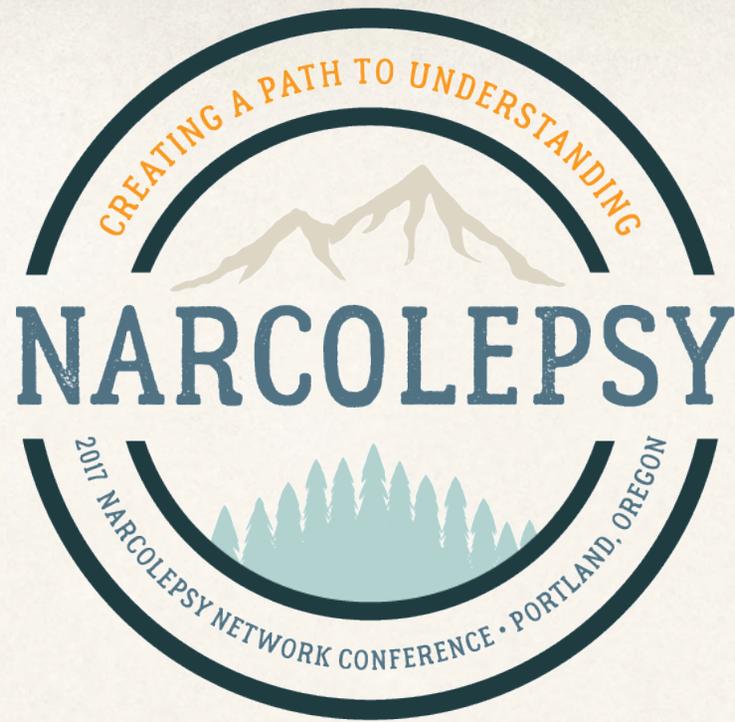


Creating an Elevator Speech

Dean Suhr, President and co-Founder
MLD Foundation

October 28th, 2017



What's the Conference Theme?

What is Narcolepsy?



narcolepsy

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Narcolepsy Symptoms, Treatment & Remedies - National Sleep ...
<https://sleepfoundation.org/sleep-disorders-problems/narcolepsy-and-sleep> **Narcolepsy** is a sleep disorder characterized by excessive sleepiness, sleep paralysis, hallucinations, and in some cases episodes of cataplexy (partial or total loss of muscle control, often triggered by a strong emotion such as laughter). ... For example, cataplexy is the muscle ...
What is Narcolepsy? Are there Different Types of ... Medication and Treatment

Narcolepsy - Wikipedia
<https://en.wikipedia.org/wiki/Narcolepsy> **Narcolepsy** is a long-term neurological disorder that involves a decreased ability to regulate sleep-wake cycles. Symptoms include periods of excessive daytime ...
Usual onset: Childhood **Medication:** Modafinil, sodium oxybate, methyl...
Treatment: Regular short naps, sleep hygiene **Symptoms:** Excessive daytime sleepiness for s...

Narcolepsy Fact Sheet | National Institute of Neurological Disorders ...
<https://www.ninds.nih.gov/Disorders/Patient-Caregiver.../Fact.../Narcolepsy-Fact-Sheet> **Narcolepsy** is a chronic neurological disorder that affects the brain's ability to control sleep-wake cycles. People with narcolepsy usually feel rested after waking, ...
What is narcolepsy? What causes narcolepsy? How is narcolepsy diagnosed?

Narcolepsy - Mayo Clinic
www.mayoclinic.org/diseases-conditions/narcolepsy/basics/definition/con-20027429 **Narcolepsy** is a chronic sleep disorder characterized by overwhelming daytime drowsiness and sudden attacks of sleep. People with narcolepsy often find it ...

What is narcolepsy, symptoms & causes - WebMD
<https://www.webmd.com/sleep-disorders/guide> **Sleep Disorders | Guide** **Jan 28, 2017** - Narcolepsy is a neurological disorder that affects a person's sleep/wake cycle. Learn more from WebMD about the causes, symptoms, and ...

Portraits of Narcolepsy in New York City - The Atlantic
<https://www.theatlantic.com/health/archive/2014/04/portraits...narcolepsy-in-.../360981/> **Narcolepsy** is a chronic neurological disorder caused by a loss of the brain's neurotransmitters that regulate sleep-wake cycles.

How Having Narcolepsy Messes with My Love Life - Women's Health
www.womenshealthmag.com/sex-and-love/dating-with-narcolepsy **On June 7**, news broke that one of TV's most iconic unions is on the rocks. Thanks to Homer's narcolepsy, he and Marge are reportedly going ...

What It's Like to Have Narcolepsy -- Science of Us - NYMag
nymag.com/.../what-it-s-like-to-periodically-collapse-and-pass-out-for-several-hours.ht... Roughly translated from Greek, narcolepsy means "seized by numbness," and the primary symptoms of this chronic neurological disorder are ...

Narcolepsy Overview and Facts - Sleep Education
www.sleepeducation.org/essentials-in-sleep/narcolepsy **Narcolepsy** is a sleep disorder that makes you feel overwhelmingly sleepy, and have sleep attacks in cases of narcolepsy with cataplexy.

FAQs « Narcolepsy Network
narcolepsynetwork.org/about-narcolepsy/faq/ **Answer:** Narcolepsy is a neurological disorder that impacts 1 in approximately 2,000 people in the United States. Many people are unaware of the condition and ...

Narcolepsy Network
narcolepsynetwork.org/ **Narcolepsy** is a medical disorder that impacts 1 in approximately 2,000 people in the United States of America. The disease is a sleep disorder, involving ...

Narcolepsy
Also called: excessive uncontrollable daytime sleepiness

ABOUT SYMPTOMS TREATMENTS

Sleep disorder causes overwhelming drowsiness



A chronic sleep disorder that causes overwhelming daytime drowsiness.

Rare
Fewer than 200,000 US cases per year

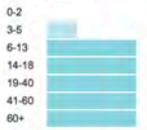
- Treatment can help, but this condition can't be cured
- Chronic: can last for years or be lifelong
- Requires a medical diagnosis
- Lab tests or imaging often required

The cause of narcolepsy isn't well understood but may involve genetic factors and abnormal signaling in the brain.

Narcolepsy causes sudden attacks of sleep. Sudden loss of muscle tone and hallucinations might occur.

Stimulants, antidepressants, and other medications can help.

Ages affected



Age Group	Relative Frequency
0-2	Very Low
3-5	Low
6-13	Medium
14-18	High
19-40	Medium
41-60	Low
60+	Very Low

Consult a doctor for medical advice
Sources: Mayo Clinic and others. Learn more

Download PDF Feedback

What the public likely “knows” about Narcolepsy

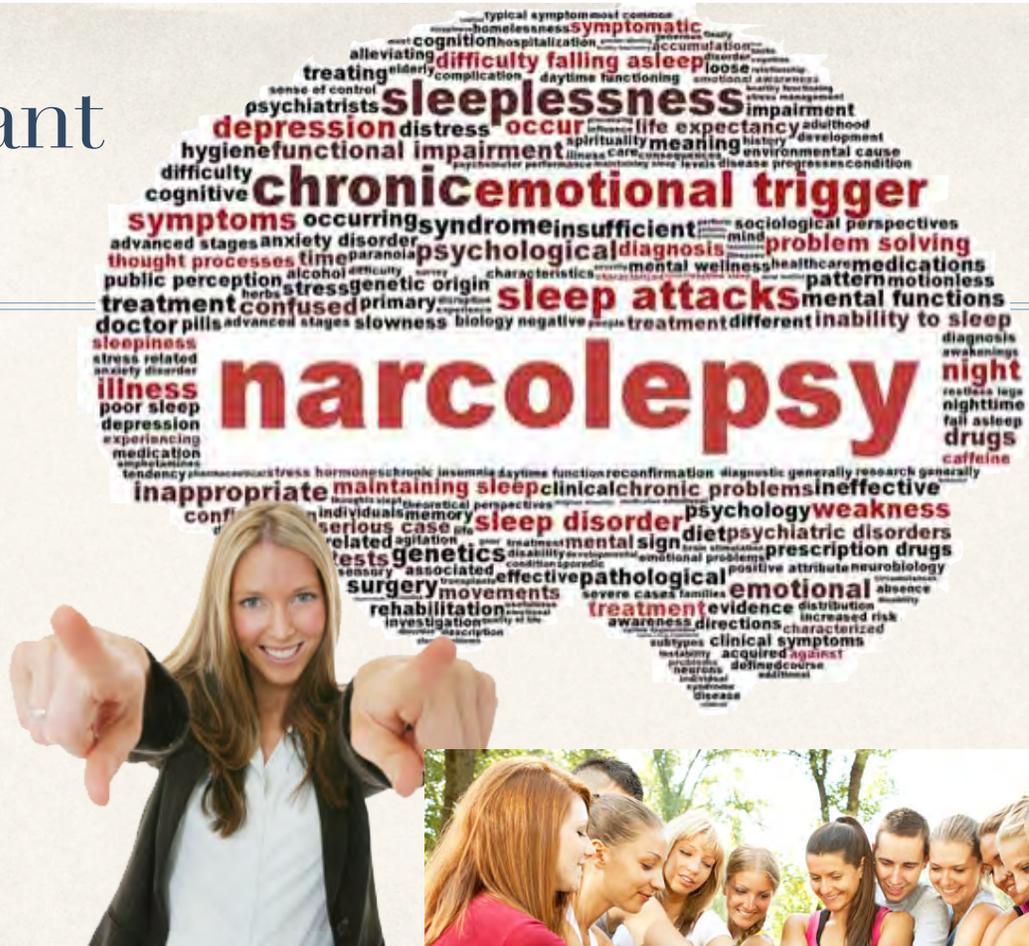


INSOMNIAL CLUB



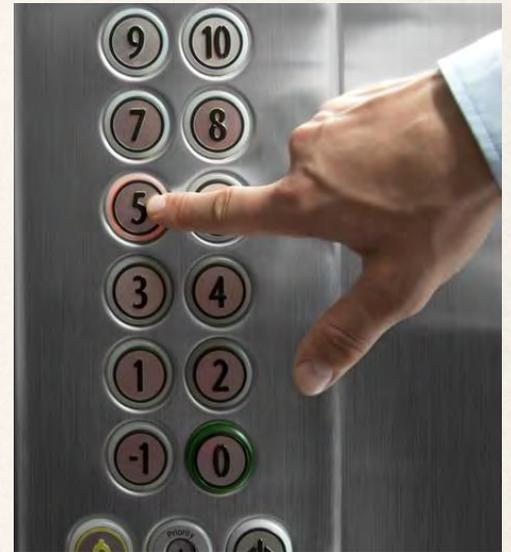
What do You want us to know?

- ❖ Narcolepsy is ...
- ❖ people
- ❖ complicated
- ❖ serious
- ❖ It's you!



What's an elevator speech?

- ❖ A message that is ...
 - ❖ Clear
 - ❖ Concise
 - ❖ Understandable
 - ❖ Engaging
 - ❖ Brief ... think 30 seconds – the time to ride an elevator



An example

Who am I and what is MLD?

Dean Suhr ... MLD



Darcee ...

Passed away at age 10, ≈22 years ago.

Experimental early stage bone marrow transplant – MN/Krivit



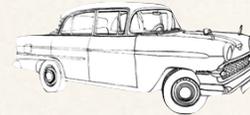
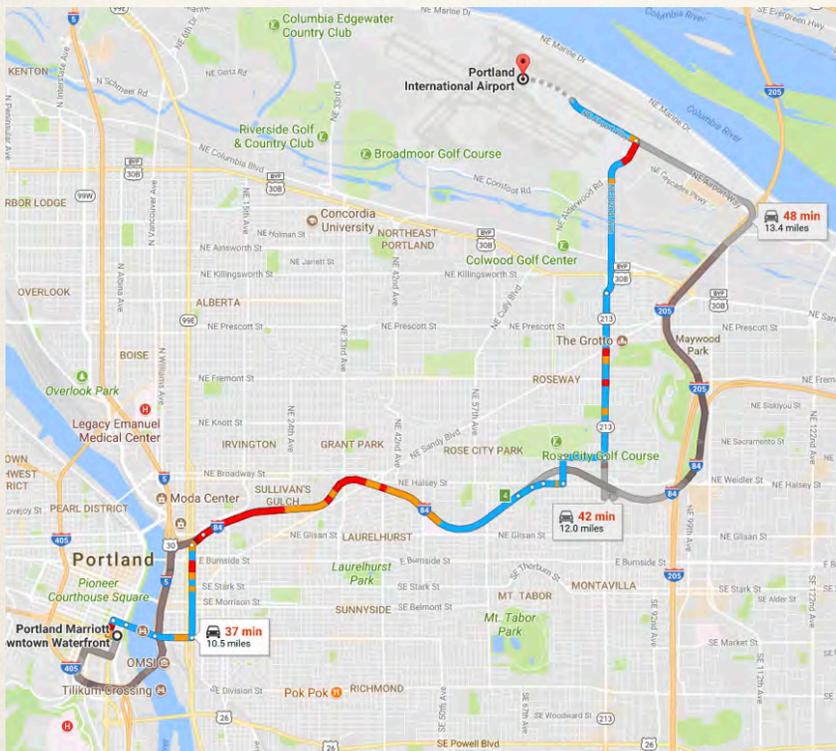
Lindy ...

Diagnosed at 14 (1995) after a 6 year diagnostic odyssey

Docs told us 4-6 yrs.

She's 37 now and doing much better than we/they anticipated

How far is the airport?



11-17 mi – 37-48 min
or 20 min w/o traffic



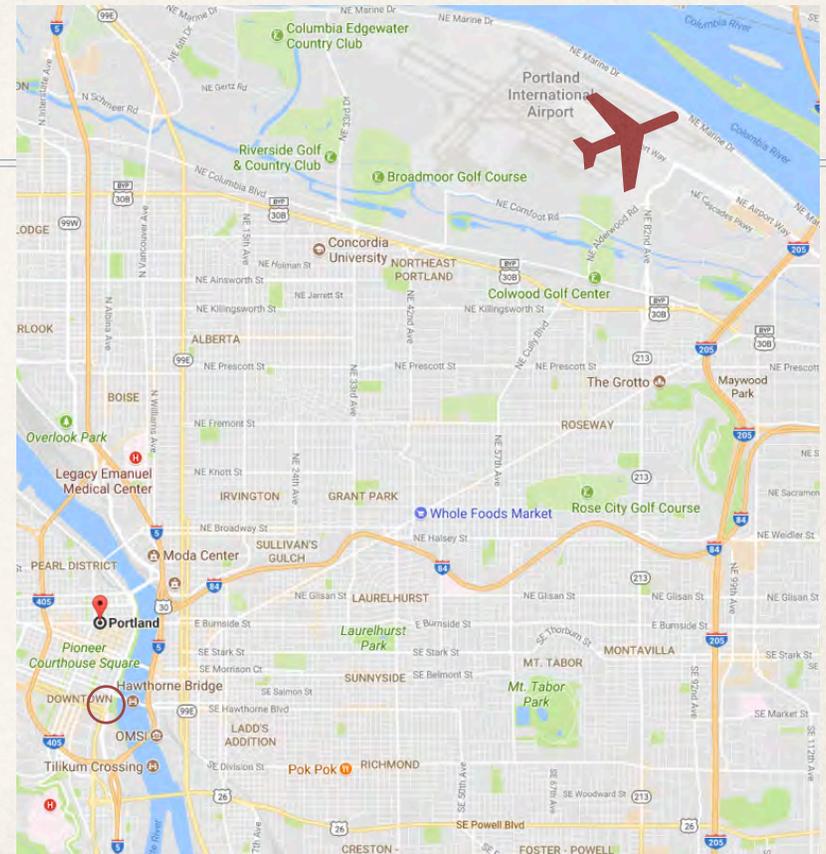
46 min by MAX
31 min by express bus



By bike – *it's Portland!*
10.3 miles, 60 minutes

How far is the airport?

- ❖ About 10 miles
- ❖ Why do you ask?



Share smartly ...

- ❖ Who
- ❖ What
- ❖ Where
- ❖ When
- ❖ Why
- ❖ Leave time to **interact**
- ❖ And make sure this doesn't happen ...



A little planning ...
leads to natural
sharing



Who is your audience?



What do you want others to know ...?

- ❖ **Something personal** about you
- ❖ Narcolepsy as a condition ... **the science**
- ❖ How narcolepsy affects you ... **narcolepsy's personal impact**
- ❖ How your narcolepsy might (*or might not*) **impact them**
- ❖ ...

Where & When

- ❖ When you have their attention
- ❖ When they can retain what you share
- ❖ Share openly when you can ...

Why do you want them to know ...?

- ❖ To better **understand you** ... relate & care
- ❖ To better **understand the condition** ... gain perspective & knowledge
- ❖ To know **what to expect or how to react** ... not to worry, panic, over-react
- ❖ ...

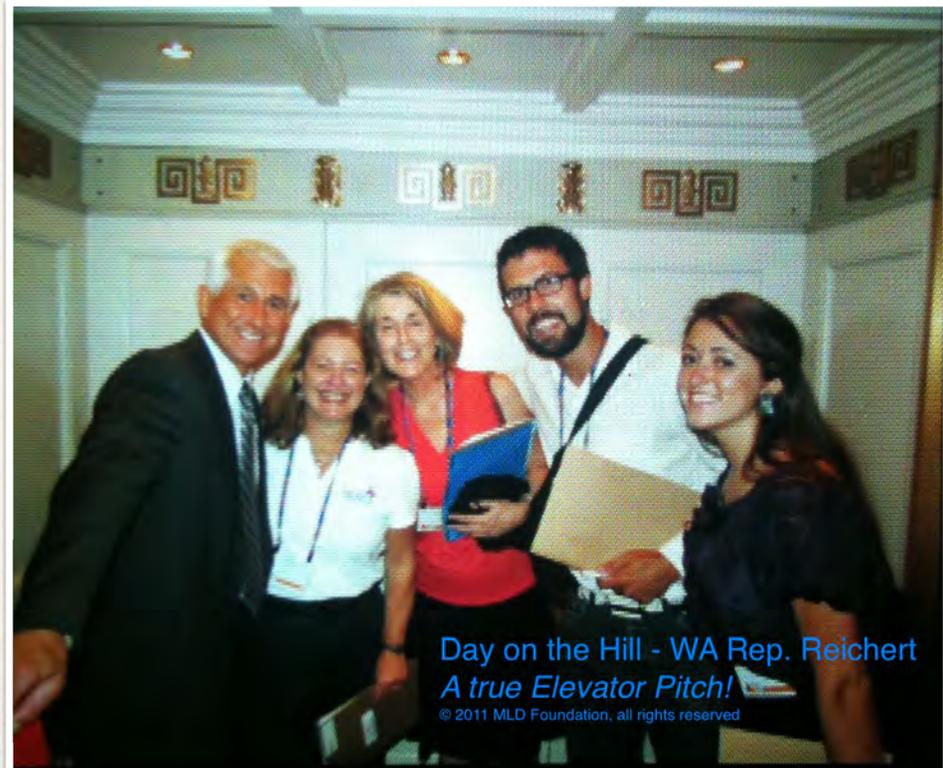
Leave time for them to interact

- ❖ It's more **caring, respectful, and engaging**
- ❖ You have something **you want them to know ...**
 - ❖ but you probably don't know **what they want to know**
- ❖ **Every audience** cares about and **hears something different**
- ❖ **Interest** them, don't overload them
- ❖ Give them a chance to **engage and react**

A “real” elevator speech

An elevator speech ... in an elevator!

- ❖ Rep. Dave Reichert (WA)
Rare Disease Day 2011
US Capitol



Tearing apart my elevator speech

What I want to say ...

Dean is co-founder and president of MLD Foundation serving families around the world with metachromatic leukodystrophy, a rare terminal genetic neuro-metabolic condition. Two of his three children have MLD, Darcee passed away at age 10 in 1995; and Lindy just turned 37 and doing much better than expected. She was diagnosed in 1995 after a 6-year diagnostic odyssey and they told us she might live to her early 20's. With MLD the myelin sheath, the insulator around the nerves, decays leading to motor and cognitive problems. Kind of like how an extension cord with frayed insulation will short circuit.

Dean is active on behalf of MLD, leukodystrophy, lysosomal and Rare Disease communities with special interests in global health policy ([Rare.Army](#)), newborn screening ([NewbornScreening.us](#) /RUSP Roundtable), registries (PCORI, cross-disease and linking data silos, patient driven researcher quality data, dynamic privacy/sharing, and consent are hot buttons), diagnostics, consent, privacy, ethics, openNHS, FDA/NIH issues, empowering advocacy organizations, research consortiums (GLIA and LDN/WORLD) and the emerging trend of centers of clinical research excellence.

A better approach

Dean is co-founder and president of MLD Foundation serving families around the world with metachromatic leukodystrophy, a rare terminal genetic neuro-metabolic condition. MLD, like narcolepsy, is a rare disease.

Two of his three children have MLD; Darcee passed away at age 10 in 1995; Lindy just turned 37 and doing much better than expected.

With MLD, the myelin sheath, the insulator around the nerves, decays leading to motor and cognitive problems.

Let's get to know each other ...

Let's get to know each other ...

Thank You!

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