Creating an Elevator Speech

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MLD Foundation

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What’s the Conference Theme?
What is Narcolepsy?
What the public likely “knows” about Narcolepsy
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
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
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.Arm), 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 …
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Thank You!

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