

Myeloma Link

Empower Black communities in 16 metropolitan areas through free educational support, better access to multiple myeloma care, and information about clinical trials

Why It Matters

Myeloma is the most common blood cancer among Black Americans, who have twice the risk of developing myeloma compared to White Americans and other racial groups and are more likely to be diagnosed at a younger age.

Myeloma survival rates have improved more for White Americans than for Black Americans. Research suggests Black Americans receive significantly less autologous cell transplantation and novel combination therapies, incur higher hospitalization costs, and face longer time from diagnosis to initiation of therapy. Lower income Black Americans are more vulnerable to suboptimal care leading to poorer quality of life and outcomes.

Although disproportionately affected by myeloma, Black patients are significantly less likely to enter a clinical trial further perpetuating disparities in survival rates and quality of care.

Solution

Connect Black patients and caregivers to trusted, free myeloma information and support, as well as enhanced access to care and the latest treatments.

Myeloma Link has partnered with trusted institutions in Black American communities, particularly churches, senior centers, and community health centers to:

- Raise awareness among Black Americans about the disparities in myeloma incidence and treatment, signs and symptoms of the disease, and resources offered by the Leukemia & Lymphoma Society (LLS)
- Provide support services to empower Black myeloma patients with the knowledge and tools needed to seek state of the art treatments including clinical trials

The program deploys a network of volunteers, healthcare professionals (HCPs), and supporters, plus extensive free support services available through LLS, to reach Black patients and caregivers through:

- Trained community outreach volunteers
- Church outreach
- Community education programs
- HCP led patient education programs
- Myeloma education programs for HCPs at FQHCs
- LLS information specialists



Impact

In FY23, LLS served nearly **4,000 Black households** with a blood cancer patient across **16 cities** and immediate surrounding areas.

Since its inception in 2017, Myeloma Link has:



Connected with **>250,000** people including patients, caregivers, HCPs, key stakeholders, and members of the general community



Conducted more than **400** education programs and outreach activities



Increased partnerships with credible religious, social, cultural, and medical infrastructures within Black communities that are critical bridges between the community and LLS



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Key Learnings

- Listen to patient and community voices to inform outreach, patient-facing literature, promotional materials, and communication strategies to ensure they resonate.
- Hire local community specialists dedicated to Black community outreach.
- Collaborating with local and national trusted groups is critical for increasing connections to Black communities.

