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Podcast intro

Welcome to Health Hats, the Podcast. I'm Danny van Leeuwen, a pathologically optimistic, catastrophizing, saxophone-tooting old white man of privilege living with MS. I'm a nurse and C-suite survivor. I've led the implementation of electronic health records and walked with family members through their end-of-life journeys. Healthcare is an awesome circus. Let's wear some hats, make sense of this, and see if we can find our way to best health.

Proem

I love retirement. I have plenty to do on my own schedule. I can nap almost whenever I want. I'm no better at saying no. Every day feels rich, although I don't always know what day it is.

From Mom to AI

My [podcast](#) about best health continues to flourish and nourish. Thank you very much. I embrace the tension between creativity and productivity as I test new approaches and media. I published fifteen new episodes in 2025, plus 32 [YouTube episodes](#), and countless social media shorts. What do you think of my new intro and outro? Grandsons Leon and Oscar encouraged me to update them. Leon has been updating my website, as a growing proportion of people access my back catalog. Both Leon and Oscar advise me on direction, content, and strategy, especially using social media. I meet regularly with my virtual, supportive, and challenging podcasting peeps. I enjoy experimenting with AI in production to find and create images and suggest brief descriptions and section headings. My favorite prompt is "Suggest three ironic titles, brief descriptions, and section headings, a tech-savvy teen would appreciate." I rarely use the suggested responses, but I chuckle and take an unexpected path. AI does



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not make me more productive; it changes the work a tad. When I first started blogging, I would read draft episodes to my mom. Her feedback was more often helpful than AI's. I miss my mom.

50 Years of Love and Privilege Roasted

The highlights of the year included celebrating our 50th wedding anniversary with old friends and my grandsons. Our son, Ruben, served as Master of Ceremonies. Nine people from our 1975 wedding joined us in July on Bloom Mountain in West Virginia to tell stories. We played the Dating Game and Danny and Ann Trivia. We, rather, I, got roasted. Oscar, Bruce Kimmel, and I played Simple Gifts on clarinet, bass, and baritone sax. We sang Simple Gifts at our wedding. Listeners and viewers, you can find full performances of this and other referenced tunes at the end of the podcast. Readers, click the links in the transcript or check the show notes.

Rolling in Cuba

Another highlight was our week-long trip to Cuba for a music extravaganza. Dan Fox and [Morningside Studios](#) arranged it, and the [Havana Music School](#) hosted a week of the [Havana Jazz Festival](#), daily lessons and ensemble work, culminating in a gig at a restaurant attended by many Havana musicians in town for the Festival. One of the tunes I recorded from the gig, "[Sofrito](#)" by [Mongo Santamaria](#), has had 48,000 views on YouTube as of this writing. Before this, my most-viewed videos had 300 views. I'm grateful to Pachy Silveria for saxophone instruction and to Claudia Fumero and Gisselle Perez for their kindness in hosting. I worried about wheelchair access before we went to Cuba, but I needn't have. My wheelchair was no more of a barrier there than it is anywhere else.

Too Many and Too Few Horns

Speaking of music, I'm playing in two bands now-[Lechuga Fresca Latin Band](#) and [Summer Street Stompers Dixieland Band](#). Lechuga Fresca is reconstituting after several musicians moved on to other projects. I'm often the only horn player at rehearsals, while we have five horn players in the Summer Street Stompers. Too few and too many. Both situations have challenges. I've never had to hold my own in a band completely; usually, I hide behind someone. With a horn section, the music at its best is controlled cacophony. Too many horns are nuts. I'm learning to lay back, not hide, drop out sometimes, join the rhythm section other times, and leave more white space in my solos. I'm grateful to my teacher of 17 years, Jeff Harrington. Oscar and I figure that I must be a professional musician. While I don't make a living playing, I made \$150 this year. I average 1 hour a day with my music, and it feeds my soul and creates new pathways in my Swiss-cheese brain.

Best Governance

I'm in my sixth year on the PCORI (Patient Centered Outcomes Research Institute) Board, focused on shifting the balance of power in [community-research partnerships](#) and in the [participatory governance of AI](#) used in research. If reappointed, I'll enthusiastically re-up for another six years. PCORI has the best Board, leadership, and staff dynamics, as well as the output, of any organization I've participated with during my 50-year career. A nod to Jan Oldenburg for outstanding coaching that kept me focused on two goals at a time.



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Game-Changing Startup

A year ago, I would have said serving on the PCORI Board of Governors was the pinnacle of my career but let me tell you about my new career gig. For twenty-five years, I've worked with many collaboratives to advance patients' abilities to turn their health data into useful information to make choices about their health and care. "Gimme my damn data" is a great slogan and first step, but success could be drinking dirty water out of a firehose. I virtually met my start-up partners, Tomas Moras and Marianne Hudgins in April and started working together in August. We're seeking seed funding to build a [Personal Health Data Bank](#), an owner-controlled health data bank that promotes individual data ownership, safety, security, and trust by storing personal health data from any source and using AI-assisted synthesis to serve the data owner.

Data owners' needs vary. We might need our data for research participation, health data summarization, clinician visit prep, care coordination with family in whatever diaspora, or tracking data over the years, across health systems and locations. We have a sandbox where we are testing and enhancing existing open-source technology while we figure out participatory governance to address ethical, privacy, and usability issues. We favor a bottom-up rather than a top-down approach as we build community and services for owners and their trusted networks. I'm excited about the challenge of finding the smallest viable community that can use these Data Banks, with everyone making enough money to sustain the banks, service providers, and networks. No data broker would make money on the data. I'm revved up as I learn about a new audience – investors. The diversity of investors rivals that of any culture I'm new to.

Onward

I traveled to DC, Portland OR, New Orleans, and Colorado. In 2026, we booked a trip to Belize with Linda and Mike DeRosa. We are also planning a trip to Ireland and Wales with my brother-in-law, Paul Boland, I'll be sharing more about my adventures on my podcast and social media.

Best Health Now

Oh, I almost forgot. My health is excellent, meaning I spend a decent share of time in a state of best health. Talked to a friend, Shel. How do you answer people when they ask how you are doing? On a scale of 1 to 10, with this administration, the best is a seven. Considering the annoyances of MS, that brings it down to a five. So, how are you doing? Five out of ten is best health. I lost 50 pounds this year after a Type II Diabetes diagnosis. Mobility remains steady, though I was slowing down before the weight loss. I rate symptoms as annoying, seriously annoying, or disabling. Episodes of disabling symptoms are rare and brief. I know how to handle most symptoms most of the time. I'm delighted with a five.

Endorphins and Gratitude

I'm grateful for my health, my pathological optimism, my privilege, my honey, my grandkids, and my health team. I appreciate all of you - family, friends, and colleagues. You infuse me with energizing endorphins, the best antidote to fatigue. May you celebrate the energizing moments you find in these disturbing times.



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A <https://goodlistening.org> poet wrote this poem for me.

A Guide To Pathological Optimism

My life's rich; fulfilling
I wear many hats:
End-of-life carer -
Saxophonist, at that!

I avoid complaining;
Will the process to slow
I'm an optimist -
Pathologically so!

But here is the thing
With MS progression:
I dip, then I rise -
Face fragmented depression

"Take two minutes to bitch!"
A trick from a dear friend -
So sometimes it's just "FUCK!"
Then reset: start again.

www.goodlistening.org



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Podcast Outro

Health Hats is produced by me with Kayla Nelson, Team van Leeuwen, Leon, Oscar, and Joey. Joey arranged and recorded the intro and outro music. AI tools assist production; I make all creative decisions. If you like it, share it. Subscribe at linktr.ee/healthhats. See you around the block.



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