**Division Introduction**

The Division of Child Neurology represents an academic practice with commitment to patient care, teaching and research.

Formed in the 1980s as part of the Department of Neurology, the Division maintained a successful academic and training program through the 1990s. Dr. Berge Minassian became the Division Chief in 2016, and the Division has been a part of the Department of Pediatrics since 2006.

Under Dr. Minassian's direction, the Division provides comprehensive diagnosis and management for children at Children's Health from newborn to late adolescence who have disorders of the brain, spinal cord, nerve, or muscle. Faculty members specialize in providing neurological care, consultations, and second opinions for children afflicted by virtually any neurological disorder.

Division faculty conduct a variety of neurologic bench/basic research and clinical studies, including clinical trials. Current studies are focused in seven main areas:

- Gene therapy
- Movement Disorders
- Metabolic disorders of the nervous system
- Neuromuscular disease clinical trials
- Anti-epileptic drug trials
- Clinical trials in pediatric stroke
- Clinical studies in the autism spectrum
- Neuroimaging studies in pediatric movement disorders

It is a priority in the Division to maintain a competitive Child Neurology (CN) Training Program and Neurodevelopmental Disabilities (NDD) Training Program that will supply high-quality faculty for many years to come. Together with the Department of Neurology, the division offers:

- a three-year Child Neurology Residency Program (integrated with 2-years preliminary UTSW Pediatrics residency),
- a four-year Neurodevelopmental Disabilities Residency Program (integrated with 2-years preliminary UTSW Pediatrics residency),
- fellowship training in pediatric neurology subspecialties, including Clinical Neurophysiology, Epilepsy, Headache Medicine, Neuromuscular Medicine

Each year, in collaboration with the Departments of Pediatrics and Neurology and Neurotherapeutics at UT Southwestern, Children's Health™, Texas Scottish Rite Hospital for Children, and the Muscular Dystrophy Association, the Division presents the Carrell-Krusen Neuromuscular Symposium for muscular dystrophy clinic directors, case managers, nurses, and members of interdisciplinary care teams. The Symposium is directed by Dr. Iannaccone, and most residents and fellows from the Division of Pediatric Neurology and from the Department of Neurology and Neurotherapeutics present at the Symposium.

The division of Pediatric Neurology hosts the New Frontiers in Pediatric Neurology symposium in collaboration with UT Southwestern and Children's Health™, covering updates in the field of Pediatric Neurology. This is a one-day CME event for Pediatric Neurology physicians, advanced practice providers, residents and fellows. The symposium is directed by Drs. Castro, Golla and Sirsi.
The Pediatric NeuroConcussion Clinic, led by Medical Director Tonia Sabo, is the leading clinical enrolling site for the UTSW North Texas Concussion Registry (ConTex) which is a multicenter, prospective longitudinal registry for concussion established in 2015.

The Clinical Pediatric NeuroConcussion Program has expanded greatly in capacity to diagnose, treat and help youth with mild traumatic brain injury (mTBI) from sports and non-sports causes. The program recently moved operations to the newly opened Children’s Health Pediatric Multispecialty Center at Cityville that offers the latest in diagnostic and treatment capabilities for clinical care and includes specialized testing equipment, nursing, social work, school services and rehabilitative services. Medical student and resident education in these facilities allows proper training in safe “Return to Play” and current Neurological published standards for concussion management.

The Pediatric Headache Program offers an unparalleled clinical and academic program in the Southwest under the leadership of Pediatric Headache Fellowship Director, Tonia Sabo, MD and is now training its second Pediatric Headache fellow. Eric Remster, MD, the first graduate of the Pediatric Headache Fellowship, recently joined the Pediatric Headache faculty and is involved with the ongoing clinical research studies in the division which includes a Quality Initiative Care Pathway for Headache Treatment (which includes clinical templates for orders and published hospital policy) and a Pseudotumor database initiative. The clinical Pediatric Headache Program, which is also located in the Cityville Center, has capabilities of urgent headache care to help keep patients out of the Emergency Department and for procedures such as nerve blocks and botulinum therapy.

**Faculty**

The Division has 18 faculty, two with a major commitment to research and all focused on clinical and teaching responsibilities. They represent a mix of young and mature individuals, each of whom brings special talents and experience that promise to contribute to further growth and development of the Division. Three faculty, Drs. Steven Gray, Eric Remster and Jeff Waugh joined the faculty in 2017.

**Steven Gray, Ph.D.**

Associate Professor, Pediatrics, Eugene McDermott Center for Human Growth & Development, Hamon Center for Regenerative Science & Medicine, Molecular Biology, and Neurology & Neurotherapeutics

B.Sc., Auburn University, Auburn, Al, 2000

Ph.D. Vanderbilt University, Nashville, TN, 2006

**Postdoctoral Training**

University of North Carolina, Chapel Hill, NC, 2006-2008

**Interests**

Adeno-associated virus (AAV) vector engineering, developing AAV vector-based treatments (gene therapy) for nervous system diseases, facilitating bench-to-bedside translation of gene therapy into Phase I clinical trials, improving AAV vector manufacturing processes, understanding and overcoming immune responses associated with viral vector-based gene therapy approaches
Eric Remster, M.D.
Assistant Professor, Pediatrics and Neurology & Neurotherapeutics

B.S., cum laude
Clemson University, Clemson, SC, 2006

M.D.
Indiana University School of Medicine, Indianapolis, IN, 2010

Postdoctoral Training
Residency, Pediatrics
Orlando Health/Orlando Regional Medical Center, Orlando, FL, 2010-2013
Fellowship, Pediatric Neurology
UT Southwestern Medical Center/Children’s Health, Dallas, TX, 2013-2016
Fellowship, Pediatric Headache Medicine
UT Southwestern Medical Center/Children’s Health, Dallas, TX, 2016-2017

Interests
Headache and Concussion, Pediatric Migraine and Headache Disorders, Pediatric Intracranial Pressure Disorders, Pediatric Concussion and Traumatic Brain Injury, Pediatric Dysautonomia and General Child Neurology

Jeffrey Waugh, M.D., Ph.D.
Assistant Professor, Pediatrics and Neurology & Neurotherapeutics

B.A. cum laude
Washington University, St. Louis, MO, 1999

M.D. and Ph.D.
UT Southwestern, 2007

Postdoctoral Training
Residency, Pediatrics
UT Southwestern/Children’s, 2007-2009
Residency, Pediatric Neurology
Boston Children’s Hospital, Harvard University, Boston, MA, 2009-2012
Fellowship, Pediatric Movement Disorders
Massachusetts General & Boston Children’s Hospitals, Boston, MA, 2012-2014

Interests
Clinical: Pediatric movement disorders, functional neurological disorders, business of medicine
Research: Structural basis of dystonia, functional consequences of dystonia treatment, such as deep brain stimulation, the neurophysiology of the neostriatum, methods developmental in diffusion MRI

Honors / Awards

Best Pediatric Specialists, D Magazine

- Susan Arnold
- Michael Dowling
- Susan Iannaccone
- Deepa Sirsi
- Rana Said

Texas Super Doctors, Texas Monthly Magazine

- Sailaja Golla
- Susan Iannaccone
2017 Annual Report

Mom Approved Doctor, *DFW North Texas Child Parent Magazine*

- Sailaja Golla

**Tonia Sabo**

- Neuro NEXT PI selected course member, UT Southwestern

**Deepa Sirsi**

- (Dec 2017) - Fellow of American Epilepsy Society

**Invited Lectures**

**Susan Arnold**

- 10th International Colloquium on Intractable Focal Epilepsy Miami FL, June 2017
  - “Epilepsy Surgery in Special Situations”

**Diana Castro**

- Grand Rounds, Dell Children’s Hospital, Austin, TX, January 2017
  - “DMD and SMA: Clinical evaluation and current research”
- Mexican Academy for Cerebral Palsy and Neurodevelopmental Disorders, Monterrey, Mexico, January 2017
  - “Differential Diagnosis of Myopathies”
  - “Management of the patient with DMD”
  - “Neuromuscular evaluation of the hypotonic patient”
- Webcast, Biogen Pharmaceutical, Dallas, TX, January 2017
  - “Broadcast Launch: SPINRAZA”

**Michael Dowling**

- 9th Annual Neurovascular Symposium: Pediatric Neurovascular Disease, Santa Monica, CA, January 2017
  - “Pediatric vasculopathy and vasculitis”
- Texas Neurological Society Annual Conference, Austin, TX, February 2017
  - “Dead Dead, Brain Dead, Better off Dead”
- Texas Neurological Society Annual Conference, Austin, TX, February 2017
  - “Dead Dead, Brain Dead, Better off Dead”
- 2017 Trauma and Stroke Symposium hosted by St. Francis Hospital, Tulsa, OK, September 2017
  - “Neurologic Complications of Sickle Cell Disease”; “Why Kids Have Strokes”
- Grand Rounds, Texas Children’s Hospital, Houston, TX, October 2017
  - “Pediatric Stroke”
- Grand Rounds, Cincinnati Children’s Hospital, Cincinnati, OH, November 2017
  - “Ethical Issues in Brain Death”

**Sailaja Golla**

- Neurodevelopmental Outcomes after ECMO Support, Platform Presentation, 2017 Child Neurology Society Meeting, Kansas City, MO
- Song Bird interview - CBS 11 – “How would bird brain study help child with autism?”
- MELAS Interview - Aired on Univision 23
- Rett’s syndrome interview – Aired on UTSW media page and Center news: “Why patients with Rett’s display repetitive hand behaviors?”
Susan Iannaccone

- Muscular Dystrophy Association family support group meeting, Dallas, Texas, January 2017
  - "Congenital myotonic muscular dystrophy"
- National Meeting of the Wellstone Muscular Dystrophy Centers, UTSW, Dallas, TX
  - Opening meeting for patients and public
  - Clinical Management of Boys with DMD
- MDA Discovery and Impact Meeting, Dallas, TX
  - DMD

Andrea Lowden M.D.

- 2nd Latin American Symposium in Critical Care EEG. Mexico City, Mexico- November 2017
- “Management of seizures and status epilepticus in children”
- “ICU EEG reading session: Pediatric cases”
- Global Health Initiative- Santo Domingo, Dominican Republic, October 2017 - A part of the GH initiative was able to participate in a medical mission trip to Dominican Republic with Propel DR and Mission Emmanuel. Various physicians around the country as well as therapist, wheelchair technicians, professors, missionaries participate each year in this weekly trip to provide medical care to the Dominican community (along with Dominican physicians) and education to local physicians, residents in training, other medical staff, patients and families. Lectures included Epilepsy basics, SUDEP, Pediatric epilepsy syndromes, Down Syndrome and neurological manifestations and Autism and epilepsy. Various sites around Santo Domingo, Dom. Rep. were visited including the Dominican Rehabilitation Association (ADR), Pediatric center for integrated attention for patients with disability (CAID) which focuses care in children with Autism, Downs Syndrome and Cerebral palsy, Plaza de la Salud which is one of the largest hospital around the country and Cielo clinic which is a primary clinic founded by Mission Emmanuel.
Tonia Sabo

- Children’s Health 49th Annual Kenneth C. Haltalin Pediatrics for the Practitioner, Irving, Texas, April 2017
  “Management of Pediatric Concussion”

Rana Said

- American Academy of Neurology Annual Meeting, Boston, MA, April 2017
  o “Clerkship and Program Directors Leadership Academy”

Jeff Waugh

- Neurology Grand Rounds, Rush University Medical Center, Chicago IL, February 2017
  o “Where is the Abnormality in Dystonia? Explorations with Diffusion Imaging”
- Essentials for Trainees webinar series, American Academy of Neurology, April 2017
  o “Bill smarter – a practical approach to billing and documentation.”
- Pediatrics Grand Rounds, Texas Tech University Health Sciences Center at Amarillo, December 2017
  o “Recognizing Abnormal Movements in Children.”

Conference Presentations

Arnold ST, Dolce AM

Poster, American Epilepsy Society Annual Meeting, December 2017
“Clinical experience with Aspire VNS: Association between heart rate detection, autostimulation and clinical seizures.”
Sabo T, Supnet C, Purkayastha S.

Poster, 12th World Congress on Brain Injury, New Orleans, LA, March 2017
“Post Traumatic Intracranial Hypertension (Pseudotumor Cerebri) in Mild Traumatic Brain Injury: A Specific Post Traumatic Headache Subtype; The Importance of Recognition, Evaluation and Management”

Purkayastha A, Frantz J, Sabo T, Bell K.

Oral, 12th World Congress on Brain Injury, New Orleans, LA, March 2017
“Impaired Cerebral Vasoreactivity Persists Beyond Symptom Resolution Following Concussion in Collegiate Athletes”

Sabo, T

Oral, Second International Conference on Pediatric Acquired Brain Injury, Rome, Italy, September 2017
“Post Traumatic Intracranial Hypertension (Pseudotumor Cerebri) in Mild Traumatic Brain Injury: A Specific Post Traumatic Headache Subtype; The Importance of Recognition, Evaluation and Management”

“Transcranial Doppler will become the Gold Standard in Concussion Diagnosis”

Sirsi, D; Arnold, ST

Platform presentation at Pediatric Epilepsy Highlights session of American Epilepsy Society meeting.
“Infantile epilepsy with prolonged focal myoclonus: A distinctive syndrome associated with TBC1D24 mutation.”
2017 American Epilepsy Society Meeting, Washington DC.

Waugh, JL

Oral presentation, Cerebral Palsy: Prep for Life, Southlake, TX, August 2017
Platform presentation and panel discussion, 2016 symposium: “Deep Brain Simulation in Children with Cerebral Palsy.”

Education and Training

Dr. Rana Said is Director of the Child Neurology Residency Program. The program offers an ACGME-accredited 3-year training program and a combined 5-year program in Pediatrics and Child Neurology based at Children’s Health™ Dallas. The program accepts three Child Neurology residents each year. Graduates are eligible for boards in Pediatrics and Neurology with special qualifications in Child Neurology.

Dr. Patricia Evans is the Director of the Neurodevelopmental Disabilities residency program. The NDD residency is a four-year core residency program, of which there are only 8 nationally. The program accepts one NDD resident per year. The program offers an ACGME-accredited 4-year program in Neurodevelopmental Disabilities and a combined 6-year program in Pediatrics and Neurodevelopmental Disabilities. Graduates are eligible for boards in Pediatrics, Neurology with special qualifications in Child Neurology and Neurodevelopmental Disabilities.

Dr. Deepa Sirsi is the Associate program director of the Clinical Neurophysiology and Epilepsy fellowship programs. She is the director of the Pediatric tracks of these fellowships. These ACGME programs accept 1 fellow per year for each fellowship. Graduates are eligible for boards in Clinical Neurophysiology or Epilepsy.
Research Activities

Division faculty conduct a variety of neurologic bench/basic research and clinical studies, including clinical trials. Current studies are focused in five areas:

- Gene therapy
- Movement Disorders
- Metabolic disorders of the nervous system
- Neuromuscular disease clinical trials
- Anti-epileptic drug trials
- Clinical trials in pediatric stroke
- Clinical studies in the autism spectrum

Faculty research projects include:

- Berge Minassian is an international authority on Lafora disease, a glycogen storage disorder of the brain with intractable and fatal epilepsy. His laboratory has uncovered large amounts of knowledge on the metabolism of glycogen in the brain. In addition, he is, with his colleague Dr. Gray and others of the faculty, building the premiere national Gene Therapy Center. The goal is a complete transformation of pediatric neurology whereby children with single gene defect brain diseases, as appropriate, would receive treatment in the form of replacing the missing gene.
- Susan Arnold is involved in multiple industry-sponsored clinical research trials. In 2017, she was the site-principal investigator for three epilepsy clinical trials sponsored by UCB Pharma. She was also site principal investigator for a multi-center study of the pharmacokinetics of antiepileptic drugs in obese children funded by the National Institute of Child Health and Human Development. She has worked with Drew Thodeson on an evaluation of the utility of next generation gene sequencing in the evaluation and management of childhood epilepsy.
- Diana Castro serves as the Principal Investigator and Co-Investigator of several research projects funded by industry and federal grants. The main research areas are Spinal Muscular Atrophy and Duchenne Muscular Dystrophy. She is also developing unfunded projects in other areas including Guillain Barre Syndrome, RYR1 myopathies and Myasthenia Gravis.
- Michael Dowling is involved in clinical research in the areas of stroke in children, Sturge-Weber syndrome, and neurologic complications of sickle cell disease.
- Patricia Evans is an active participant in translational research, both for the disorders of autism spectrum disorders and fragile X syndrome. She is participating in a range of studies, including the genetics of autism spectrum disorders, neurodevelopmental outcomes in children after extra-corporeal membrane oxygenation, and mechanisms of fragile X syndrome cognitive deficits.
- Sailaja Golla is involved with multiple grants including Industry funded, federal funded and unfunded projects. She is part of the NIH trial for circulatory support in pediatric heart failure patients using the Infant Jarvik 2000 to assess long term neurodevelopmental outcomes. In 2015, Dr. Golla submitted a grant proposal to The Pediatric Epilepsy Research Foundation (PERF) to describe the correlation of clinical features of autism with EEG abnormalities and epilepsy.
- Steven Gray is the PI on several grant-funded projects. These include an NIH R01 grant to develop novel AAV capsids for CNS gene transfer, an NIH R01 grant to understand and treat Giant Axonal Neuropathy, and a sponsored research agreement from Abeona Therapeutics to support the initiation of a Phase I clinical trial for CLN1 Batten disease. He also has funding from several small foundations to support the development of gene therapy treatments for CLN7 Batten disease, Tay-Sachs disease, Sandhoff disease, Krabbe disease, Multiple Sulfatase Deficiency, Rett syndrome, Aspartylglucosaminuria, Angelman Syndrome, Pitt-Hopkins disease, and Charcot Marie Tooth disease types 4J and 6. Dr. Gray is actively working to create a working core facility for research and clinical AAV manufacture, and also facilitate the initiation of gene therapy clinical trials for multiple rare neurological diseases.
- Susan Iannaccone has expanded the Pediatric Neuromuscular Clinical Trials Program (Pediatric NMCTP) that she started in 2005. She and the NM team are running clinical 12 trials for our patients...
with several neuromuscular diseases. Funding for studies in spinal muscular atrophy and Duchenne muscular dystrophy is largely through industry contracts making it possible for us to offer our patients access to state of the art and cutting-edge research. She is Associate Director of the Wellstone Muscular Dystrophy Center at UTSW for which the focus is gene editing for Duchenne muscular dystrophy.

- Tonia Sabo is involved in clinical industry related studies in Pediatric Headache. She is involved in faculty led research in Intracranial Hypertension. She is involved in Quality Initiative Research on the treatment of headache and she is the Children’s Medical Center Site Principal Investigator for the UTSW North Texas Concussion Registry (ConTex) which is a multicenter, prospective longitudinal registry for concussion established in 2015 which has enrolled over 900 patients to date. ConTex includes data on medical and injury history, self-reported symptoms and co-morbid symptoms, and balance evaluation, to help identify the most precise methods for concussion diagnosis and prognosis, refine outcome assessment, and compare the effectiveness of concussion care in youth. She works with other researchers, who have launched a computerized online system in partnership with the UIL University Interscholastic League (UIL), which serves as the governing body over competitions in Texas public schools and includes approximately 1,250 school districts and represents an effort to obtain basic data on concussions occurring across the state at the high school and middle school levels to examine patterns of injuries across the state in order to study and inform best practices. The same research collaborators recently were chosen as one of 8 finalists teams asked to give a final written proposal and oral presentation in a highly competitive NFL Scientific Advisory Board Research Grant Opportunity which would allow study of advanced neuroimaging, biomarkers and treatment arms to further the advancement of youth concussion.

- Rana Said is involved in multiple industry-sponsored clinical research trials. Currently she is the site principal investigator for three studies assessing efficacy and safety of synthetic cannabidiol (CBD) for children with refractory epilepsy and Dravet syndrome and Lennox-Gastaut syndrome, and she is involved in a phase-3 trial with INSYS Therapeutics.

- Deepa Sirsi is involved in a range of clinical research studies concerning EEG & autism, yield of EEG & imaging in complex febrile seizures, genetic epilepsy syndromes and industry funded anti-seizure medication studies. She collaborates with other clinicians and basic scientists in research involving treatment of sodium channelopathies and other genetic causes of epilepsy such as GLUT1 disorder.

- Drew Thodeson has collaborated with the Hsieh laboratory in designing an in vitro model of genetic epilepsy using induced pluripotent stem cells specifically looking at ARX and CHD2 gene mutations. He also has a research collaboration with Jason Park in the Department of Pathology evaluating the clinical diagnostic testing of childhood epilepsy using clinically available next generation sequencing.

- Jennifer Thomas is involved in clinical research in the area of neonatal neurology. She is currently site co-principal investigator in a multi-center trial designed to study the efficacy of high dose erythropoietin for neuroprotection in term infants with hypoxic-ischemic encephalopathy, known as the HEAL trial.

- Jeffrey Waugh is involved in neuroimaging projects that utilize MRI to study the brain in patients with the movement disorder dystonia. In addition to these disease-related research projects, he develops novel methods for improving the accuracy of quantitative diffusion imaging and for identifying compartments within the human striatum in vivo that have previously been visualized only via post-mortem histology. Dr. Waugh collaborates with researchers and clinicians at the Harvard-MIT Martinos Center for Biomedical Imaging, Boston Children’s Hospital, the University of Lübeck in Germany and the University of Santo Tomas and the University of the Philippines, both in Manila, PH. He has current grant funding from the American Academy of Neurology and the Collaborative Center for X-linked Dystonia Parkinsonism.

Clinical Activities

The Pediatric Neurology multidisciplinary teams include board-certified pediatric neurologists, pediatric nurse practitioners, physician assistants, genetic counselor, licensed pediatric nutritionists, occupational therapists, physical therapists and speech therapists. Our teams offer accurate diagnosis and comprehensive management plans as well as access to state-of-the-art clinical trials.
Pediatric Neurology faculty treat:

- Brain tumors
- Cerebrovascular disease and stroke
- Developmental delay
- Neurobehavioral disorders and Autism
- Neuroimmunologic disorders, such as Multiple Sclerosis
- Neurologic complications of Sickle Cell Disease
- Neurometabolic, neurogenetic and complex/rare diseases
- Neuromuscular disorders, such as Muscular Dystrophy and Myasthenia Gravis
- Movement disorders, such as dystonia, chorea, myoclonus, tremor, parkinsonism, and tics
- Urgent epilepsy for new onset afebrile seizures
- Neonates with neurological complications
- Pediatric Headache Disorders including urgent headache treatment and intracranial hypertension
- Pediatric mild traumatic brain injury including concussion diagnosis and Return to Play treatment plans

**Center of Autism and Developmental Disabilities (CADD)**

The Center of Autism and Developmental Disabilities (CADD) is a multi-disciplinary center which provides assessment and management for children and adolescents who have autistic or severe developmental disabilities. CADD provides the integration of psychiatry, psychology, and neurodevelopmental disabilities specialists, as well as behavioral therapies. Dr. Patricia Evans serves as one of three clinical co-directors for the center. Dr. Sailaja Golla, Associate NDD Residency Program Director, is an expert in rare autism variants and directs the Phelen Mc-Dermid Syndrome and Pitt Hopkins Syndrome clinics and also participates in clinical trials for these rare syndromes. The center also houses a clinic for rare genetic variant Fragile X Syndrome.

**Comprehensive Epilepsy Center**

The Comprehensive Epilepsy Center at Children’s Medical Center, Dallas strives to provide excellence in all areas of epilepsy care. Priorities are patient access, excellence in management of straightforward and complex conditions, promotion of research and education, and community outreach to families and health care providers.

**Access**

The Epilepsy Center continues to schedule patients at the downtown Dallas and Plano locations and expanded clinics at Texas Heath Presbyterian Hospital in Dallas in 2017. It plans to open a fourth location in the Dallas region at Texas Scottish Rite Hospital in 2018. Patient demand remains high with a record number of 2550 referrals received in 2017.
Neurophysiology Services

The number of neurophysiology studies interpreted by the epilepsy center physicians increased markedly in 2017. The biggest increase was in EEGs, with a total of 4356 studies interpreted in 2017, an 18% increase compared to 2016 volumes. Inpatient video EEG monitoring also increasing, particularly in the intensive care units. Physicians continue to provide EEG interpretation services to the NICUs at Texas Health Presbyterian Hospital Dallas and Clements University Hospital in Dallas in addition to the CMC Dallas NICU, and pediatric ICUs.

Epilepsy Surgery Program

The Comprehensive Epilepsy Center is certified as a Level 4 Epilepsy center by the National Association of Epilepsy Centers, indicating provision of the highest level of complexity of epilepsy services. Seizure-free outcomes for surgery at CMC Dallas equal or exceed those in pediatric series published in peer-reviewed literature. Combined with the adult program, UTSW has one of the largest epilepsy surgery programs in the country. Pediatric surgery volume increased markedly in 2017, with a total of 28 intracranial surgeries performed. The center also performed its first stereo-EEG evaluations in 2017. This new technology reduces morbidity from invasive monitoring and enables us to offer surgical evaluation to patients with poorly defined or multifocal epileptic zones. Addition of MEG source localization in 2018 is anticipated to further enhance our ability to evaluate complex epilepsy patients. Approximately 45% of the Center’s surgical patients originate as consultations from the Children’s Health inpatient or ER services, 32% come from referrals for second opinions, and the remainder as new-onset seizure patient referrals.
**Epilepsy Disease Specific Certification**

The Comprehensive Epilepsy Center was first certified in 2011 by the Joint Commission Disease Specific program for Distinction in the management of Pediatric Epilepsy, and continues to be the only pediatric epilepsy center in the country with this certification. The program was commended for its educational resources and services aimed at helping teens with epilepsy transition to adulthood. A new focus for this program in 2017 was the addition of periodic depression screening for teens with epilepsy, in collaboration with our dedicated epilepsy center psychologist and neurology social worker.

**Epilepsy Center Outreach**

The faculty and staff of the Epilepsy Center continue to partner with the Epilepsy Foundation of Texas, and provide medical staff to three epilepsy camps. The staff also provides educational programming for both children and parents through the camp programs. The largest and most complex of these camps is the summer teen camp, Camp Kaleidoscope, which provides services to 100 teens with epilepsy and related neurological disabilities. In 2017 the center also developed a new group for teens and parents in collaboration with the Epilepsy Foundation of Texas, focused on preparing families for the transition to adulthood. Several Epilepsy Center physicians also continue to serve on the professional advisory board of the Epilepsy Foundation of Texas, and are regular speakers at their community events.

**Epilepsy Fellowship Training**

The pediatric Epilepsy and Neurophysiology Fellowship programs continue to attract talented applicants and the majority of fellows go on to university faculty positions. The UT Southwestern Epilepsy Fellowship Program was one of the first 7 epilepsy training programs in the country to receive AGME accreditation and was reaccredited after a successful site visit in 2016. Two fellows presented original research at national meetings in 2017.

**Current Grant/Contract Support**

**Susan Arnold**

- **Grantor:** Duke Clinical Research Institute, funded by National Institute of Child Health and Human Development
- **Title of Project:** Pharmakokinetics of Antiepileptic drugs in Obese Children, NICHD-2015-AED01.
- **Role:** Site Principal Investigator
- **Dates:** 2016 – present

- **Grantor:** UCB Pharma
- **Title of Project:** An open-label study to determine safety, tolerability and efficacy of long-term oral lacosamide (LCM) as adjunctive therapy in children with epilepsy
- **Role:** Site Principal Investigator
- **Dates:** 2017 – present

- **Grantor:** UCB Pharma
- **Title of Project:** Protocol EP0060 a multicenter, open-label study to investigate the safety and tolerability of intravenous lacosamide in children (≥4 to <17 years of age) with epilepsy phase 2/3
- **Role:** Site Principal Investigator
- **Dates:** 2016 – present

- **Grantor:** UCB Pharma
- **Title of Project:** A Multicenter, Open-Label, Long-Term Extension Study To Investigate The Efficacy and Safety of Lacosamide as Adjunctive Therapy in Pediatric Subjects with Epilepsy with Partial-Onset
- **Role:** Site Principal Investigator
- **Dates:** 2015 – present
Grantor: UCB Pharma
Title of Project: A Multicenter, Double-blind, Randomized, Placebo-controlled, Parallel-group Study to Investigate the Efficacy and Safety of Lacosamide as Adjunctive Therapy in Subjects with Epilepsy greater or equal to 1 month to less than 4 years of Age with Partial-onset Seizures
Role: Site Principal Investigator
Dates: 2015 – present

Diana Castro
Grantor: NIH/NINDS
Title of Project: NeuroNEXT SMA Biomarker Protocol Development
Role: Site Principal Investigator (Ohio State University); Susan Iannaccone, Co-Principal Investigator
Dates: 2012 - present

Contractor: Sarepta Therapeutics
Title of Project: A study to evaluate the safety, tolerability, and pharmacokinetics of a single dose of SRP-5051 in participants with DMD
Role: Site Principal Investigator
Dates: 2017 – present

Contractor: Figrogen
Title of Project: Trial of Pamrevlumab (FG-3019), in Non-Ambulatory Subjects with Duchenne Muscular Dystrophy (DMD)
Role: Site Principal Investigator
Dates: 2016 – present

Contractor: ReveraGen Biopharma
Title of Project: A phase 2a open label, multiple ascending dose study to assess the safety, tolerability, pharmacodynamics and exploratory efficacy of Vamorolone in Boys with Duchenne Muscular Dystrophy
Role: Site Principal Investigator
Dates: 2016 – present

Contractor: Biogen Pharmaceutical
Title of Project: EMBRACE: A Study to Assess the Safety and Tolerability of ISIS 396443 (ISIS SMNRx) in Participants with Spinal Muscular Atrophy
Role: Site Principal Investigator
Dates: 2015 – present

Contractor: Biogen Pharmaceutical
Title of Project: A Phase 3 Study to Assess the Efficacy and Safety of ISIS-SMN Rx (CS11) in Infants and Patients with Later-onset Spinal Muscular Atrophy
Role: Site Principal Investigator
Dates: 2015 – present

Contractor: AveXis
Title of Project: Gene replacement therapy clinical trial for patients with Spinal Muscular Atrophy Type 1 (STRIVE)
Role: Site Co-Principal Investigator
Dates: 2017 – present
Contractor: AveXis  
**Title of Project:** Study of Intrathecal Administration of AVXS-101 for Spinal Muscular Atrophy (STRONG)  
**Role:** Co-Principal Investigator  
**Dates:** 2017 – present

Contractor: Sarepta Therapeutics  
**Title of Project:** Study of SRP-4045 and SRP-4053 in DMD Patients (ESSENCE)  
**Role:** Site Co-Principal Investigator  
**Dates:** 2017 – present

Contractor: Sarepta Therapeutics  
**Title of Project:** Study of Eteplirsen in patients with DMD amenable to Exon 51 Skipping  
**Role:** Site Co-Principal Investigator  
**Dates:** 2017 – present

Contractor: PTC Therapeutics  
**Title of Project:** A Phase 3 Efficacy and Safety Study of PTC124 in Subjects with Nonsense-Mutation-Mediated Duchenne and Becker Muscular Dystrophy  
**Role:** Site Co-Principal Investigator  
**Dates:** 2013 – present (extension study)

Contractor: Sarepta Therapeutics  
**Title of Project:** A Phase 2 Safety Study of Eteplirsen to Treat Early Stage Duchenne Muscular Dystrophy  
**Role:** Site Co-Principal Investigator  
**Dates:** 2015 – present

Contractor: Eli Lilly and Company  
**Title of Project:** A Phase 3 Randomized, Double-Blind, Placebo-Controlled, Trial of Tadalafil for Duchenne Muscular Dystrophy  
**Role:** Site Co-Principal Investigator  
**Dates:** 2013 – present

Contractor: ISIS Pharmaceuticals  
**Title of Project:** An Open-label Safety and Tolerability Study of ISIS SMNRx (CS12) in Patients with Spinal Muscular Atrophy Who Previously Participated in ISIS SMNRx-CS2 or ISIS SMNRx-CS10  
**Role:** Site Co-Principal Investigator  
**Dates:** 2012 – present

Contractor: ISIS Pharmaceuticals  
**Title of Project:** A Phase 3 Study to Assess the Efficacy and Safety of ISIS-SMN Rx (CS4) in Patients with Later-onset Spinal Muscular Atrophy  
**Role:** Site Co-Principal Investigator  
**Dates:** 2015 – present

Contractor: ISIS Pharmaceuticals  
**Title of Project:** A Phase 3 Study to Assess the Efficacy and Safety of ISIS-SMN Rx (CS3b) in Infants with Spinal Muscular Atrophy  
**Role:** Site Co-Principal Investigator  
**Dates:** 2015 – present
Contractor: Quintiles/Biogen Idec
Title of Project: Phase 2 Study of ISIS 396443 (BIIB058) for Spinal Muscular Atrophy
Role: Principal Investigator
Dates: 2015 – present

Michael Dowling

Grantor: Seattle Children’s Hospital
Title of Project: TIPSTERS: Thrombolysis in Pediatric Stroke Extended Results
Role: Site Principal Investigator
Dates: 2017 – 2018

Grantor: NIH
Title of Project: PumpKIN: Pumps for Kids, Infants, and Neonates Clinical Trial
Role: Neurologist
Dates: 2017 - 2021

Grantor: NIH/NINDS
Title of Project: SPRING: Primary Prevention of Stroke in Children with SCD in Sub-Saharan Africa II
Role: Neurologist, Member of Data Safety monitoring Board
Dates: 2015 - 2021

Grantor: NIH/NINDS – R56
Title of Project: VIPS2: Vascular Effects of Infection in Pediatric Stroke II
Role: Site Principal Investigator
Dates: 2016 – 2018

Grantor: NIH/NINDS – R01
Title of Project: VIPS2: Vascular Effects of Infection in Pediatric Stroke II
Role: Site Principal Investigator
Dates: 2017 - 2018

Grantor: Pediatric Epilepsy Research Foundation
Title of Project: SIPSII: Seizures in Pediatric Stroke
Role: Site Principal Investigator
Dates: 2015 – 2019

Grantor: Syncardia, Inc.
Title of Project: Ventricular Assist Device Trial
Role: Site Neurologist
Dates: 2016 - 2018

Patricia Evans

Grantor: Fragile X Foundation
Title of Project: Fragile X Clinical and Research Consortium Registry and Database Study
Role: Site PI
Dates: 2012-present

Grantor: Internal
Title of Project: Study: Center for Autism and Developmental Disabilities Phenotyping Database and Repository
Role: Co-PI
Dates: 2016 – present
Grantor: internal
Title of Project: Study: Repository for the study of the molecular basis of rare and undiagnosed encephalopathies
Role: Co-PI
Dates: 2010 –present

Grantor: Internal
Title of Project: Study: Prevalence of Neurocognitive Impairment in Dystrophinopathies
Role: Co-PI
Dates: 2010 –present

Grantor: Internal
Title of Project: Neurodevelopmental Outcomes in Children after Extra-corporeal Membrane Oxygenation therapy
Role: Co-PI
Dates: 2013 –present

Grantor: Internal
Title of Project: Studies of human tissue function in health and disease using induced-pluripotent stem cells
Role: Co-PI
Dates: 2015 -present

Steven Gray

Contractor: Angelman Syndrome Foundation
Title of Project: Angelman Syndrome Gene Therapy
Role: Principle Investigator
Dates: 9/1/17-8/31/19

Contractor: Mila’s Miracle Foundation to Stop Batten
Title of Project: CLN7 Gene Therapy
Role: Principle Investigator
Dates: 5/1/17-4/30/19

Contractor: University of Pennsylvania/International Advocate for Glycoprotein Storage Diseases
Title of Project: Evaluation of adeno-associated virus gene therapy in the feline model of mucolipidosis II
Role: Principle Investigator of the subcontract
Dates: 12/15/16-12/14/18

Contractor: Pitt-Hopkins Research Foundation
Title of Project: Gene therapy for Pitt-Hopkins Syndrome
Role: co-Principle Investigator
Dates: 12/1/16-11/30/18

Contractor: Abeona Therapeutics
Title of Project: Completion of CLN1 Efficacy Studies and Novel CNS Capsid Evaluations
Role: Principle Investigator
Dates: 10/1/16 – 9/30/18

Contractor: NIH/NINDS
Title of Project: Directed Evolution of Novel AAV Capsids for Global CNS Gene Delivery in Rodents and Primates
Role: Principle Investigator
Dates: 9/30/16 – 7/31/21
Contractor: NIH/NINDS  
**Title of Project:** Giant Axonal Neuropathy Gene Therapy  
**Role:** Principle Investigator  
**Dates:** 4/01/14 – 3/31/19

Contractor: U. Penn/NIH/NINDS (subcontract)  
**Title of Project:** Combination Therapy, Biomarkers, and Imaging in Canine Krabbe Disease  
**Role:** Principle Investigator of the subcontract  
**Dates:** 8/01/16 – 7/31/21

Contractor: Rett Syndrome Research Trust  
**Title of Project:** A gene therapy consortium to develop and evaluate gene therapy approaches in Rett syndrome  
**Role:** co-Principle Investigator (1 of 4)  
**Dates:** 1/15/14 - 1/14/20

Contractor: NIH/NINDS  
**Title of Project:** Development of Intravenous AAV Vectors for Intractable Epilepsy  
**Role:** Principle Investigator  
**Dates:** 9/15/13 – 9/14/18

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**Sailaja Golla**

Grantor: Novartis  
**Title of Project:** Biomarkers associated with Phelan-McDermid (22q13) Syndrome  
**Role:** Co-PI  
**Dates:** 2012-2018

Grantor: NINDS via Neuronext  
**Title of Project:** Study: Effects of AFQ056 on Language Learning in Young Children with Fragile X Syndrome (FXS)  
**Role:** Site PI  
**Dates:** 2017 – 2020

Grantor: RDCRN- Rare Disease Clinical Research Network  
**Title of Project:** Mapping the Genotype, Phenotype, and Natural History of Phelan McDermid Syndrome  
**Role:** Co-PI  
**Dates:** 2015 – 2017

Grantor: Fragile X Foundation  
**Title of Project:** Fragile X Clinical and Research Consortium Registry and Database Study  
**Role:** Co-PI  
**Dates:** 2012-present

Grantor: Internal  
**Title of Project:** Study: Center for Autism and Developmental Disabilities Phenotyping Database and Repository  
**Role:** Co-PI  
**Dates:** 2016 – present

Grantor: unfunded  
**Title of Project:** Neurodevelopmental Outcomes in Children after Extra-corporeal Membrane Oxygenation therapy  
**Role:** PI  
**Dates:** 2013 – present
Susan Iannaccone

Contractor: NIH, Wellstone Muscular Dystrophy Center
Role: Associate Director and co-chair of Administrative Core
Dates: 2015-2020

Grantor: NIH, 1U10 NS 077323-01
Title of Project: Network of Excellence in Neuroscience Clinical Trial (NeuroNEXT)
Role: Co-Investigator
Dates: 2011 – 2018

Contractor: PTC Therapeutics
Title of Project: Extension Study of Ataluren in Subjects with Nonsense-Mutation-Mediated Duchenne and Becker Muscular Dystrophy
Role: Site Principal Investigator
Dates: 2011 - Present

Contractor: Biogen
Title of Project: EAP to provide Nusinersen (SPINRAZA) to patients with infantile-onset SMA
Role: Site Principle Investigator
Dates: 2016-2017

Contractor: Sarepta
Title of Project: Essence: double-blind, placebo-controlled, multi-center study with an open-label extension to evaluate the efficacy and safety of SRP-4045 and SRP-4053 in patients with DMD
Role: Site Principle Investigator
Dates: 2015 - Present

Contractor: AveXis
Title of Project: AVXS-101 for participants with SMA, 2017 - present
Role: Site Principle Investigator
Dates: 2017 - Present

Contractor: Fibrogen
Title of Project: FG-3019, phase 2 in DMD
Role: Co-Principal Investigator
Dates: 2017 - Present

Contractor: Regeneron
Title of Project: Vamorolone Phase 2 in DMD
Role: Co-Principal Investigator
Dates: 2017 - Present

Contractor: Biogen
Title of Project: SHINE, CS II, open label extension for Nusinersen in SMA
Role: Site Co-Principal Investigator
Dates: 2017 - Present

Berge Minassian

Contractor: National Institutes of Health
Title of Project: Lafora Epilepsy – Basic Mechanisms to therapy
Role: Principal Investigator
Dates: 2016-2021
**Contractor:** The Ontario Brain Institute  
**Title of Project:** New approaches to intractable epilepsy: Phase II of The Epilepsy Discovery Project.  
**Role:** Principal Investigator  
**Dates:** 2014-2019

**Contractor:** The Ontario Brain Institute  
**Title of Project:** EpLink: Phase II of The Epilepsy Discovery Project Genetic Database.  
**Role:** Principal Investigator  
**Dates:** 2014-2019

### Tonia Sabo

**Contractor:** Texas Institute of Brain Injury and Repair  
**Title of Project:** Texas Institute for Brain Injury and Repair (TIBIR) North Texas Sports Concussion Network (CON-TEX) Prospective Registry  
**Role:** Co Investigator, Site PI, Children’s Medical Center  
**Dates:** 2015 – present

**Contractor:** Texas Institute of Brain Injury and Repair  
**Title of Project:** Association between Brain Blood Flow Regulation, Cognition and Balance in Concussion  
**Role:** Co Investigator  
**Dates:** 2016 – present

**Contractor:** Unfunded Headache Division Research  
**Title of Project:** Texas Sports Concussion Network Registry (CON-TEX-2)  
**Role:** Co Investigator, Site PI, Children’s Medical Center  
**Dates:** 2016 – present

**Contractor:** Unfunded UTSW Medical Student Initiated Research  
**Title of Project:** A study of the optic nerve sheath diameter to predict Intracranial Hypertension in Pediatric Brain Injured Patients  
**Role:** Co Investigator, Co-faculty sponsor  
**Dates:** 2016– present

**Contractor:** Texas Institute of Brain Injury and Repair  
**Title of Project:** Association between Brain Blood Flow Regulation, Cognition and Balance in Concussion  
**Role:** Co Investigator  
**Dates:** 2016 – present

**Contractor:** Impax Laboratories and PRA Health Sciences  
**Title of Project:** A Multicenter, Randomized, Double-blind, Placebo-controlled, Crossover Study to Evaluate the Efficacy and Safety of Zolmitriptan Nasal Spray for the Treatment of Acute Migraine in Subjects Ages 6 to 11 Years, with an Open-Label Extension  
**Dates:** 2017 – present

### Rana Said

**Contractor:** Insys  
**Title of Project:** A multicenter, randomized, double-blind, placebo-controlled, interventional study to assess the safety and efficacy of pharmaceutical Cannabidiol Oral Solution as an adjunctive therapy for treatment of subjects with inadequately controlled Dravet Syndrome (INS011-14-025)  
**Role:** Principle Investigator  
**Dates:** 2014 – present
**Contractor:** Insys  
**Title of Project:** A multicenter, randomized, double-blind, placebo-controlled, interventional study to assess the safety and efficacy of pharmaceutical Cannabidiol Oral Solution as an adjunctive therapy for treatment of subjects with inadequately controlled Lennox-Gastaut Syndrome (INS011-14-024)  
**Role:** Principle Investigator  
**Dates:** 2014 – present

**Deepta Sirsi**

**Contractor:** Quintiles  
**Title of Project:** Randomized, Double-Blind, Placebo Controlled, Parallel-Group Study of Clobazam as Adjunctive Therapy in Pediatric Pts 1-16 yrs with Dravet Syndrome  
**Role:** Principle Investigator  
**Dates:** 2015 - 2017

**Contractor:** Quintiles  
**Title of Project:** Open Label, Long Term, Flexible Dose Study of Clobazam as Adjunctive Therapy in Pediatric Pts 1-16 yrs with Dravet Syndrome  
**Role:** Principle Investigator  
**Dates:** 2015 – 2020

**Grantor:** UCB Pharma  
**Title of Project:** A Multicenter, Double-blind, Randomized, Placebo-controlled, Parallel-group Study to Investigate the Efficacy and Safety of Lacosamide as Adjunctive Therapy in Subjects with Epilepsy greater or equal to 1 month to less than 4 years of Age with Partial-onset Seizures  
**Role:** Site Co-Investigator  
**Dates:** 2015 – present

**Grantor:** NIH  
**Title of project:** Study: Dietary treatment of Glucose Transporter Type 1 Deficiency (G1D).  
**Role:** Co-Investigator  
**Dates:** 2017 – present

**Grantor:** NIH  
**Title of project:** Study: Treatment development of triheptanoin (C7) for Glucose transporter type I deficiency (G1D): A Phase I Maximum Tolerable Dose Trial  
**Role:** Co-Investigator  
**Dates:** 2016 – present

**Grantor:** unfunded academic, fellow research project  
**Title of project:** Etiologies and Outcomes of New Onset Refractory Status Epilepticus (NORSE) in A Tertiary Care Pediatric Population  
**Role:** Co-Investigator  
**Dates:** 2016 – present

**Jennifer Thomas**

**Contractor:** NINDS  
**Title of Project:** HEAL Trial: Randomized, double-blinded, multi-center, placebo-controlled trial designed to test the efficacy of high dose erythropoietin for neuroprotection (Epo) in term infants with hypoxic-ischemic encephalopathy (HIE). [NINDS 1U01NS092764]  
**Role:** Site Co-principal investigator  
**Dates:** 2017-2022
Jeff Waugh

**Contractor:** American Academy of Neurology, Career Development Award
**Title of Project:** Evaluating a potential mechanism for dystonia: the role of impaired inhibition
**Role:** Principle Investigator
**Dates:** 2018 – 2020

**Contractor:** Collaborative Center for X-linked Dystonia Parkinsonism
**Title of Project:** Evaluating functional network derangements in XDP using PET imaging
**Role:** Co-Investigator
**Dates:** 2018 – 2020

### Peer-Reviewed Publications


11. Dowling MM, Kirkham FJ. **Stroke in sickle cell anaemia is more than stenosis and thrombosis: the role of anaemia and hyperemia in ischaemia.** *Br J Haematol* 2017;176:151-3. PMID: 27858986


17. Fox CK, Mackay MT, Dowling MM, et al. **Prolonged or recurrent acute seizures after pediatric arterial ischemic stroke are associated with increasing epilepsy risk.** *Dev Med Child Neurol* 2017;59:38-44. PMID: 2742813


41. Rollins N, Dowling M. Response by Rollins and Dowling to Letter Regarding Article, "Dynamic Arterial Compression in Pediatric Vertebral Arterial Dissection". Stroke 2017;48:e228. PMID: 28679851


**Book Sections**


