**Clinic Name**

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| **I. KNOWLEDGE & EXPERIENCE** |
|  | **Question** | **Notes** |
| 1 | Does the clinic follow the most recent Clinical Consensus Guidelines for diagnosis, surveillance, and management of TSC? [www.tscalliance.org/consensus](http://www.tscalliance.org/consensus). Keeping up with these annual tests can provide the best treatment options for you/your child. |  |
| 2 | Does the clinic have doctors who are specialists in problems that affect you/your child? (e.g. seizures, brain, kidney or heart tumors, skin growths, learning or behavior issues, etc.) |  |
| 2a. | Are the doctors board-certified in their specialty?(This means they have successfully passed an examination to test their knowledge and skills within their specialty.)  |  |
| 3. | How many patients with TSC has the doctor treated in his/her medical practice? |  |
| 4. | Are you able to see all the specialists on the same day and location? |  |
| **II. ACCESSIBILITY & RESPONSIVENESS** |
|  | **Question** | **Notes** |
| 1. | Is there a person whose primary responsibility is to assist patients and their families with scheduling their doctor appointments will all relevant specialists and tests/scans?   |  |
| 2. | Do they have a dedicated phone line specifically for the TSC Clinic for you to reach a nurse to ask questions outside of office visits? |  |

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| **II. ACCESSIBILITY & RESPONSIVENESS** |
|  | **Question** | **Notes** |
| 3. | Do they give you access to a secure online patient portal allowing you to access medical records, review test results, email questions to nurses and providers, request medication refills and schedule follow-up appointments? |  |
| 4. | Are there emails, phone calls, mailers, or text reminders sent when it is time for your/your child’s annual follow-up appointments and tests/scans? |  |
| 5. | Has the clinic given you information on how you can reach your/your child's doctors after office hours or on the weekend if there is a problem that can’t wait until a clinic appointment?  |  |
| 6. | If you leave a message for your/your child’s doctor, how soon will you get a return call? |  |
|  **III. QUESTIONS TO ASK IF YOUR/YOUR CHILD’S DOCTOR RECOMMENDS SURGERY** If not applicable, skip to Part IV |
|  | **Question** | **Notes** |
| 1. | Why does the doctor recommend surgery instead of non-surgical options? |  |
| 2. | Will you have a consultation with the surgeon? |  |
| 3. | What type of surgical procedure is recommended?    |  |
| 5. | If diagnostic tests\* are necessary to confirm that surgery may improve your/your child’s condition, will these tests be done at one location? \*These may include but are not limited to blood, imaging, and neuropsychological. |  |

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| **IV. OTHER SUPPORT** |
|  | **Question** | **Notes** |
| 1.  | Does the clinic have a social worker, administrative coordinator, nurse manager, or TSC Alliance Clinic Ambassador who is available to help direct you to resources\* within their institution or in the community? \*Such as educational, financial, respite care, etc.  |  |
| 2. | Does the clinic provide ways for families to connect with others who are also dealing with TSC individuals such as support groups, summer camps, educational meetings, or any other events to bring people together? |  |

**ADDITIONAL NOTES**

Resource/TSC Clinic Screening Tool 7.27.2021