**Appendix 1: Available Search Terms within TSC Core Registry**

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| DEMOGRAPHICS | SEGA Dx Date | Infant Spasm Date Dx | Clobazam  | Pentobarbital | Anxiety Test Date |
| Date of Birth | Condition Status | Epilepsy Treatment Status | Clobazam Ongoing | Pentobarbital Ongoing | Other Psych Disorder |
| Gender | SEGA Ongoing Assessment | Infantile Spasm Tx Header | Clonazepam  | Perampanel | Other psychiatric disorder  |
| Transgender | Multiple SEGA | ACTH | Clonazepam Ongoing | Perampanel Ongoing | Other Disorder Eval |
| Race | Bilateral SEGA | ACTH Ongoing | Clorazepate dipotassium | Phenobarbital | Other Disorder Test Date |
| Ethnicity | SEGA Growing | Oral Steroids | Clorazepate dipotassium Ongoing | Phenobarbital Ongoing | Depressive Test Date |
| Country of Birth | Date Scan | Oral Steroids Ongoing | Diazepam | Phenytoin | Neuropsychological Skills |
| State of Birth | Sega Symptomatic | Cannabinoids | Diazepam Ongoing | Phenytoin Ongoing | Neuropsych Assessment |
| Country of Residence | SEGA Symptoms | Cannabinoids Ongoing | Divalproex sodium | Pregabalin | Performance Deficit |
| Verbal | Behavior Disturbance | Vigabatrin | Divalproex sodium Ongoing | Pregabalin Ongoing | Neuropsych Deficit Date |
| Primary Language | Eye movement abnormalities | Vigabatrin Ongoing | Ethosuximide  | Primidone | Difficulties in School |
| Handedness | Headache | Ketogenic Diet | Ethosuximide Ongoing | Primidone Ongoing | Academic Assessment |
| GENETICS | Intracranial pressure | Ketogenic Ongoing | Ethotoin  | Retigabine | Academic Assessment Date |
| Genotype | Neuroendocrine dysfunction | Other Antiepileptic Drugs | Ethotoin Ongoing | Retigabine Ongoing | Common Behavior Problems |
| Molecular Testing | Papilledema | Other Antiepileptic Drugs Ongoing | Felbamate | Rufinamide | Behavior Symptoms |
| TSC1 Mutation | Regression | Other Treatment | Felbamate Ongoing | Rufinamide Ongoing | Default No Behavior |
| TSC2 Mutation | Seizure increase | Other Infantile Tx Specify | Gabapentin | Tiagabine | Anxiety |
| PKD1 Mutation | Sleep disorder | Other Treatment Ongoing | Gabapentin Ongoing | Tiagabine Ongoing | Depressed Mood |
| TSC1 Test Results | Ventriculomegaly | Surgery | Ganaxolone | Topiramate | Hallucinations |
| Date of Testing | Visual impairment NOS | Corpus Callosotomy | Ganaxolone Ongoing | Topiramate Ongoing | Impulsivity |
| Mutation Description | Other SEGA Sx Specify | Hemispherectomy | Lacosamide  | Zonisamide | Mood Swings |
| g Designation | SEGA Treatment Status | Lobectomy | Lacosamide Ongoing | Zonisamide Ongoing |  |
| c Designation | SEGA Tx Received | MRI-guided laser ablation | Lamotrigine  | **NEUROPSYCHIATRIC** |  |
| p Designation | Shunt | Tuberectomy | Lamotrigine Ongoing | Intellectual Testing |  |
| r Designation | Shunt Start Date | Vagus Nerve Stimulator | Levetiracetam | Intellectual Eval Type |  |
| Variation Type | Shunt End Date | Other Surgery | Levetiracetam Ongoing | IQ |  |
| Large Scale Deletions | Shunt Ongoing box | Surgery Specify | Lorazepam | Standardized assessment done |  |
| ISCN 2013 | Surgery | Epilepsy Treatment Outcome | Lorazepam Ongoing | Intellectual Test Date |  |
| Inheritance | Surgery Start Date | Focal Seizures | Mephobarbital | Clinical assessment of IQ |  |
| TSC2 Test Results | Surgery End Date | Focal Seizure Date Onset | Mephobarbital Ongoing | Autism |  |
| Date of Testing | Surgery Ongoing box | Focal Seizure Date Dx | Eslicarbazepine acetate | Autism Eval |  |
| TSC2 Testing Location | mTOR inhibitor | Cortical Tuber hamartoma | Eslicarbazepine acetate Ongoing | Autism Test Date |  |
| PKD1 Test Results | mTOR inhibitor Start Date | Cortical Tuber Dx Date | Methsuximide | ADHD |  |
| Date of Testing | mTOR inhibitor End Date | Subependymal nodule | Methosuximide Ongoing | ADHD Eval |  |
| PKD1 Testing Location | mTOR inhibitor Ongoing box | Subependymal nodule Dx Date | Midazolam nasal spray | ADHD Test Date |  |
| NEUROLOGICAL | Other | **ANTIEPILEPTIC DRUGS** | Midazolam nasal spray Ongoing | Depressive |  |
| Neurological | Epilepsy | Brivaracetam | Nitrazepam | Depressive Eval |  |
| SEGA | Type Epilepsy | Brivaracetram Ongoing | Nitrazepam Ongoing | Depressive Test Date |  |
| SEGA Dx Date | Infantile Spasms | Carbamazepine | Oxcarbazepine | Anxiety |  |
| Condition Status | Infant Spasm Date Onset | Carbamazepine Ongoing | Oxcarbazepine Ongoing | Anxiety Eval |  |

TSC, tuberous sclerosis complex; PKD, polycystic kidney disease; ISCN, international system for human cytogenetic nomenclature; SEGA, subependymal giant cell astrocytoma; Dx, diagnosis; NOS, not otherwise specified; mTOR, mammalian target of rapamycin; ACTH, adrenocorticotrophic hormone; Tx, treatment; MRI, magnetic resonance imaging; IQ, intelligence quotient; ADHD, attention deficit hyperactivity disorder; Eval, evaluation