



Janine Reed reflects on her years of service and shares her confidence in ASF's future:

*"I first learned of ASF through a gathering of Alport patients and professionals in Philadelphia, Pennsylvania in 2014 and via occasional contributions to the Facebook Support Group where I was invited to moderate the growing forum. At about the same time, ASF co-founder Sharon Lagas invited me to collaborate on program planning. Volunteering with the Foundation helped me to transition from my work as a dialysis administrator to an engaged but retired RN where I could still use my nursing background to guide other members of the community and stay abreast of the needs and interests of fellow patients. In 2018, I was fortunate to be one of the panelists asked to testify to the U.S. Food and Drug Administration as part of the [EL-PFDD meeting](#), where mental health struggles and pregnancy complications in Alport patients were first reported and documented. Subsequently supporting ASF through staffing our exhibitor booth at the American Society of Nephrology's annual Kidney Week meeting leaned into direct engagement with interesting professional contacts. Speaking at the International Alport Workshop in Sienna, Italy allowed me to bring the ASF community voice forward to scientists and researchers. I participated in the Athena Study and until May 10, 2023, I was in the CARDINAL/EAGLE Study of bardoxolone. Serving on ASF's Board of Directors enhanced my understanding of the bigger picture and gave me a place at the table for strategic planning and ongoing discussions. I have taken every opportunity to serve or represent ASF.*

*Why I've stepped back from ASF is admittedly harder to explain. I stepped back from the Facebook Support Group administrative duties when ASF increased the number of page moderators. I had served on the Board for a 3-year term and reached a point where I needed to think less about kidneys and more about going for walks. My Posterior Inferior Cerebellar Artery (PICA) stroke last October emphasized the need to focus on my health and ASF graciously accepted my resignation. There are so many younger and more energetic Alport folks ready to take on the next chapter in supporting our community and they should do so. I have attempted to model kindness, enthusiasm, and passion for our work. I am so grateful for this amazing group of people who allowed me into the inner workings of this growing organization. I am confident that our Alport family will continue to be well taken care of by researchers, nephrologists, dietitians, and nurses because of ASF's focus and commitment to patient needs."*