RARE ON THE ROAD NV







RARE on the ROAD Rare Disease Leadership Tour

WHAT IS ADVOCACY?

ad·vo·ca·cy	/ˈadvəkəsē/	noun	public support for or recommendation of a particular cause or policy.
Examples of Advocacy	Speaking publicly about the cause you support at conferences, on the news, radio, magazines, anywhere you can share information	Talking to your legislators about your cause	Telling the medical provider numerous attempts at shots hurt and you only wish to be poked twice in one day
	Calling the speak with a a friend/ member not their	provider for or family happy with	

WHY DOES IT MATTER?

Sense of purpose knowing that you have the potential to make a difference in the lives of many

Impact made for the cause you support i.e., funding, media exposure, educational opportunities, medical advancements, addition or change in legislation to benefit your cause

Showing people, they have support, a voice and are understood in the challenges they may face

WHAT DOES ADVOCACY MEAN TO YOU?

- **Advocacy** to me is anything I do that spreads Sickle Cell Awareness, Rare Disease Awareness , making long term changes to benefit those impacted by Sickle Cell or other Rare Diseases
- **Advocacy** means that I am actively trying to mitigate the challenges my daughter will eventually face in the workforce, healthcare field, education sector, and everyday life. The things I advocate for today, will benefit my daughter and others like her tomorrow.
- **Advocacy** is sharing SCD information on social media platforms. Advocacy is writing blogs on our organization site about SCD and Rare Diseases.
- **Advocacy** is every time our foundations hashtag (#MakeSicklePopular) is used further raising Sickle Cell Awareness.
- Advocacy is the SCCNV opened in 2020, advocacy is AB254 passed in 2019, advocacy is the State Action Plan being worked on by a SCD hematologist and parents and patients affected by SCD.

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*Everylife Foundation does not endorse any of the statements or opinions shared by Georgene' Glass as a representative of Dreamsickle Kids Foundation, Inc

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