

Two Sides of a Coin: My Journey with ALS

By: Mike Ibarra, MD



Disclosures

- Pertinent to this talk:
 - ALS TDI
 - ROON
 - I AM ALS
 - ALS Association
- Not pertinent to this talk:
 - UTSW Brain Institute

Who is this for?

- Patients
- Medical
- Caregivers
- Advocates
- Everyone and Anyone

Outline

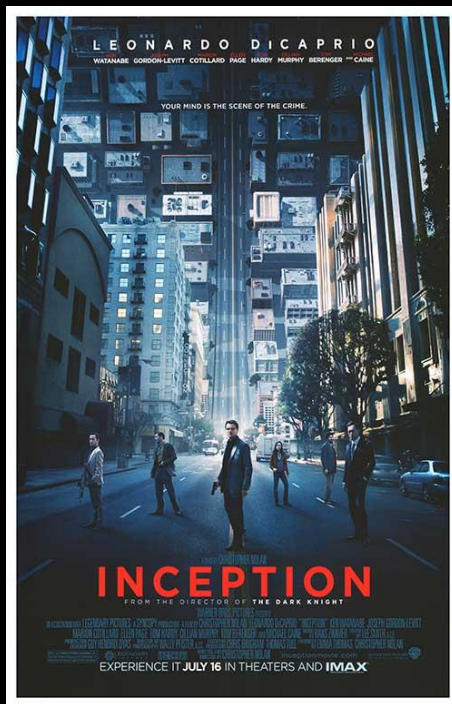
- Introduction
- The Beginning
- Diagnostic Journey
- The Struggles
- Surviving the Experience - Strength
- ALS Info
- The Patient
- The Physician
- The Coin
- Endeavors
- Faces of ALS

Introduction

- Mike Ibarra
- Texas boy

- But... who am I?





Introduction

- Bounced around Texas for school
- University: Texas Tech
- Med School : UTHSCSA
- Neuro Residency and Sleep Fellowship: URMCC
- Sleep Medicine Attending: UTSW



UT Southwestern
Medical Center



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The Beginning

- Changes
- Medical School
- Residency
- Excuses
- Fear

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Diagnostic Journey

- November 2021: First neuro appointment
 - Surprises... reflexes
 - EMG... Oh boy
- Devastated
- November – December: More tests than I care to remember
 - Autoimmune, CT, MRI, LP (2nd one... ugh)... plethora of tests
 - Paradoxical disappointment in tests
 - Confusing desperation

Diagnostic Journey

- Suspension of belief – Just poor timing
 - Sleep interviews
 - Boards
 - Travel
- Alas, all good things come to an end...

Diagnostic Journey – The Day of Reckoning

- March 2023 – happy birthday
- the EMG of truth

Compared to the previous study in November 2021, the severity of denervation and reinnervation on EMG testing has progressed in all body segments tested. In addition, right fibular, tibial, and ulnar motor response amplitudes have significantly declined.

Overall, these findings support the presence of progressive motor neuron disease. There is also incidental evidence of a mild right ulnar neuropathy at the elbow.

Diagnostic Journey – The Day of Reckoning

- World spiraling before me
- Keeping myself grounded
- Information overload

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The Struggles

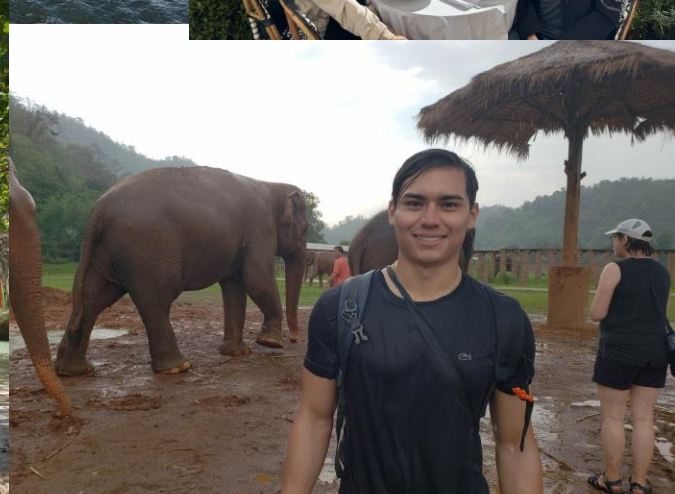
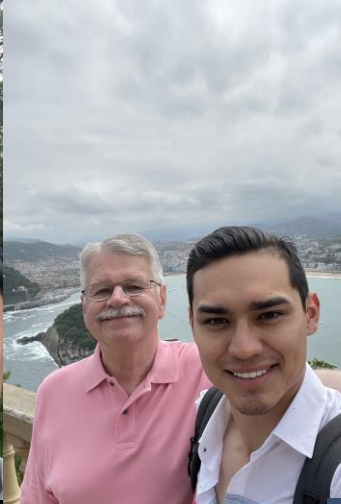
- Flurry of emotions
- Next steps?
- How to break the news? Family? Friends? Work? Relationship?
- Loss of Identity

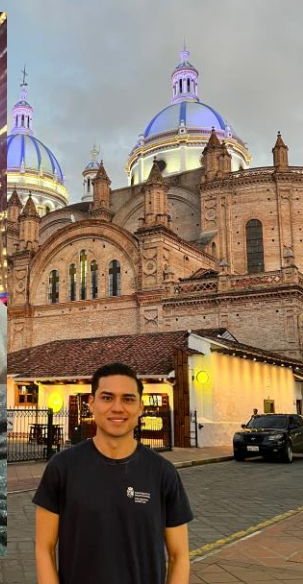
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Strength







Strength



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ALS Info

- Amyotrophic Lateral Sclerosis / Lou Gehrig's Disease
- UMN + LMN
- 90% sporadic, 5-10% familial
- Onset: 40-70 years, average age is 55 years
- Life expectancy: 2-5 years
- Annual incidence: 2 per 100,000
- Prevalence: ~7 per 100,000
- Around 30,000 people in the US



ALS Info – Lesser Known

- ~10% of patients less 45 years old
- Veterans are 2x more likely
- Cases expected to increase by up to 70% over the next 25 years
- Ethnic groups: more likely in Caucasians and Non-Hispanics
- Riluzole – 1995
- Radicava (Enderavone) - 2017
- ~~Relyvrio (sodium phenylbutyrate and taurursodiol) – 2022~~
- Tofersen (Qalsody) 2023 for SOD1 variant

Heartbreak

- April 4th, 2024

Following the news on March 8 that the PHOENIX trial did not meet its primary or secondary endpoints, this morning we announced that Amylyx has started a process with the FDA and Health Canada to voluntarily discontinue the marketing authorizations for **RELYVRIO®/ALBRIOZA™** and remove the product from the market in the U.S. and Canada. **RELYVRIO®/ALBRIOZA** will no longer be available for new patients as of today. People currently on therapy in the U.S. and Canada who, in consultation with their physician, wish to continue can be transitioned to a free drug program.

BrainStorm's ALS cell therapy resoundingly rejected by FDA advisers

By Max Bayer · Sep 27, 2023 6:04pm

BrainStorm Cell Therapeutics

amyotrophic lateral sclerosis

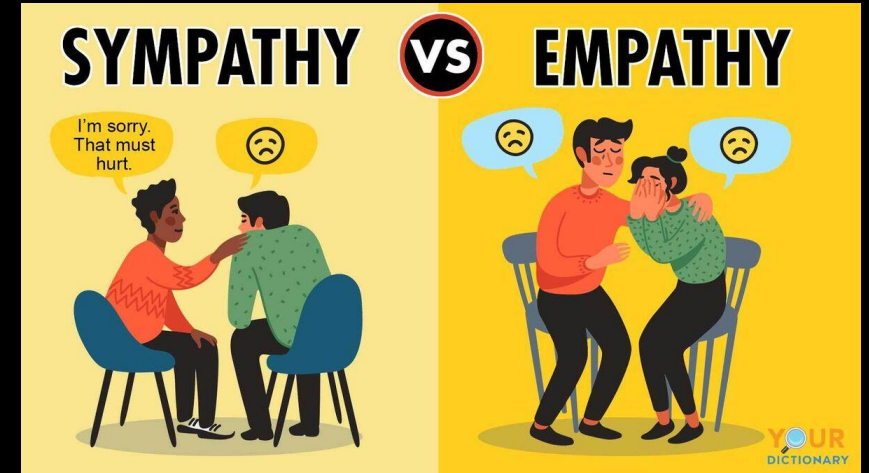
advisory committee

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The Patient

- Sympathy vs Empathy
- Loss of identity with a neurological disease
- Isolation
- Coping with support and life goals



The Patient

- Drinking through a water hose
- Time commitment
- Emotional roller-coaster
- Rejection

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Physician

- Neurologist
- Sleep Doctor



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The Coin – What I Learned

- What can we do better?
- What has my experience revealed?
- Bridging gaps

The Coin – The Model In an Ideal World



The Coin – ALS Association Chapter Liaison



The Coin – ALS Association Chapter Liaison



The Coin – PT/OT



The Coin - Respiratory



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The Coin

- Mental Health Professional
- Registered Dietician
- SLP
- Nursing Professional
- Social Worker



The Coin

- Expectations for follow-up
- Insurance
- Checklist?



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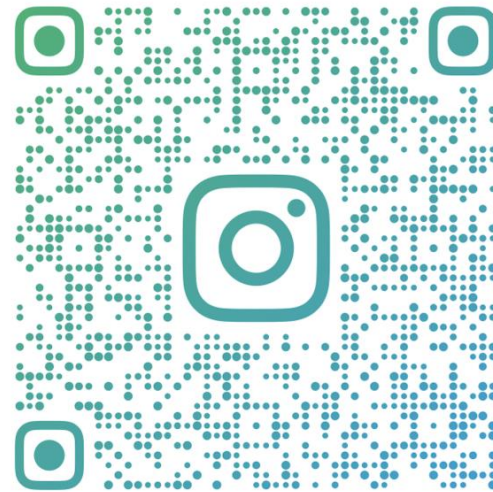
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Current and Future Endeavors

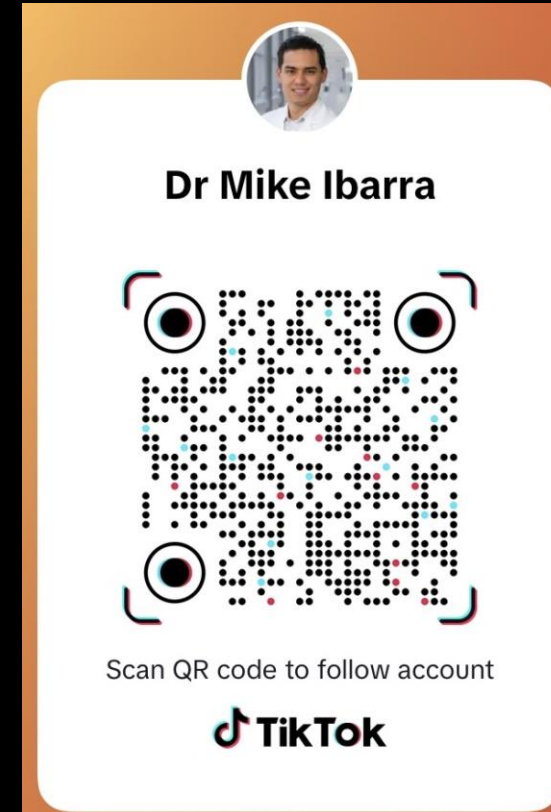
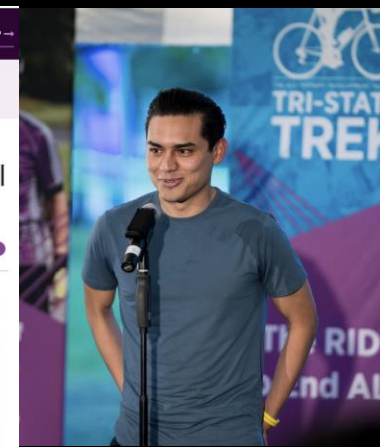
- Advocacy
- Speaking out about bills – national level
- Pushing for more trials
- Providing my expertise
- Integrating ALS Patients into clinic
- Social Media



Instagram



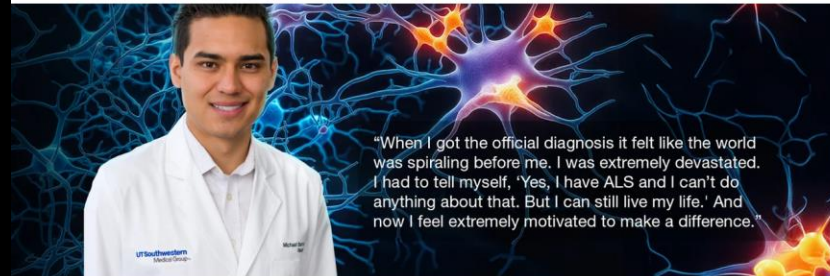
@MIIBARRA92



A young neurologist diagnosed with ALS is inspiring a call to action

September 25, 2024

*Brain;
Patient Stories*



Michael Ibarra, M.D., a neurologist at UT Southwestern, was diagnosed with ALS at age 30. Amyotrophic lateral sclerosis is a disorder that affects motor neurons and gradually erodes the brain's ability to control voluntary and breathing muscles.

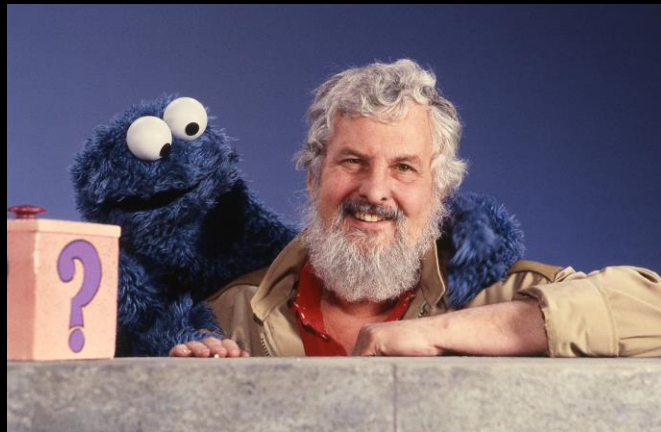
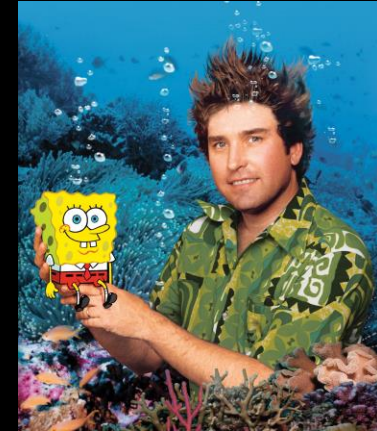
By [Renee Yan](#)

Ever since he was a boy, [Michael Ibarra](#) was fascinated by the human brain – its complexities, its secrets.

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Faces of ALS



Faces of ALS – Many More



Faces of ALS

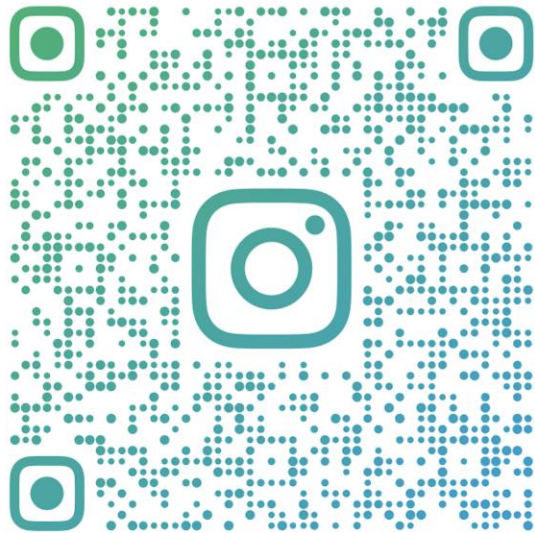


10 Year Anniversary – Ice Bucket Challenge



Questions?

Instagram



@MIIBARRA92



Dr Mike Ibarra



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 TikTok