

Wicked Diseases, Advocacy, and Gifts, Oh My!

My Journey from Disease into Advocacy powered by P.R.I.S.M and P.U.S.H

Community member Kevin Kvarda has created a sculpture to represent the hope and optimism behind his advocacy for people living with dementia and caregivers, medical professionals, researchers, and support associations.



Hello Friends! My name is Kevin Kvarda or you can call me “K-Squared.” Since June 2019, I’ve had new friends in my life--a diagnosis of Alzheimer’s and Primary Progressive Aphasia: “PPA”. I’ve not necessarily been one to stand up on the public stage, but my diseases have pulled me out and given me a voice ... a positive VOICE and HOPE.

I have a GREAT Caregiver team: My wife Norma, 4 kids (Riley, Andrew, Quinlan, and Jordan), extended family in other states, and many friends from past work teams, and my men's spiritual groups.

I sometimes think of my new experience in the terms of “The Wizard of Oz” movie, in that we have a Scarecrow that needs a brain (and I have a brain that is different due to the diseases), a Tin Man who needs a heart (and I have a huge heart because of family, friends, and awesome physicians, etc.), a Lion that needs courage (and I have strong courage from family, spiritual Men’s groups, and taking one day at a time). And even though there is the Wicked Witch of The West in my story, we have many organizations that are working around the clock trying to find the CURE! Remember what happened to the Wicked Witch of The West in the end!



And now, it's time to go on down the "yellow brick road" and give you a glimpse of my early days and the diseases/medical issues up to now (young to now): **Tonsils and Adenoids Removed** — **Glasses** — **Cholesteatoma surgeries (4 times from 5 to 19) in right inner ear** — **Breathing-treatments in the ER, usually at night** — **Allergies** — **Orthodontics (Head Gear)** — **Scoliosis** — **Pituitary gland tumors (4 surgeries, 1 Gamma-Knife** — **Thyroid issues (Hypo, Hyper...varies)** — **AFIB episodes (2 times)** — **Lumbar puncture** — **Alzheimer’s** — **PPA** — **Dementia** — **What's Next?** — **HOW ABOUT A CURE FOR ALZ, PPA, and Dementia!! -We need Wizards!**

Overall, I have embraced my diagnosis, which is causing my Dementia, Aphasia, and Disability. YES, I really did say that! Crazy huh...but it's true. They are unique and go with me every day. Since I found them, they have given me opportunities to make others laugh, get mad, and cry too.

I believe that NOTHING comes by “accident”. There is ALWAYS a reason! I also believe that all of us have a higher power that guides us. It doesn't matter what your faith (or not) is. Mine is my Roman Catholic Christian faith. What is your higher power? Embrace it, cling to it, use it to help others and yourself! I believe that we ALL have our Guardian ANGELS. I'm convinced that those angels do amazing feats EVERY day. I'm deeply thankful! BELIEVE!!

My Mission:

As an Advocate “in training” for the cure for Alzheimer’s, PPA, and Dementia, I co-create a world where these diseases are eradicated by 2025 by working with local agencies in Olympia, WA and Washington D.C. I educate myself via my medical professionals, local events, MANY support groups, family, and friends.

P.R.I.S.M: Patients, Researchers, iHumanity, Support Associations, and Medical Professionals

As a Systems Engineer, Product Manager, Robotics Coach, and Project Manager by trade, I’ve always been interested in how things fit together. I drew on my passion for engineering and visual thinking to communicate my big idea: A prism with 4 facets. This prism is no ordinary prism. It has its own acronym: **P.R.I.S.M**. All sides support each other, to increase strength and hope. The golden ball you see hanging inside the prism symbolizes humanity. ALL 4 facets MUST be running and “In Mission” to ENSURE that Humanity is in BALANCE. We ALL have a part to keep the BALANCE! We all need to keep pushing up the hill in our own ways. In other words: P.U.S.H: Power, Unity, yields Solidarity and Hope. Here are my wishes to help you work towards your own Missions. If you have a personal/professional Mission and would like to share, I would be grateful. As they say...**“Iron sharpens Iron”**. >>>

P.R.I.S.M.:

Patients and Caregivers, Researchers, iHumanity, Support Associations, and Medical Professionals

BLUE: Patients & Caregivers:



I wish you **PATIENCE** when working with the doctors, nurses, aides, etc.

I wish for you to **EMBRACE LIFE** one day at a time.

I wish you **TRUST** between **BOTH** Patients and Caregivers.

RED: Medical Professionals



I wish you **IMMENSE EMPATHY** everyday!

I wish you **ADEQUATE TIME** for your patients, families, studies, and you.

I wish you **COMPASSION** and **STRENGTH** for the journey with every patient.

PURPLE: Support Associations



I wish you a **TENACIOUS HEART** when working with legislators at the State and National levels for funding for the cure for **ALZ**.

I wish for you to continue **SERVICE LEADERSHIP** (especially at community events).

I wish for you to continue **EXPANDING TO MORE CITIES** so that new folks can get the information.

GREEN: Researchers



I wish you an **HONEST** heart when working on a cure and enough time to get it right.

I wish you never-ending **CURIOSITY**.

I wish you a **SHARP INTELLIGENCE** when communicating to others.

Advocacy Day 2020 in Olympia, WA

On February 18, 2020, I traveled to Olympia to act as an Advocate for the WA State Chapter of the Alzheimer's Association. It was Advocacy Day, when anyone can participate and urge public officials to support additional resources for Alzheimer's disease. I decided to share my personal story.

I had nerves that morning—after all, I haven't been one to get up and give speeches all of the time! But, I felt I needed to right then. I just took the opportunity and gave it what I could. And, it came out good. I talked about how I turned 180 degrees after my diagnosis and made a not-great thing into a great thing, through advocacy. In all, I visited five different legislative offices. It was pretty cool because at every meeting, I heard things like, "Wow, I never heard a story like yours before."

What we do is really critical to keeping the balance for patients and caregivers, researchers, medical professionals, and support associations. Think of these groups as the 4 sides of the P.R.I.S.M. If one side isn't running at 100%, then all of the other 3 sides will have to pick up the load. -Kevin Kvarda



Anyone can BECOME AN ADVOCATE through the Alzheimer's Association. Advocates are invited to engage public officials and policymakers in a variety of ways, from trip to Congress, to emails and Facebook posts, urging their support for critical Alzheimer's legislation and policy changes. <https://tinyurl.com/88z5jv7>

Excerpted from Dimensions Magazine - Spring 2020: Pg 26

Recommended Apps and Virtual Resources >>>

Recommended Apps!

When Kevin Kvarda presented his story at the MBWC's Primary Progressive Aphasia Education Day 2019, he shared some Smart Phone apps, including brain games, cognitive exercises, and education modules, that he has found beneficial for some time. Here is a list!

> **The Alzheimer's Association Science Hub** (*Free*) is an app that provides the latest news, information and expert views about Alzheimer's and dementia research. The Alzheimer's Association shares the latest research news and perspectives from scientists and other credible sources. Website: <https://www.alz.org/help-support/resources/the-alzheimer-s-association-science-hub>

> **Brain Yoga** (*Free*) Eleven puzzle games train your memory, vocabulary, numeracy, spatial ability and pattern matching. Website: <https://apps.apple.com/us/app/brain-yoga-brain-training-game/id660526568>

> **Constant Therapy**: is a science-based mobile solution for highly personalized, continuous exercises for people with aphasia, dementia and other speech, language, and cognitive disorders caused by stroke or traumatic brain injuries. Constant Therapy was designed by scientists at Boston University and provides tools for self-help and tools for patients to work with their clinicians. Website: <https://thelearningcorp.com/constant-therapy/>

> **The National Aphasia Association** has compiled a list of apps for people living with Aphasia. Website: <https://www.aphasia.org/aphasia-resources/aphasia-apps/>

> **Alzheimer's Universe** Created by Weill Cornell Medicine & New York Presbyterian, AlzU is an educational tool to assist on the journey to protect brain health. Website: <https://www.alzu.org/what/>

> **3D Brain** Use your touch screen to rotate and zoom around 29 interactive structures. Discover how each brain region functions, what happens when it is injured, and how it is involved in mental illness. Each detailed structure comes with information on functions, disorders, brain damage, case studies, and links to modern research. Created by Vivid Apps and AXS Biomedical Animation Studio for the Cold Spring Harbor Laboratory DNA Learning Center. 3D Brain was produced for the Genes to Cognition (G2C) Online website funded by the Dana Foundation and Hewlett Foundation. Website: <https://dnalc.cshl.edu/resources/products/3d-brain-app.html>

> **PopWords** A simple and fun word finding game Website: <https://apps.apple.com/us/app/popwords/id472853634>

> **A Walk through Dementia** is a Google Cardboard app designed to put the player in the shoes of someone living with dementia. Website: <https://www.awalkthroughdementia.org/>

ACKNOWLEDGMENTS

- My family of 5, my mother, father, brother, and many relatives in different states.
- All of my doctors and nurses along the way (Everett Clinic, Virginia Mason Hospital, and Providence Everett, and, of course, the UW Memory and Brain Wellness Center and UW Radiology teams.
- All the workers at the wahealthplanfinder (medical insurance).
- Marigrace Becker, Dr. Kimiko Domoto-Reilly, Genevieve Wanucha, Brad Rolf, and James DeLappe (UW Medicine) and Megan Caldwell (UW Speech & Hearing Sciences)
- Hazel Borden, Katya Strohl, and Peter Newbould (Alzheimer's Association WA State Chapter).
- My 3 spiritual men's groups.
- The staffers I talked to at the Capitol in Olympia at Advocacy Day 2020.

LEARN MORE

- Contact Kevin Kvarda: kevin.kvarda@gmail.com
- Linked In Profile: <https://www.linkedin.com/in/kevinkvarda/>
- Facebook: <https://www.facebook.com/kevin.kvarda>
- Watch Kevin Kvarda's presentation at the MBWC Primary Progressive Aphasia Education Day, on the MBWC video channel here: <https://youtu.be/P-uTsrrx-i0>.
- Enjoy Kevin Kvarda's Powerpoint presentation from PPA Education Day, 'From Disease to Advocacy.' Download: <https://tinyurl.com/y8fdox7q>



“The struggle you're in today is developing the STRENGTH you need for tomorrow. Peace Out” - K-Squared

Excerpted from Dimensions Magazine - Spring 2020: Pg 27