



2022 LEAD Capstone Poster Session

Improving Follow-Up Access in the High-Risk Ambulatory Clinic
Patient Population: A Comprehensive Epilepsy Center Pilot
Program

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Abstract

- 1 in 26 people will develop epilepsy in their lifetime
- There are 3.4 million people living with epilepsy in the US
- SUDEP or *sudden unexpected death in epilepsy* occurs ~ 1 in 1,000 of PWE (people living with epilepsy)
- 30% of PWE are not well controlled on antiseizure medications (ASM) and are deemed intractable or having DRE (drug resistant epilepsy)
- We have over 30 FDA approved ASM on the market and maintenance entails not only ensuring seizure control, but monitoring/avoiding toxicity
- With two adult EMUs (epilepsy monitoring units), we are one of the top 3 busiest level 4 NAEC Epilepsy Surgical Programs in the Nation
- Delays in care, late referrals, and lack of access to care have negative psychosocial, SES, mood, cognitive, and memory outcomes
- Morbidity is frequent and at its most devastating, suboptimal care leads to higher rates of mortality than quoted above
- Our high patient volumes, inpatient/on-call duties, and unpredictable declines in clinical status frequently pose barriers to prompt care





Objectives

- **Strengthen community relations** with neurologists and other healthcare providers in the DFW community to obtain a stronger referral base. As it stands, many individuals do not refer to us because it is notoriously difficult to get epilepsy patients into our clinic and there is also concern that they will “lose” patients to us. The reality is we are a high-volume surgical and specialty multidisciplinary program which would benefit from a structured pipeline to evaluate patients/establish management and potentially be able to serve as consultants to other neurologists seeing these patients thereafter
- Establish a “**preferred neurology referral network**” in the community to refer epilepsy patients. After 2 years post-interventions/establishing seizure control, patients may feel confident continuing care with our community partners or at least alternating periodically with us. This would alleviate backlog and ensure broader reach.
- Creation of specific “**follow-up/urgent clinic sessions**” so our care team may see continuity patients who need to be seen urgently or for programming of neuromodulation devices. These will be blocked or *frozen* slots to be used as needed (need to be approved by physician)
- Continuation or Expansion of **Telehealth** component for concierge-like service, consultations, and follow up clinics when patients have barriers to care (distance, no transportation, seizure patients cannot drive)
- Full integration of our **NP partners** to alternate visits and provide continuity of care, especially for medications, lab results follow-up, neuromodulation programming





Background Information

- 3.4 million people live with epilepsy in the US
- Delays or lack of access to subspecialty care are highly detrimental to patients and their family/caregivers (“caregiver burden”)
- Poorly controlled seizures lead to decline in function and add to unnecessary healthcare costs (ED visits, hospitalizations, need for care, others)
- Functional impairments include decline in mood, anxiety, cognition, memory impairment, job loss, loss of income, loss of independence, low SES
- It is critical to have the 30% of people with DRE evaluated early in disease course to avoid intractability, comorbidities, impairment, death (SUDEP)
- Numerous DRE cases are not referred to epilepsy clinic by community providers because of prolonged wait times and perceived inability to “get them in” to see us; there is also concern they will lose patients to UTSW



Brain
 Disney star’s death shows it’s time to end the epilepsy stigma
 Sasha Alick Lindstrom, M.D.

| Data Table | | |
|--------------|-----------------------------|-------------------|
| Location | No. of cases (All Age... ▾) | 95% CI (all ages) |
| ● California | 427700 | (372,600-482,900) |
| ● Texas | 292900 | (255,400-330,300) |
| ● Florida | 223900 | (194,100-253,800) |
| ● New York | 215200 | (186,300-244,000) |
| ● Illinois | 136600 | (117,900-155,400) |



Background Information

- Many of our patients travel from **rural communities** within state, where they have no access to care, especially a NAEC level 4 center like us (highest ranking)
- ***Our patient population cannot drive!!*** It is against TX state law, as they pose a danger to themselves and others (until at least 3 months seizure free)
- For these people, telehealth accommodations unrolled during the COVID-19 pandemic have been highly positive
- It is exciting that the Advancing Telehealth Beyond COVID-19 Act of 2021 allows for continued access, remote care, and other emerging health care technologies through December 31, 2024
- This is beneficial to our patients and helps improve access
- It is yet to be determined if telehealth coverage will continue after 2024





Project Plan

- Each physician in the Epilepsy Division identifies a certain day of the week when not on inpatient service to open special recurring **follow-up/urgent clinic sessions** which are blocked/frozen
- These follow-up slots are only to be authorized by MDs and to be used as needed (they are beyond the # of our committed clinic sessions with dept)
- Proper session use would be for: neuromodulation programming, urgent patients with uncontrolled seizures/ED follow ups
- Our NP colleagues will be alternating with us in tandem for patient care and discussing challenging cases (ex: every 3-6 months; case specific)
- As Epilepsy Foundation PAB board member, I would reach out to community groups and educate/reinforce the need for higher level of care referral once patients remain intractable despite two ASM trials or for atypical feature, especially frequent convulsions
- Symbiotic approach: Community neurologists refer to us/request second opinions, we evaluate patients promptly and perform surgery/neuromodulation, as needed. Then can guarantee that we would be able to offer to send patients back to our **preferred neurology network**
- Intervention measures: pre/post assessment of wait times for clinic access, patient satisfaction scores, measuring provider satisfaction, QOLIE (quality of life in epilepsy) inventory; door or diagnosis to OR times pre/post program implementation (2 years post commencing project)





Project Plan

- Downstream revenue: (Radiology) MEG, fMRI, MR-PET, CT-PET, 3T brain MRI, Neuropsychology, Psychiatry, Neurosurgery are all part of our individual patient evaluations
- This improves patient care, propels OBI reputation and ensures mutual success, including increased revenue
- Analyzing data will hopefully allow for expansion to other similar statewide hospital systems
- Future Goals: creation of **TEN** (Texas Epilepsy Network) across the UT system with NAEC level 4 centers. This expands access, even for smaller rural communities between us (in 5+ years)
- Data/Research and comparison to current MO/wait times



Application of What You Learned at LEAD

- Recognize key stakeholders and evaluate their engagement
- Identify and appoint a diverse team of invested key players (leveraging my knowledge of potential DISC profiles) and complimentary styles
- Maximize shared wealth of resources in the institution to advanced clinical and research opportunities (i.e., personnel, technology, capital/funds)
- Effectively listen and communicate in a clear manner, taking audience into account
- Devise a pragmatic plan with clear goals and deliverables
- Create timeline and pre/post intervention qualitative and quantitative measures to assess intervention outcomes
- Anticipate potential challenges and preemptively conceive practical solutions
- Capitalize on my leadership qualities, including adaptability/flexibility, resilience, high emotional and social intelligence



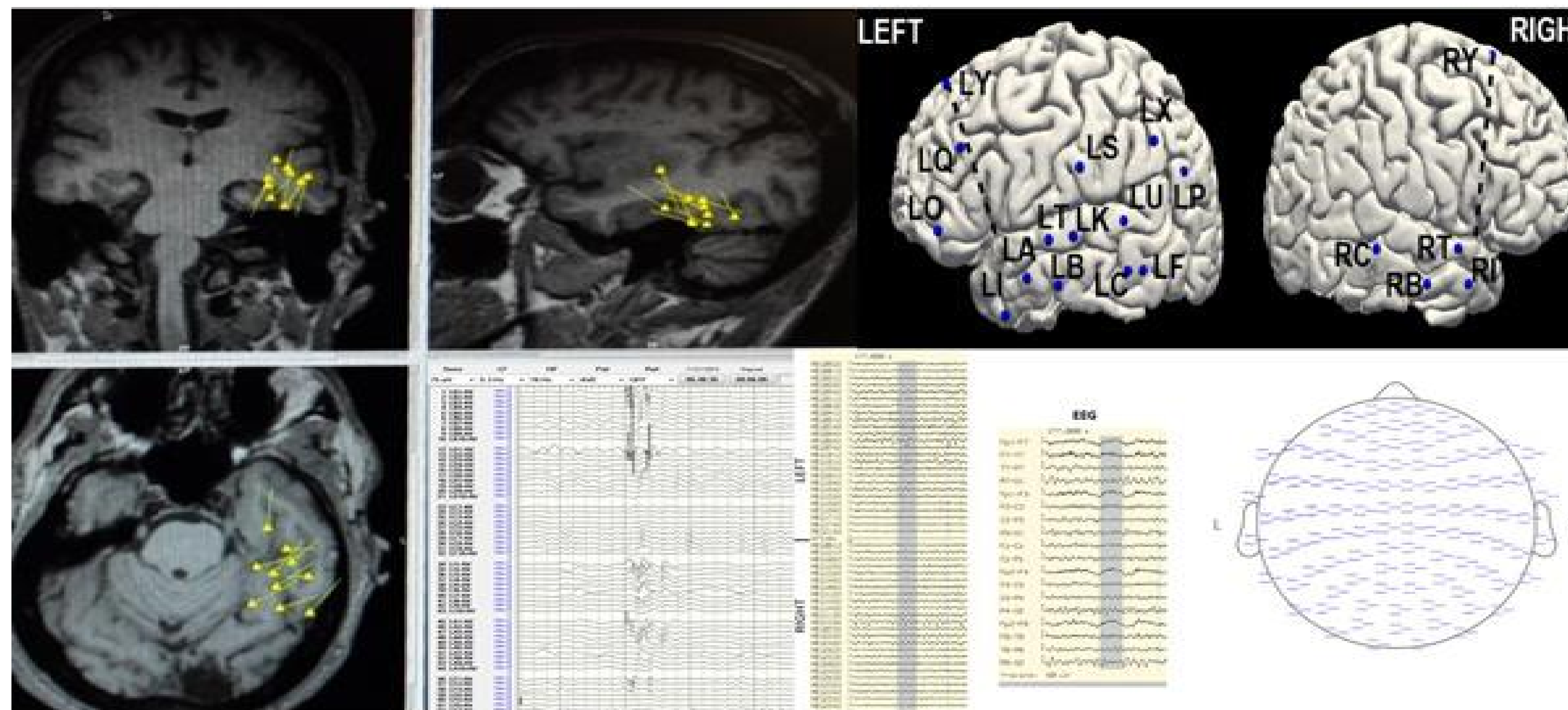
Proposed Budget

- Addition of 2-3 Epilepsy MD/DO/MBBS over next 1-2 years: \$230k/pp
- Hiring of another NP this year: \$90-\$100k/pp
- Telehealth equipment/services: Already implemented/\$0 (also frees up clinic space for use)
- Creation of blocked follow up slots and collaboration with clinic staff/schedulers to ensure training and most efficient scheduling/prioritization: 5% FTE per physician



Innovation and Significance

- National and International neurological societies are unrolling programs to improve access to specialized epilepsy care
- Possible mitigation of evaluation/surgical delays (“Time is Brain!”)
- Promoting the knowledge within our DFW referral community that people with uncontrolled seizures post two ASM/medication trials will achieve the best outcomes if promptly referred to a NAEC level 4 epilepsy center
- It would increase our referrals and lead to a decrease in unnecessary healthcare spending by our patient population
- It may serve as a model for other systems to potentially emulate





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