



2021 LEAD Capstone Presentation

Access Granted:

Building a Neuromuscular Pulmonology and Home-Based Ventilation Clinic at Parkland Hospital

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Background

Show me the way to go home!

- Miss Haley B.
 - 17 year old female with spastic functional quadriplegia, cerebral palsy, chronic seizure disorder s/p tracheostomy in July 2019 and now on chronic continuous ventilation. Trach changed at private ENT out of pocket by parents. Saw a pulmonologist once but lungs were clear and no changes made to ventilator.
- Mr. Bobby T.
 - 18 year old man with congenital myopathy, provided for by single mother. Wheelchair dependent on nocturnal NIV and sip ventilation while followed at Childrens q3-4 months for nutrition, prosthetics, ventilation needs. Had no provider lined up for transition, limited insurance coverage. Was admitted 3 times in past year for pneumonia, s/p tracheostomy. Visits ER for tracheostomy exchange. No ventilator adjustment since tracheostomy.
- Mr. Jesus R.
 - 56 year old man with spinal ALS. Has progressed over last 6 months, was referred to pulmonary by neurologist who explained early initiation of noninvasive ventilation can improve life expectancy and quality of life. Was seen in general pulmonary clinic 3 months later. Was admitted to hospital with pneumonia and respiratory failure while on waiting list for sleep study.



Background

- UT Southwestern is a premiere referral center for patients with neuromuscular disorders
- Unique neuromuscular pulmonology access

UT Southwestern
Clinical Center for Sleep and Breathing Disorders

Sleep & Breathing Disorders Center

Sleep Better
Breathe Easier



Population needs



- Neuromuscular disease with chronic ventilatory support needs
 - most common diagnoses: ALS, Muscular dystrophy, CIDP,
 - 14 patients currently followed in general pulmonary
 - 12 patients as of January 2021 awaiting referral with 6 month wait
 - no consistent pulmonary service provided to patients with SCI, diaphragm paralysis, or CP requiring ventilation at this time



- approximately 35 of 142 patients over the age of 16 with a diagnosis of congenital myopathy or muscular dystrophy with tracheostomy + invasive ventilation or noninvasive ventilation are preparing for transition to adult healthcare services
- 32 patients over the age of 18 requiring chronic invasive ventilation for primary neurologic etiology awaiting transition



Neuromuscular and Chronic Ventilation Clinic

Goals

1. Provide specialized care with continuity to patients of Parkland Hospital with neuromuscular respiratory failure.
2. Provide a access to multidisciplinary care to patients with tracheostomy and chronic ventilation due to primary neuromuscular / neurologic etiology
3. Provide a transition clinic for patients requiring chronic ventilation previously cared for at Childrens Health



Neuromuscular and Chronic Ventilation Clinic

Year 1

First Friday Clinics

Location- ENT clinic

Services in clinic:

- tracheostomy care
- ventilator education (RT)
- PFTs (RT)
- DME coordination
- sleep study coordination
- ventilation initiation
- preventative care

18 months

Nutrition consultation services

PEG changes

speech pathology consultation

24 months

Reassess population needs/demand

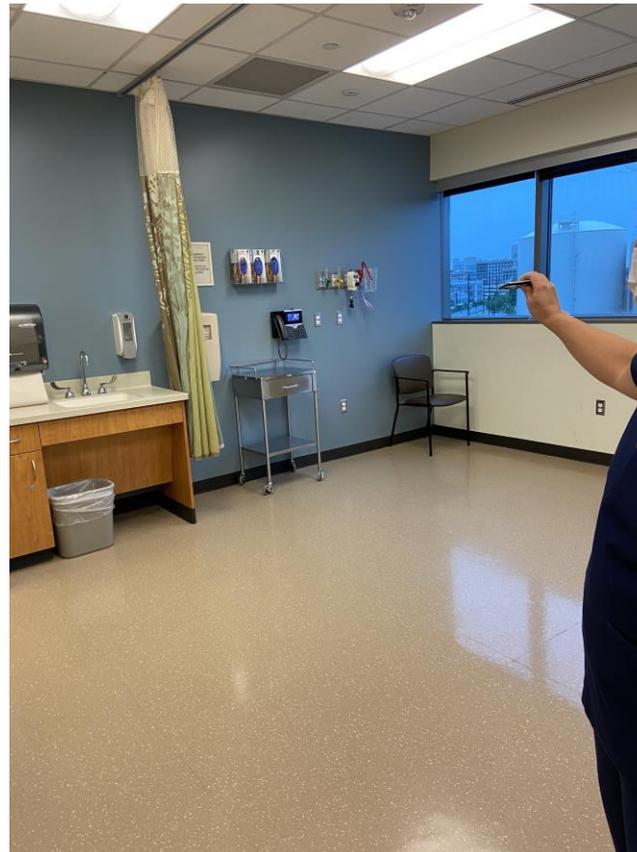
Palliative care integration

PM&R integration

Rotation option for med/peds residents and pulmonary fellows



Proposed Location





Proposed Budget

- Utilizing ENT space not used during proposed clinic day due to education series: No additional cost for 5 hours of clinic
 - provides: clinic manager, nursing / MAs, stocked tracheostomy closet with backup supplies/equipment for tracheostomy care, social work.
- Respiratory therapy support: currently supported by Edward Best, Dr. Rochelle Ruggiero based on Parkland population needs.
 - Funding dedicated RT to be present for clinic entirety to be assessed if clinic remains full at 12 months.
 - Likely to be incorporated into rotation for RT students with instructor
 - spirometry equipment available through the Parkland RT department currently not in use and capable of doing spirometry at bedside on non-tracheotomized patients
- Interval follow up may require up to 0.1 FTE coverage for primary neuromuscular pulmonary provider. Additional med/peds pulmonologist available for coverage.



Innovation and Significance

- This clinic meets a disparity in healthcare by providing access to otherwise unavailable life-sustaining treatment.
- This particularly challenging patient population is best managed by sub-specialty providers in a multidisciplinary setting.
- Utilizing resources already established and reorganizing a team to meet these needs
- Long-term goals:
 - improve quality of life, morbidity and mortality for neuromuscular patients¹
 - decrease EM service utilization by this chronic ventilation population
 - provide unique education experience to pulmonary fellows, IM/pediatric residents, RT students
 - develop a unique model for a multidisciplinary clinic at Parkland Hospital



Application of what you learned at LEAD

- Understanding and leveraging DISC profiles to effectively communicate with diverse stakeholders
- Developing an effective situational leadership style
- Identifying concrete, discrete aspects of a complex problem
- Strategic planning to accomplish a high-value project
- Managing time and resources in a balanced commitment to the needs of the community, the organization, and what is important to me and my career personally.



References

Bertella E, Banfi P, Paneroni M, et al. Early initiation of night-time NIV in an outpatient setting: a randomized non-inferiority study in ALS patients. *European Journal of Physical and Rehabilitation Medicine*. 2017 Dec;53(6):892-899. DOI: 10.23736/s1973-9087.17.04511-7. PMID: 28382811.

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Onofri, A., Tan, HL., Cherchi, C. *et al.* Transition to adult care in young people with neuromuscular disease on non-invasive ventilation. *Ital J Pediatr* 45, 90 (2019). <https://doi.org/10.1186/s13052-019-0677-z>