

Rachel (Rae) Adler

Rachel (Rae) Alder always has been an advocate by heart. She is a transracial adoptee and has spent years working to better the foster care and adoption systems, particularly cost differentials in adoption due to race and transracial family education. Her unusual start in life led her to her life's work and passion in the art of advocacy and authenticity. She has been able to pack a lot of life into her 26-plus years. Her advocacy has led her to:

- Keynote Speaking
- Group Facilitation and Panel Education
- Translation and Interpretive services (Spanish/English)
- First black Miss North Ogden (Miss America Scholarship Org.)
- Dual sport collegiate athlete (water polo & swimming)
- Current Board of directors: Utah Pride Center
- 2022 Collegiate Forensics National Champion in public speaking

In her professional life Rachel has worked in the Social Work and Victim Advocacy world since 2014. She began with the Division of Children and Family Services (DCFS) but eventually found her calling as a Diversity, Equity, & Inclusion Victim Advocate working primarily with survivors of human trafficking, sexual assault, and crisis intervention.

Growing up black in a white family and town left Rachel no stranger to racism. As a queer black woman, healthcare has always felt incredibly unsafe yet as the years went on her health continued to deteriorate. In 2014, she first learned of having family history of Cystic Fibrosis (CF). Unfortunately racial bias came into her life again in her struggle to receive the correct diagnosis. Her disparity in healthcare led to repeated hospitalizations, disease progression, trauma, and confusion from the rapid health deterioration yet lack of further diagnostic investigation.

Rachel's health journey began during infancy and with next to no family health history to go on and lack of racial equity in healthcare she was often passed off, dismissed, gaslit, and belittled. As a queer black woman, healthcare has always felt incredibly unsafe yet as the years went on her health continued to deteriorate.

In 2014 she first learned of having family history of Cystic Fibrosis. Not much thought was given at the time as most of the health complications thus far were more orthopedic and pain related. Ehlers-Danlos Syndrome (EDS) and Postural tachycardia syndrome (PoTS) were eventually diagnosed at Mayo Clinic in 2020, yet other symptoms kept appearing though inconsistent with EDS.

It was then that she was tested for CFTR mutations. The shock came when it was positive for two mutations! Unfortunately the bigger shock came over time. The mutation on her black side of the family had only been documented 9 times. The other being the shared mutation with her cousins was a bit more common and known to cause CF. Unfortunately, racial bias came into her life again when her local pulmonology and CF center failed to further investigate the correct diagnosis. Her disparity in healthcare led to repeated hospitalizations, disease progression, trauma, and confusion from the rapid health deterioration yet lack of further diagnostic investigation.

This is where the National Organization of African Americans with Cystic Fibrosis (NOAACF) comes in. Rachel came to know Michele and Terry Wright and the NOAACF foundation they co-founded through a pleading post for help she posted on social media. It was through them that Rachel was quickly connected with Dr. Jennifer Taylor-Cousar, Professor of Internal Medicine and Pediatric and Adult Pulmonologist at National Jewish Health. Through a Nasal Potential Difference Test and just one day in clinic, she was formally diagnosed with Cystic Fibrosis. She credits both NOAACF and Dr. Taylor-Cousar's life work with saving her life. The damage cannot be undone, but she now is getting the proper treatment she needs and deserves. This diagnosis came 26 years late and following her calling for advocacy, Rachel is deeply honored to be named and to serve as NOAACF's first ever patient ambassador.