



I am a subscribed member to the largest employer sponsored health insurance program in the country, the Federal Employee Health Benefits Program (FEP) worth 50 billion dollars. My prescription benefit – which covered my prescribed medical food for PKU – was rescinded in the middle of the 2015 benefit year because of my age. Three years later, this has culminated to civil action against a federal agency after having exhausted all my appeals rights with the contracted carrier to FEP. I have gone through a bureaucratic nightmare, lawyers, appeal after appeal to distinguished authorities, nonprofits, for-profits and accrediting organizations, reconsideration, EEO, and have requested help with a federal agency numerous times from Maryland Congressional delegation Members in challenging prohibited practices such as discrimination based on age and disability and continue to fight. The FEP must comply with civil law and enforcement of Orphan Drug Act Amendment (federal definition of medical foods), and I am pending a hearing. I welcome the platform of PPMNE Coalition to amplify my story which underscores the call for social justice and what happens when diagnosed patients do not have such critical consumer protections assuring access to treatment and are excluded from landmark legislation such as ACA and 21st Century Cures Act because treatment does not fit traditional drug development paradigms. My spouse's employer is self insured and does not afford coverage either, so I have no choice but to fight despite the good mandates in my state. It is my lifelong experience insurers are uninformed about safe and intended use of medical foods for PKU. Moreover, insurers fail to recognize that medical foods pale in comparison to costly pharmaceuticals, but are still not affordable without adequate, working health insurance. I would like to add that I am also a provider for the Department of Veterans Affairs and there has been an increase in prescriptions for medical foods to treat Veterans. VA efforts should align better with TRICARE to allow seamless transition for Veterans from DoD especially since VA is leading an initiative on whole health for which nutrition is a significant part of whole health and wellness. However, outside of work and VA walls, my life is a living nightmare in trying to access lifesaving nutrition with medical foods that saved my life and my children's lives from devastating birth defects and a lifetime of disability. I need protein and adequate nutrition to continue to survive. Please pass a mandate to assure equitable and affordable access to medical foods and stop the arbitrary limitations on coverage (age, gender, zip code, employer) once and for all so these problems are not passed to my children's generation.

See above, (included with relevant details about coverage)

More on my PKU story in published media:

<https://patientworthy.com/2018/02/09/does-bluecross-blueshield-think-pku-patients-can-outgrow-their-dna/#>

<https://patientworthy.com/2017/10/03/us-government-refuses-cover-pku/>

<https://patientworthy.com/2017/12/04/rare-disease-revolutionary-shares-music/>



My story on moving the needle for equity as featured in the permanent online gallery, national community art show on visualizing health equity, hosted by the National Academies of Medicine:

<http://nam.edu/visualizehealthequity/#/artwork/85>

<http://nam.edu/visualizehealthequity/#/artwork/84>

<http://nam.edu/visualizehealthequity/#/artwork/83>

Rare Disease Day 2018, Jennifer Payne holding a 2 inch thick civil action case in her hands to graphically show what happens to patients – being left to fend on their own – in the absence of a federal mandate for coverage. No one should have to go through this.