **To learn more, visit** [www.tuberous-sclerosis.com](http://www.tuberous-sclerosis.com) **today!**