



# **BEING AN EFFECTIVE PATIENT ADVOCATE**

# WHAT IS A PATIENT ADVOCATE?

- Any individual or an organization who publicly supports or promotes the interests of a cause or a specific group of disorders.
- Advocacy is a huge word. It has so many levels and layers. It never looks one way.
- Emphasis on “publicly”

# What's the point of a patient advocate?

- Patient advocacy came out of a need because of challenges faced by patients
- Hospital based advocates have been around since the 70's with the need to monitor patient safety and care.
- The current field of patient advocacy has its roots in the patient rights movement of the 1970's including the American Cancer Society and March of Dimes.



# Accomplishments of early Patient Advocacy

- Patient advocacy has provided a forum for support groups and self-help groups, joining those who have a common illness/disease to assist those who are diagnosed and who have survived
- Today there are many patient advocacy groups, and these are increasingly more involved in the pharmaceutical, regulatory and policy-making process.
- FDA created an office to work with patient advocates. This work in particular has evolved in the 90's with the Patient Representative Program, which solicits the involvement of patients to inform the regulatory decision-making process through advisory committees and panels. Today, this program now includes over 300 diseases and conditions.

# Why is advocacy needed for the Sickle Cell community ?

- Voiceless, Powerless, Misunderstood
- Lack of treatment options - results of lack of funding - results of lack of awareness/concern?
- Unfair treatment in hospitals
- Overall lack of public awareness, knowledge and education
- Potential low quality of life



# What has advocacy looked like in the SC community?

- **Community based organizations** (*Support groups, blood drives, fundraisers, conferences*)
- **Social Media** (*spread of information, forums for personal sharing*)
- **Advocacy Day** (*legislation*)
- **Books**
- **Clinical Trials**

# Advocacy Wins

- Newborn Screening (Legislative Win)
- Camp Sunshine: Founded in 1984, Camp Sunshine provides camp sessions for children with life-threatening illnesses and their families. (Awareness Win)
- Sickle Cell Awareness Month (Legislative Win)

# Barriers to Effective Advocacy

- Education
- Lack of shared success
- Internal community support
- Since Sickle Cell Disease is so complex, it has the potential to cause many negative effects on a person's quality of life. There are many potential challenges. Where do you start?



## Effective advocacy/Measuring advocacy

- Is the advocacy action resulting in a tangible change?

# Using your life to advocate

- Share your story
- Transparency
- Action (informed action)
- Tenacity/Perseverance
- Networking/Partnerships
- Advocating for yourself *\*\*approach\*\**
- Use the resources available
- Internal appreciation for the one who came before you

# What I do as a Patient Advocate

- Support events!
- Tell my story
- Become informed and educate myself
- Have productive conversation with provider
- Support others
- Participate in studies
- Participate in legislative work