



PATIENT PANEL

Wells Larsen, John Ortiz, & Duane Sunwold



WELLS LARSEN'S CKD JOURNEY

Wells Larsen

Where I live Minneapolis – St. Paul, MN Area
Family Married (Ali), Puppies (Maisie & Walter)
Education BS: CSCI / Math; MS: Security Technologies
Occupation IT Director & Chief IT Security Architect (Healthcare)
Linked In <https://www.linkedin.com/in/wells-larsen-905a531a>

My Life's Best Work

- 25 years In IT; 14 years w/ focus in Security
- Work Organizations: Boston Scientific, Target, Optum, Integris Health

What Drives Me & My "Why"

- Patient Experience (Kidney Transplant in 2021)
- Volunteer Experience Mentor: kidney & bariatric patients of the Mayo Clinic
- Innovation & Transformation (Better technology driving better healthcare)

Leadership Tendencies

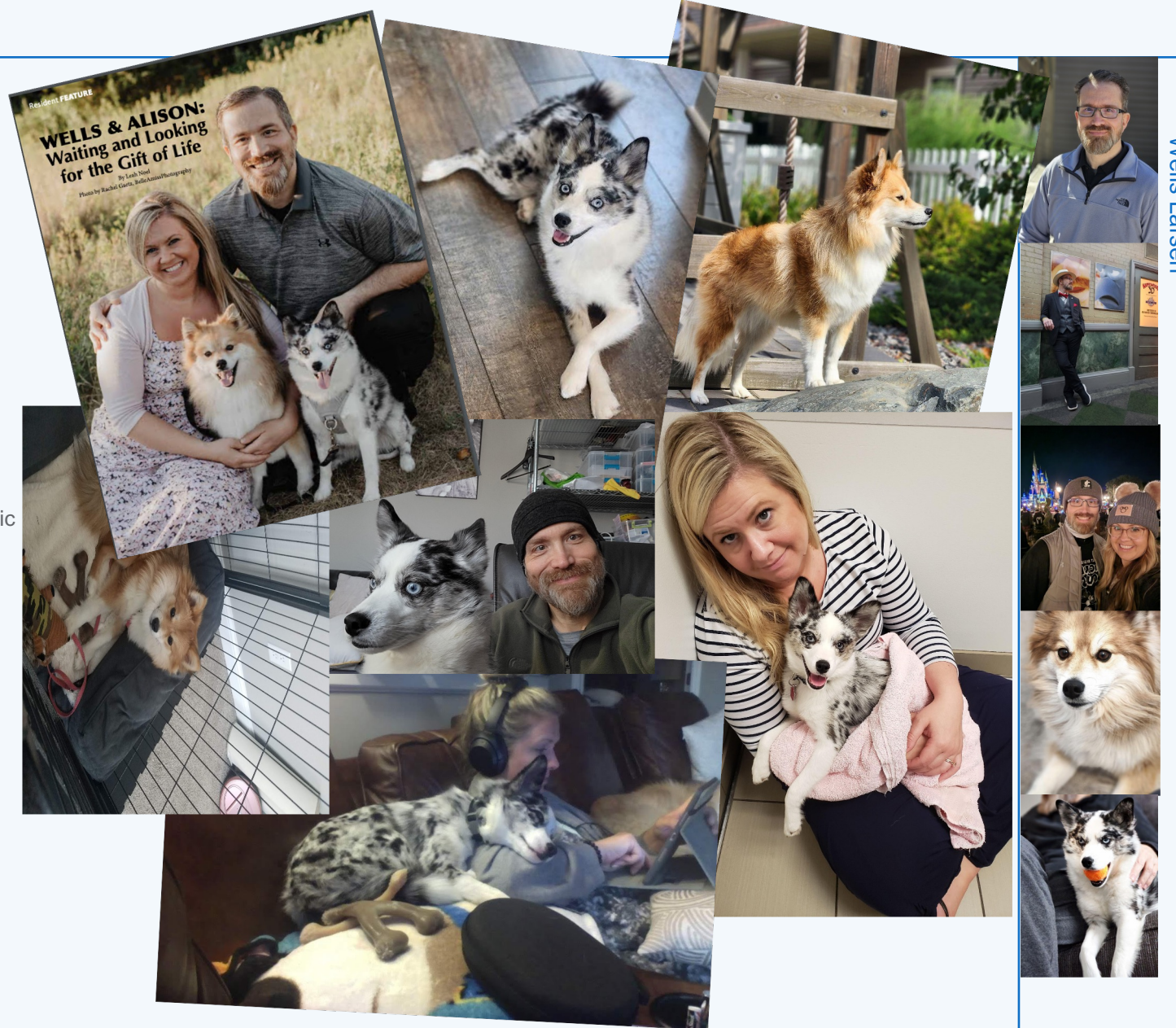
- Servant Leadership (Empowering people to do their life's best work)
- Mentorship (Helping people find their "why")

Personality Traits

- I am Myers-Briggs: INFJ
- Traits: Insightful, Strategic, Determined, Empathetic, Loyal
- Weakness: Anxiety
- How I turned anxiety into a strength – Preparation, Security, My contingencies have contingencies
- I am most energized when I am part of a team, contributing to making a difference in something important.
- I feel good when I help others

My Downtime

- I love travel, seeing new places and learning about new cultures
- My happy place is hiking in the woods with my pups



Wells Larsen

CKD Progression

Early Childhood & Teen Years

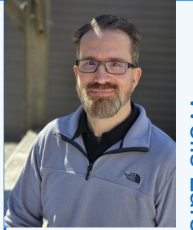
- Struggled with childhood obesity
- Discovered sports in my early teens and lost substantial weight; Bad eating habits mixed with crash dieting

Twenties & Thirties

- Lost my father to heart disease (1997); Lost my mother to PKD (2004)
- ~2001 - Diagnosed with Polycystic Kidney Disease (PKD) (hereditary - mother)
- Depression. Focused on career; Adopted bad eating and exercising habits; Loosely tracked kidney decline. (Buried head in the sand)

Forties

- ~2010 - 13 - Started tracking CKD progression with Mayo Clinic @ around 30% function
- ~2015 - Weight ballooned to over 300lbs (as much as 350lbs). Tired all of the time; Minimal exercise; Poor diet; Workaholic
- ~2017 – Better diet (veggies; low protein). Weight dropped to 290.
- ~2018 - CKD progression continued to 20% function; Crash / Yo-yo Dieting; Transplant List Inactive.
 - Medical team suggested bariatric surgery; Said I would think about it. Fear of the stigma & major surgery.
 - Continued to try to lose weight on my own; More Yo-yo dieting. As much exercise as I could handle.
- ~2019 - CKD progression continued to 15% function – Realized I couldn't lose weight by myself; Investigated bariatric options
 - Met with Endocrinology; Struggles with Endocrinology & Insurance requirements;
 - Weight loss program with chiropractor successful – 270lbs - Took about ~1 Year;
 - Endocrinology & Insurance wanted me to start over because I look too long. Could barely walk a block; Major fatigue.
- ~2020(Late) – Met Dr. Diwan & Dr. Kukla – Introduced me to the cross-functional Endocrinology/Transplant program. ~10% function
 - March 2021 – 310lbs; Gastric Sleeve;
 - August 2021 – 250lbs Active on Transplant List
 - September 2021 – 225lbs – Double Nephrectomy & Transplant (Kidneys weighed ~20 pounds); 200lbs 2 weeks later
- ~2022 – Walking 10 miles per day; Lowest weight at 170lbs; Ideal weight 180lbs – 190lbs
- ~2024 – Very healthy kidney; Still struggle with diet & exercise consistency; Lifelong challenge. Surgery not a magic pill forever.



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JOHN'S CKD JOURNEY

CKD timeline

2005 I found out my Kidneys were functioning at about 50%

2012_2013 Kidney function declined sCr 5 mg/dl GFR15. Weight 265

Changed doctors and diagnosed with Polycystic Kidney disease

Started and exercise program and diet. Stayed off dialysis for 3 years

2016 2018 Started dialysis, left kidney removed due to complications with the Polycystic kidney disease, weight was dropping

2018 May 18, 2018. Kidney Transplant. Weight 235, Nine months post-surgery the surgery herniated

2019 Transplant kidney started failing,

2021 Started dialysis for the second time Dry weight 213

2023 Diagnosed with PVD and had a CABG X 3

2024 10/22 Transplant Evaluation 2025 New Kidney



CHEF DUANE'S JOURNEY

CHEF DUANE

- Before MNT

2001

Creatinine >4.7

Micro Albumin >12 grams

Lowest eGFR 13

113 Kilograms

- After MNT

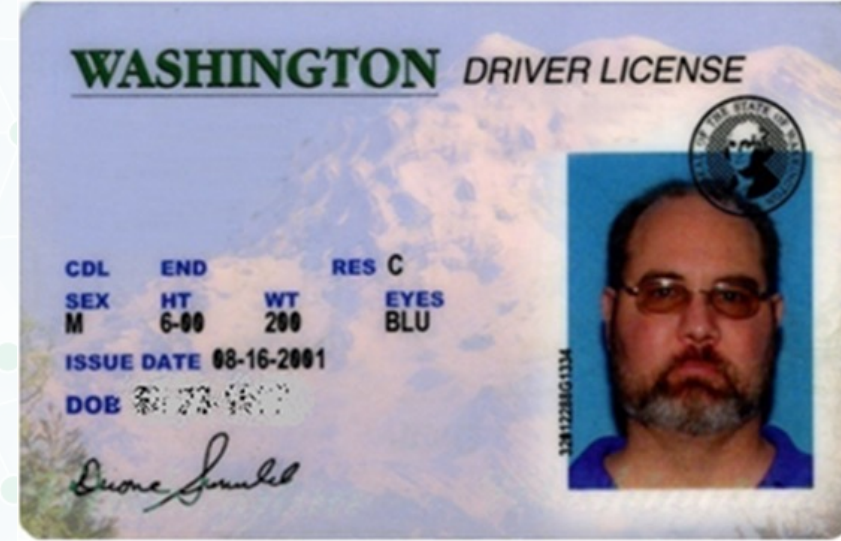
2006

Creatinine 1.1 (today 0.8)

Micro Albumin 14 mg (today 8 mg)

81.5 Kilograms

Today eGFR 88





PATIENT TOPICS OF INTEREST

Patient Topics of interest - Wells

What are the challenges education, diet management before and during dialysis

- Never on dialysis; The restrictions to maintain kidney function taught me a framework to utilize for weight management
- Managing potassium and other restrictions were very challenging.
- Different people use different mental tools to keep focus. Rigidity is my tool. Structure, order. Pre-determined meals.
- I struggled with the limited guidance from nutritionists (ie. Items, portions; but no meal examples, cooking classes, meal prep). Being able to balance notional guidance would have been helpful.

Diet and exercise need to become as important as taking your daily meds.

- Absolutely! Good eating habits are a lifelong commitment. Beginning life with poor dietary habits forces life-long struggles.
- Getting off routine for 2 weeks set me up for 6-8 months of trying to re-establish routine.
- Emotional eating (stress) is a trigger for me.

Changes requires the patient to buy into the process.

- Change is critical, but finding the mental tools that can be leaned on is the challenge. I think someone's mental approach determines success. For me, structure, rigidity was key. I'm not good with vague instruction, such as what a nutritionist provided. What worked for me was a specific list of meals that I could eat; staying away from other things.

The team concept needs to be emphasized more. The patient needs to feel confident and positive about the themselves that they are going to achieve

- Absolutely! What I found was lacking was an active community that shared tips, tricks, recipes, etc. For me, it wasn't about the social structure (though I appreciate others need that); For me it was clear, ideas of what to eat, how much to eat, etc. I always read forums. Looking for knowledge I can use.
- Weighing food for me is key; Tracking (via myfitnesspal or tool like it) is key.

TOPICS OF INTEREST - JOHN

- What are the challenges education, diet management before and during dialysis
- Diet and exercise need to become as important as taking your daily meds.
- Changes requires the patient to buy into the process.
- The team concept needs to be emphasized more. The patient needs to feel confident and positive about the themselves that they are going to achieve their goals.

TOPICS OF INTEREST – CHEF DUANE

- Nutrition Therapy
 - 1 in 5 nephrologists discussed diet
 - “You might feel better” by lifestyle and dietary changes
 - I like enjoy my diet!!!!
- Team Approach
 - Culinary and nutrition experts working together
 - Peer-to-peer support system

