Role of Community/Patient Advocacy in the success of New Therapies and Programs.....

Working Together to Change Lives

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The Sickle Cell Disease Association of America, Inc. (SCDAA) serves as the nation’s oldest and largest advocacy organization working full time on a national level to resolve issues surrounding sickle cell disease.
Our Mission

"To advocate for and **enhance our membership's ability** to improve the quality of health, life and services for individuals, families and communities affected by sickle cell disease and related conditions, while promoting the search for a cure for all people in the world with sickle cell disease."
Our Services

- National Awareness
- Research Support
- Professional Health Education
- Public Health Education
- Capacity Building & Technical Assistance
- Advocacy
Our Members

“MO’s are the foundation to both SCDAA and the SCD community.”

- Community based organizations designed to serve individuals and families in their respective communities by offering program and outreach services.
- Assist clients with finding quality healthcare
- Maintain databases of individuals and families that have been served over the years
- Perform Community Outreach
- Educate local communities
**SCDAA Accomplishments**

- Instrumental in establishing SCD a National Health Priority through HHS

- Extensive legislative milestones to include:
  - Sickle Cell Treatment Act 2003
  - Procurement of over $40 million through grassroots advocacy
  - Spearheaded Newborn Screening grant program which led to the improvement of screening and follow up activities

- Over 48 member organizations throughout US

- Spearheaded the establishment of the Congressional Caucus on SCD

- Awarded to date approximately $1 million in scholarships and fellow awards to support research

- Distribute SCD Educational materials nationally
Community & Patient Advocacy

Influencing the Success of New Therapies & Programs
The Movement......

➢ **Yesterday**
SCD Advocacy efforts began as a result of lack of medical attention to, screening for, and education about SCD and related conditions. This led to:
* Establishment of Sickle Cell Clinics; Screening, Education, and Counseling Centers; Clinical and Research Centers in major hospitals;
* Morbidity and mortality significantly decreased in children due to newborn screening, penicillin prophylaxis, stroke prevention Clinical research and effective management

➢ **Today**
Advocacy efforts continue to seek solutions for transition issues and increasing mortality of young and older adults.
* Overwhelming need for improved pediatric to adult transition services.
* Limited knowledge of primary care providers about SCD treatment
Key Roles: What we can do!

Influence
Elevate
Educate
Participate
The CHALLENGE

- Sickle cell disease receives a significantly disproportionate amount of funding for programs compared to comparable diseases.
- The Sickle Cell Treatment Act has expired leaving current sickle programs vulnerable
- The need for a comprehensive care model to insure access to high quality care for SCD consumers is large.
What We Can Do …. Today

Through Patient & Community Advocacy

1. Join in a Collaborative legislative agenda

2. Advocate for increased SCD funding among all federal agencies particularly HHS. Make it a component of your legislative agenda.

3. Get your legislative Champions to support SCD and join the Congressional SCD Caucus

4. Forge good relationships & collaborations with HHS agencies and continuously reiterate the importance of a Comprehensive Model of Care structure.
Elevate Awareness

The CHALLENGE

- SCD does not receive mainstream focus
- Correlation between increased funding and increased awareness is large.
- SCD needs to be a National Priority!
What We Can Do .... Today

Through Patient & Community Advocacy

1. Make SCD a part of your national agenda.

2. Utilize Social Media weekly to raise awareness about SCD, major events, key legislation, news regarding new therapies and research.

3. Partner with key organizations to create National SCD Public Service campaigns.
The CHALLENGE

- Knowledge base of SCD among health care providers is relatively low in the US.

- Federally funded Newborn Screening follow up programs are available in only seven states, a reduction from 17.

- Misconceptions about SCD still exist.
What We Can Do .... Today
Through Patient & Community Advocacy

1. Influence your networks/partners to include SCD info, links, etc. as a part of their dissemination strategy to inform their constituents.

2. Advocate for and utilize Community Based Organizations (CBO’s) to educate your clients, families and constituents about SCD

3. Bring attention to the disparities that exist with sickle cell disease
The CHALLENGE

- Clinical research trial participation is a challenge.
- General distrust of the medical/healthcare system still exists.
- Historical events have given the African American populations reason to mistrust clinical trials.
Clinical Trial Participation Statistics

A significant percentage of Americans say it's very important to participate as a volunteer in a clinical trial to improve the health of others

- African-Americans (61%), Hispanics (57%), Asians (50%) and (47%) non-Hispanic whites

These findings are tempered by the reality that participation remains low among minority groups.

- African Americans (5%) of trial participants, Hispanics (1%), Asian less than (3%) and 83% non-Hispanic whites

- Only about a quarter of African-Americans, Hispanics and Asians say they have heard about clinical trials from their doctor, other health care provider or other source.
1. Join in a national effort to educate communities on the importance of Clinical Trial participation.

2. Help re-establish trust by educating those entities that influence patients and families (parents/caregivers, churches/spiritual leadership, providers and peers)

3. Disseminate information about open clinical trials as a part of your education plan.
Other ways to ensure the success of New Therapies and Programs …..

- Incorporate Patient and Family Involvement at all levels
- Keep the SCD Community Informed
- Ensure Transparency
- Utilize and Embrace the value of CBO’s
Working Together....

Working together will ultimately create greater synergy throughout the community for the fight for individuals and families living with sickle cell.

Only together will we effectively:
• Ensure access to care, quality treatment and new therapies
• Increase clinical trial participation
• Find a universal cure
• Increase awareness
“Coming together is a beginning. Keeping together is progress. Working together is success.”

Henry Ford