

# PATIENT AND PROVIDER CONNECTIONS POWERED BY SOCIAL MEDIA

*(a.k.a. Breaking Geographic Boundaries)*

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Intimal Fibromuscular Dysplasia patient

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# Relevant Patient History

1980 – birth

1989 – onset of major GI distress noted

1996 – gallbladder removal

1997 – double jaw relocation

2005 – renal, celiac, mesenteric artery bypass

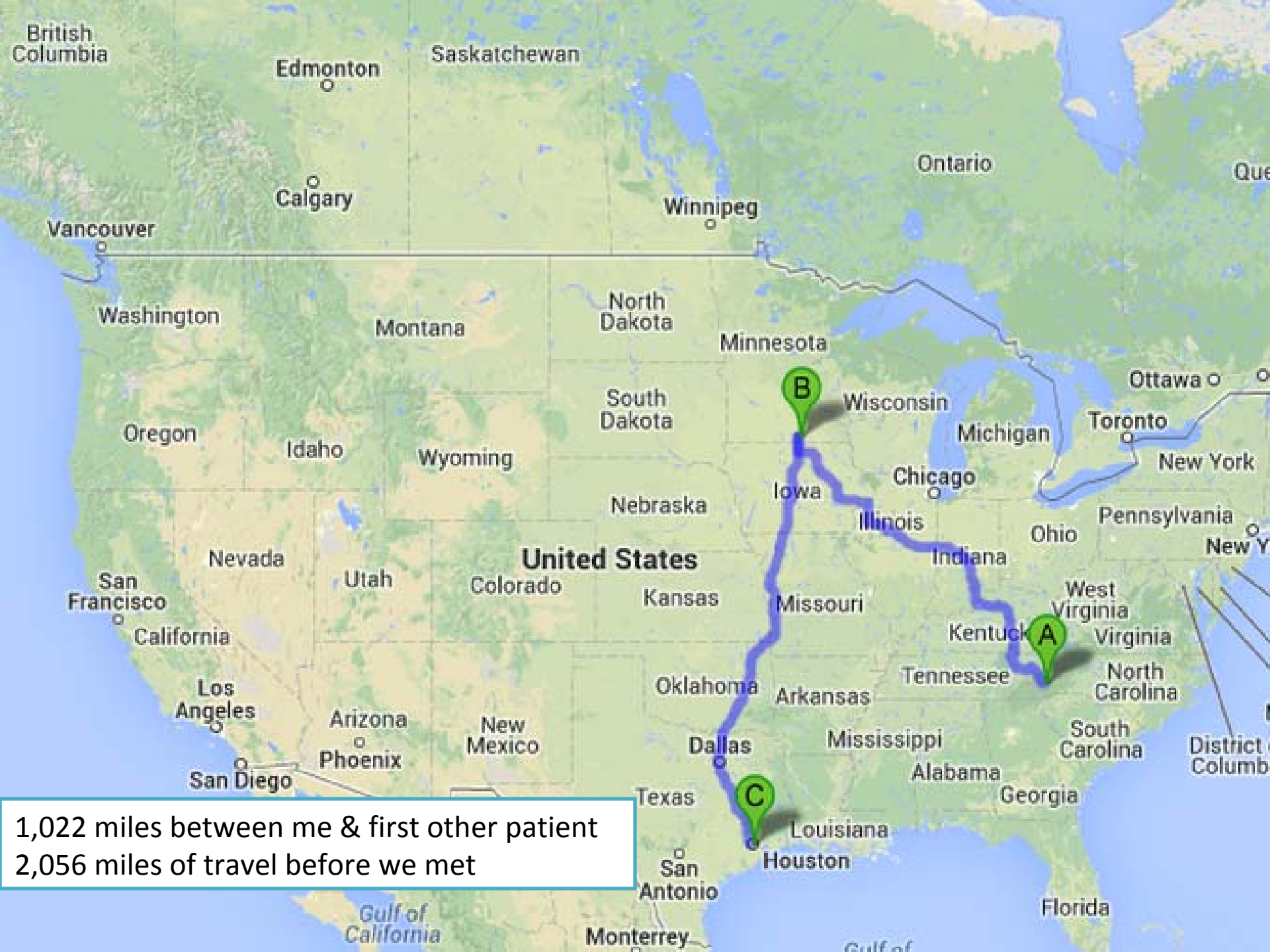
2008 – stroke (possible carotid dissection), bypass failure, kidney failure

2009 – laproscopic nephrectomy, 3 of 4 brain aneurysms treated via endovascular coiling

2011 – gastric rupture, diagnosis of intimal fibromuscular dysplasia

# Having a Name for Being Alone

- ✧ Fibromuscular dysplasia (FMD) is a noninflammatory, nonatherosclerotic arterial disease most commonly seen in women. It may present at any age, but is more between the ages of 20 and 60 years old. Patients may be asymptomatic and remain undiagnosed; however, the disease may cause arterial stenosis, occlusion, aneurysm, and/or dissection. FMD most commonly impacts the renal and carotid arteries, though it has been identified in almost every arterial bed.
- ✧ FMD is considered a rare disease; however, it is also underdiagnosed. In the U.S., a disease is defined as rare if it is believed to affect fewer than 200,000 Americans, according to the National Organization of Rare Disorders. A disease or disorder is defined as rare in Europe when it affects fewer than 1 in 2,000. FMD



1,022 miles between me & first other patient  
2,056 miles of travel before we met



# Peer-to-Peer Happens, Like it or Not

- ✧ One in five internet users (18%) have gone online to find others who might have health concerns similar to theirs.
- ✧ One in four internet users living with high blood pressure, diabetes, heart conditions, lung conditions, cancer, or some other chronic ailment (23%) say they have gone online to find others with similar health concerns.
- ✧ A greater proportion of internet users living with less common, chronic health problems have gone online to find others with similar health concerns.

# Peer-to-Peer Happens

- ✧ People going through a medical crisis are voracious information consumers: 85% say they look online for health information.
- ✧ Other groups who are likely to look online for people who share their same health concerns include: internet users who are caring for a loved one; internet users who experienced a medical crisis in the past year; and internet users who have experienced a significant change in their physical health, such as weight loss or gain, pregnancy, or quitting smoking.

# Benefits of Peer-to-Peer

- ✧ Increased patients' access to information
  - geographic boundaries, doctors' limitations
- ✧ Social media allows people to express themselves
  - process of acceptance, conversations not had in doctors' offices or with family
- ✧ Social media allows for immediate connection
  - no hours of operation
- ✧ Social media leaves lasting impressions, often searchable, that help future patients
  - reduces repeated conversations, builds body of knowledge



# However...

- ✧ 71% of adults in the U.S. say they received information, care, or support from a health professional
- ✧ 55% of adults say they turned to friends and family
- ✧ 21% of adults say they turned to others who have the same health condition

“The oft-expressed fear that patients are using the internet to self-diagnose and self-medicate without reference to medical professionals does not emerge in national phone surveys or in this special rare-disease community survey.”

# What Can Providers Do?

- ✧ Look, listen, learn
  - Search using terms kidney, renal, dialysis, nephrology
- ✧ Provide better information for your patients
  - Compile a list of the most common questions you receive & answer them in simple terms, make this information available to patients 24/7/365 via practice website & paper handouts for those who don't use the web
  - Link to information that you deem reliable,

# What Can Providers Do?

- ✧ Connect with providers and organizations you consider to be leaders in your field who are using social media
  - Twitter: @MedScapeKidney, @ASNKidney, @renalandurology, @kidneynews, @kidney\_doctor, @kidney\_boy @iamdoctord, @cjstefanidis, @DamianFog, #hcsn, #renal, #kidney, #dialysis, #nephrology (or visit [twitter.com/afternoonapper](https://twitter.com/afternoonapper) & click on Lists >> BC Renal Days)
  - Blogs: [thekidneyboy.blogspot.com](http://thekidneyboy.blogspot.com), [renalfellow.blogspot.com](http://renalfellow.blogspot.com), [kidneycare.blog.com](http://kidneycare.blog.com), [kidneyfoundation.wordpress.com](http://kidneyfoundation.wordpress.com), [twoguysonekidney.blogspot.com](http://twoguysonekidney.blogspot.com)
  - Others: [instagram.com/kennythekidneybean](https://www.instagram.com/kennythekidneybean), [youtube.com/TheAnatomyZone](https://www.youtube.com/TheAnatomyZone), [youtube.com/ClevelandClinic](https://www.youtube.com/ClevelandClinic)

*Inclusion does not indicate endorsement.*

# Ethics For All

- ✧ It's not about providing medical advice; it's about connecting with people.
- ✧ It's up to you how you engage; it's not up to you how others engage.
- ✧ Be as transparent as you can be.
- ✧ Be the kind of person you would want to follow.
- ✧ Don't fear the worst, but have a crisis plan.