The Role of Advocacy in Improving the Patient Experience and Outcomes

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Disclosures

- Consultant for Pfizer Council for Change
- Consultant for Novartis Pharmaceuticals
- Engagement Consultant for OneSCDVoice Platform
- FDA Advisory for Oncologic Drugs
- NHLBI Sickle Cell Advisory
- Health Writer for Raremark
About Me

• Born in West Palm Beach, Florida
• Neither parent knew they carried trait
• Diagnosed with Hgb SS at 3 years of age
• Without the benefit of prophylaxis penicillin
• In an environment with little knowledge of SCD
• Older brother with trait (deceased)
• Younger sister with trait
• 62 years old advocate and author
• No hospitalizations in over 10 years
Why Advocate for SCD

- Risk factors that impact mortality and morbidity
- Continue to increase knowledge in management of SCD
- Safety of blood products and need for chelation therapy
- Successful transition of children who look forward to their future
- Research for drugs that not only address pain but other complications
- Education on the long-term use of opioids and considering alternatives
- Managing the fragmented adult care system
- Peer Mentorship to drive successful outcomes
- Increasing access to care
- Creating a multidisciplinary approach to care
My Role In Advocacy – Serve and Speak

- **Serve** as an advisor for Peer Mentors
- **Speaker** at ASH Minority Recruitment Initiative to share my experience with the next generation of hematologists
- **Serve** as the coordinator of the Sickle Cell Adult Provider Network
- **Serve** on the ASH Coalition representing SCAPN
- **Serve** on Sickle cell advisory at the NHLBI
- **Serve** on Advisory Committee for Oncologic Drug Approval
- **Serve** as a Engagement Consultant for OneSCDVoice Platform
- **Serve** as a Consultant for Novartis for training MSL and creating video
- **Serve** as a Consultant for Pfizer Council for Change
As we promote the “Year of Clinical Trial Diversity”, we invite you to join us in becoming a “Clinical Trials Champion”. This communications toolkit will help your organization advance the conversation with your members about the importance of having minorities participate in clinical trials. In this toolkit you will find information on how to share the resources and promote on social media.
My Role in Advocacy – Speak to Educate

Increase Minorities Representation in Clinical Trials
https://www.fda.gov/ForConsumers/ByAudience/MinorityHealth/ucm472295.htm

Shirley’s Story

• **Video 1**: Shirley’s Story: How to Find Information about Clinical Trials
  Link: http://ow.ly/dX9m3015iEY

• **Video 2**: Shirley’s Story: Getting Access to Cutting Edge Therapies
  Link: http://ow.ly/6vhd3015je8

• **Video 3**: Shirley’s Story: You Don’t Have to be Sick to Participate
  Link: http://ow.ly/pDL73015iTq

• **Video 4**: Shirley’s Story: Diversity is Critical to Making Better Medical Products
  Link: http://ow.ly/aSax3015j0t

• **Video 5**: Shirley’s Story: Diversity is Critical to Making Better Medical Products (LONG)
  Link: http://ow.ly/nKwH3015j6w
Advocacy – Keep up with Trends, Be Aware And Share with Others

Morbidity and Mortality
Changes in statistics

Management of the Disease
Hydroxyurea and Endari

Routine Care for Children
Penicillin Prophylaxis

Red Cell Transfusions
Chelation Therapies

Pain Management
Use of non-opioid analgesia and Nsaids
Patient Advocacy

• Sickle Cell Patients deserve…..
  • Education
  • Empowerment
  • Accessibility
  • Independence
  • Empathy
  • Improved healthcare
  • Advances in patient care (research)
  • Better quality of life
  • Increased length of life
How I Advocate to Patients

- **Encourage** patients to read to increase their knowledge (resources)
- **Educate** patients on current therapies, new research findings
- **Encourage** patients to participate in research
- **Attend various conferences** on SCD to increase my knowledge
- **Participate** in focus groups to share your perspective
- **Work with** Pharmaceutical groups to **design effective studies**
- **Participate** in SCD Coalition to bring new ideas to the forefront
- **Promote** ECHO clinics to **help increase provider knowledge**
- **Make sure I am compliant in my own care**
- **Acknowledge** that my own self-efficacy has played a role
- **Meet everyone** where they are and present myself as a peer or mentor
• Patient Advocacy
  • Patients should be heard
  • Partnerships between patient and physician
  • Everyone should be respectful even in disagreements
  • Shared Decision Making to develop a treatment plan
  • Patient compliance is important
  • Sometimes you cannot support the decision of the patient
  • Some decisions the patient makes may compromise my beliefs
  • If the patient’s quality of life is not improving changes may need to be made
  • Patient’s have varying ideas of what quality of life means to them
Summary

• The role of advocacy is to *educate, empower and facilitate change.*

• The **patient experience is improved** when you **manage expectations** and **create a partnership**

• **Outcomes improve** when **new paradigms are accepted** and **patient/provider participation** in the evolutions of change are adopted.