

Kerri Nelson, DNP, MS, RN  
Assistant Professor in Nursing  
AACN Student Grassroots Ambassador

There are currently 30 million Americans living with a rare disorder. In the United States, a disease is considered rare if it affects fewer than 200,000 people. These patients deserve to be advocated for. They may individually be rare, but together they are a strong community that is willing to fight for themselves or their loved ones.

It is through our personal and professional experiences that shape who we are today. I have worked as both a staff nurse and as a nurse educator in both Pennsylvania State University's undergraduate program and World Campus program. Not only am I a health care professional, but a mother to a child with a rare disorder. Throughout my time in The Pennsylvania State University's DNP program, I dedicated my time to improving communication of both educational and supportive resources to rare disorder patients at an Academic Medical Center in a project "Facilitating Patient Awareness of and Access to The National Organization for Rare Disorders: A Systems Improvement Project". My experience with advocating has significantly increased over time, starting with my son's diagnosis.

I am an active member of the Rare Action Network (RAN), a sub-group of the National Organization for Rare Disorders (NORD). NORD is an organization that I worked with throughout my development of the "Facilitating Patient Awareness of and Access to The National Organization for Rare Disorders: A Systems Improvement Project". Since receiving the AACN's Student Grassroots Ambassador Award, I have taken on the role as South Carolina's State Ambassador in advocacy through the Rare Action Network (RAN). Since this time, along with several rare disorder families, I have made legislative visits to our State Capitol in

Columbia, South Carolina to discuss a new House Bill 3323. My goal as a Student Grassroots Ambassador is to bring patients and families together within South Carolina to work as a community in advocating for rare disorder health care policy issues we are faced with.

The use of social media is powerful with large groups that have hundreds of miles in between. I created a South Carolina Rare Action Network Facebook page that is a platform to share meeting information, health care and rare disorder issues, and events with the rare disorder community within South Carolina. Our first meeting, hosted by the Rare Action Network, will be in Columbia, South Carolina in September 2017. The South Carolina Rare Action Network page encourages the community to join the Rare Action Network which provides great resources for advocates and keeps us connected with the click of a button.

The next Rare Disease day will be on February 28<sup>th</sup>, 2018. As the AACN's Student Grassroots Ambassador, I will continue to lead the community within South Carolina in our next organized visit to Columbia while holding legislative visits to discuss current issues affecting the rare disorder population. Another project we are working on is getting the tools out to the rare disorder community within South Carolina to have their personal communities declare Proclamation's for February 28<sup>th</sup> as Rare Disease Day. I have already received a Proclamation from Dorchester County, South Carolina and from our State Governor for 2017. This enables the word to spread in a greater capacity. I am currently working with a local tv station to make an appearance discussing our advocacy efforts for the rare disorder population which will be aired in early 2018. Great strides have been made and will continue to be made to be the voice of this underserved population.