innovation impact AWARDS

2016 TOP TEN FINALIST COMPANION APPLICATION TO VIDEO SUBMISSION

This application is intended as a ***companion*** to your video application and is designed to allow you to provide additional details about your initiative, not covered in your video. Written companion applications must be received no later than 11:59 pm ET on **Wednesday, October 5, 2016** and should be e-mailed to Cathy Ferrone at cathy.ferrone@gmail.com, who is acting as the neutral third-party accepting applications on Celgene's behalf.

Applicant Organization Details

Organization name:	The Leukemia & Lymphoma Society (LLS) / The National Black Church Initiative
Initiative name:	Taking it to Church: Enhancing Myeloma Knowledge and Access to Latest Treatments in Black Communities
Key organizational contact:	Carson Jacobi, MPH
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Award Application Questions

1.Please describe the primary goal of your initiative. (Response limited to one sentence)

The goal of this collaborative, myeloma-focused pilot between The Leukemia & Lymphoma Society (LLS) and The National Black Church Initiative (NBCI) is to increase access to expert care and improve quality of life by implementing a church-based initiative in black communities, particularly low-income communities, that will: 1) heighten awareness of myeloma; 2) increase knowledge about the disease and treatment; 3) provide patients with information and resources that will empower them to seek novel treatments and clinical trials in a timely manner; and 4) encourage patients and caregivers to use a new, sustainable support infrastructure.

2. What specific steps will your organization take to achieve your goal? What is your timeline for execution? Please share either specific dates or length of time for each step. (2,500 characters, including spaces)

The church is a trusted institution that families often turn to for information, support, and advice. Increasingly, pastors see themselves as change agents in reducing health disparities; church-based health promotion efforts hold much potential to improve health outcomes in black communities[1,2,3,4]. Together, to achieve our goal, LLS and NBCI will build on a combined 100-year history of community-based outreach and health promotion by implementing the following **six intervention steps** across key churches in metro Atlanta, GA and Washington, D.C. Specifically, we will:

1) Create local networks of **Myeloma Ambassadors** in both cities, composed of myeloma patients or caregivers trained to reach out to families to provide support and information.

2) Hold "**Myeloma Sundays**" during Sunday worship at select key churches (with invitations to members of nearby churches) which will include: a) an inspirational myeloma-focused "health sermon" given by a pastor and a local, respected health care provider, which will describe the disease and steps to take in case of diagnosis; and b) use of the church's Fellowship Hour after the health sermon, when LLS staff members and Ambassadors will give information to myeloma patients and family members and connect them to medical, psychosocial, and financial resources.

3) Conduct additional **in-depth, provider-led education programs in churches for myeloma patients and caregivers** focusing on diagnosis and latest treatments, maximizing patient-provider communication, and clinical trials as a treatment option.

4) Develop **church-based myeloma support groups** facilitated by trained professionals.

5) Create a **directory of resources and cancer centers** for each area. The directory and materials to foster awareness of the initiative's programs will be distributed to the larger NBCI network of thousands of churches in these cities.

6) Connect patients and caregivers with LLS's Information Specialists through all programs, materials and the new resource directory. Information Specialists will assist with navigating treatment, financial and psychosocial resources and clinical trial enrollment.

20 Month Timeline:
1/1/17: Start of initiative
1/1/17-2/28/17: Planning, assessment of local church readiness and interest, church selection
3/17: Launch of Ambassador Network, Resource Book and Myeloma Sundays
3/17-6/17: Development of support groups and education programs, with implementation from 7/17-6/18
12/17: Interim evaluation
7/18: Final evaluation

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[1] Brand DJ, Alston RJ. The Brand's PREACH Model: Predicting readiness to engage African American Churches in Health. *Health Promot Pract.* Published online before print June 7, 2016.

[2] Campbell JK, Hudson MA, Resnicow K, et al. Church-based health promotion interventions: evidence and lessons learned. *Annu Rev Public Health*. 2007; 28:213-234.

[3] Pirkey P, Harmon Be, Draluck E, et al. African American pastors' perspectives on their role in addressing health disparities. [abstract]. In: Proceedings of the Eighth AACR Conference on The science of Health Disparities in Racial/Ethnic Minorities and the Medically Underserved; Nov 13-16, 2015; Atlanta, GA. Philadelphia (PA): AACR: *Cancer Epidemiol Biomarkers Prev* 2016; 25(3Suppl): Abstract nr A30.

[4] Eiser AR and Ellis G. Cultural Competence and the African American Experience with Health Care: The Case for Specific Content in Cross-Cultural Education. Acad Med 2007;82(2): 176-183.

3. **What do you anticipate will be the impact on the unreached population and when do you expect to see results from your efforts? What milestones and metrics will be used to measure your progress against the goal stated in Question One? How will your organization evaluate and monitor the progress of the initiative over time? Please be specific. (2,500 characters, including spaces)**

In D.C. and metro Atlanta, 48% and 54% (resp.) of the population is non-Hispanic black. Blacks have more than twice the incidence rate of myeloma than whites, at 12.8 per 100,000.[5] Survival rates have improved much more for whites than for blacks, in part due to delays in treatment, unequal access to novel therapies (especially novel combination therapies), and stem cell transplantation.[6,7,8,9,10,11] Lower income blacks are particularly vulnerable to these disparities.[12,x] *The proposed initiative aims to improve access to novel therapies and quality of life among blacks with myeloma, especially those with lower incomes, by giving them tools and resources to more effectively navigate the treatment landscape and cope with their disease.*

To evaluate our progress and ultimate impact, we will:

1) Track utilization of Ambassadors and calls to LLS's Co-Pay Program and Information Specialists from both areas.

2) Conduct post-health sermon awareness surveys in churches where Myeloma Sundays are held.

3) Assess attendance at the in-depth education programs and participants' pre-post knowledge, with sensitivity to literacy levels by using materials at a 5th grade level.

4) Capture the number of support groups formed and number of participants.

5) Conduct qualitative interviews with 30-40 individuals who participate in education programs, attend support groups, and/or receive assistance and support from Ambassadors and Information Specialists,

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[5] SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review. 1975-2012. National Cancer Institute. 2015.

[6] Ailawadhi S, Aldoss IT, Yang D, et al. Outcome disparities in multiple myeloma: a SEER-based comparative analysis of ethnic subgroups. *Br J Haematol* 2012; 158: 91-98.

[7] Pulte D, Redaneil MT, Brenner H, Jansen L, Jeffreys M. Recent improvement in survival of patients with multiple myeloma: variation by ethnicity. *Leuk Lymphoma*. 2014; 55(5): 1083-1089.

[8] Waxman AJ, Mink PJ, Devesa SS, et al. Racial disparities in incidence and outcome in multiple myeloma: a population-based study. *Blood*. 2010; 116(25): 5501-5506.

[9] Abouzaid S, Parikh K, Zhou Z, et al. Disparities in treatment patterns and outcomes between Caucasian and African American patients with multiple myeloma (MM). *J Clin Oncol.* 2016, 34 (suppl; abstr 8022).

[10] Bhatnager V, Wu Y, Goloubeva OG, et al. Disparities in black and white patients with multiple myeloma referred for autologous hematopoietic transplantation: A single center study. *Cancer*. 2015: 1064 - 1070.

[11] Warren J, Stevens L, Harlan J, et al. Multiple Myeloma Treatment Transformed: A Population Based Study of Changes in Initial Treatment Management Approaches in the U.S. *J Clin Oncol*. 2013 31(16): 1984-1989.

[12] Fiala MA, Finney JF, Liu J, et al. Socioeconomic status is independently associated with overall survival in patients with multiple myeloma. *Leuk Lymphoma*. 2015, 56(9):2643-2649.

to examine program impact on utilization of novel therapies, including clinical trials, and on quality of life.

While we want to raise awareness among black church members broadly in metro Atlanta (about 704,000) and D.C. (about 442,475), *myeloma is a rare cancer*; we estimate that during the project period, approximately 675 church members will be newly diagnosed or living with myeloma in Atlanta and D.C. (460 and 215 resp.).[13] **Key metrics are:** conduct Myeloma Sundays in 24 churches (16 in Atlanta, 8 in D.C.); train 12 Ambassadors (8 in Atlanta, 4 in D.C.); activate 3 support groups (2 in Atlanta, 1 in D.C.); and hold 12 education programs (8 in Atlanta, 4 in D.C.). *In total, we aim to raise awareness among 1.1 million people and connect at least 200 patients/caregivers to disease and treatment information, resources and support.* Based on these total metrics, **we will create quarterly milestones** to track progress to ensure that we reach the intended population and achieve desired outcomes. We expect measurable results by Dec. 2017.

4. ***[Optional]* Do you anticipate any challenges in accomplishing your goal and measuring your impact? How might you overcome these challenges? (Response limited to 2,500 characters including spaces)**

Despite the need to connect effectively with black communities, LLS has not been able to do so sufficiently because of a lack of targeted initiatives. On average, only 7% of our education program participants are black, about half what it should be based on demographic and disease data. It is essential that we find innovative ways to expand our reach to provide black communities, particularly lower income black communities, with up-to-date disease and treatment information, access to proper and timely treatment, education, financial resources, and support services.

Establishing an ongoing relationship with NBCI and local churches will help overcome the challenges we have had in engaging black communities. Nonetheless, measuring our impact will be a challenge. We recognize that by not assessing changes in health care utilization directly we may be underestimating our impact; we will implement a rigorous qualitative follow-up evaluation with program participants to begin to gauge our effectiveness in this area. At the same time, it is also important to note that the program's impact on health care utilization and quality of life is likely to unfold over time, beyond the implementation and evaluation period, as myeloma is becoming a chronic disease. Our local Ambassador program and support groups will foster an enduring connection between myeloma patients and caregivers in these communities and LLS' national resources.

Identifying myeloma patients and caregivers will likely be another challenge. To maximize success, we will hire additional local staff in Atlanta and D.C. to collaborate with pastors and community members, *specifically with churches and residents and low income areas*; work with pastors and existing local volunteers to build the Ambassador program and encourage networking to identify unreached

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[13] Copeland G, Lake A, Firth R, et al. (eds). Cancer in North American: 2009-2013. Vol. 1: Combined Cancer Incidence for the United States, Canada, and North America. Springfield, IL: North American Association of Central Cancer Registries, Inc. June 2016.

individuals with myeloma; utilize “pew cards” to identify individuals with myeloma, based on past NBCI efforts; and capitalize on relationships that LLS already has with local providers. We will also draw on the extant published evidence base[ii,14] and NBCI’s expertise in order to assess which churches are most “ready” to participate based on interest and capacity, and to optimize our efforts.

It can also be challenging to collect thorough evaluation data in communities. To maximize data quality, we will draw on the expertise of an established LLS evaluation partner and will ensure that all program and evaluation materials are developed with community input.

5. **Is there any additional information you would like to share with the judges? (Response limited to 2,500 characters including spaces)**
The proposed pilot will be the first collaboration that we know of in the country between the church and a major health advocacy organization that systematically works through churches not only to heighten awareness of myeloma, but also to create ongoing, personalized connections with myeloma patients and caregivers that can increase access to state of the art care and improve quality of life. LLS is the world's largest voluntary, nonprofit health organization dedicated to funding blood cancer research and providing education and patient services. We are excited to partner with the NBCI, a coalition of 34,000 churches whose mission is to provide critical wellness information to its members and the public. LLS and NBCI have recently begun to partner on a church-based project to promote awareness of clinical trials as a treatment option.

The LLS Information Specialists**,** who provide personalized support services to patients and families, are a crucial component of this program. These skilled masters’ level Specialists will provide up-to-date disease and treatment information, help navigate barriers to care, and assist with trial identification and enrollment. Our Ambassador program will be modeled on LLS’s Patti Robinson Kaufmann First Connection Program, which matches patients and caregivers with trained peer volunteers. We will also incorporate materials from Celgene’s *Standing in the Gaap for African Americans with Multiple Myeloma* initiative as appropriate; we view our on-the-ground effort as a complement to this initiative. Our efforts will be overseen by LLS’s Dr. Elisa Weiss, Vice President of Patient Access and Outcomes, who has over 20 years’ experience implementing community-based health promotion programs in underserved communities and leading multi-sector partnerships[15,16,17,18,19,20].

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[14] Kaplan S, Ruddock C, Golub M, et al. Stirring up the Mud: Using a Community Based Participatory Approach to Address Health Disparities through a Faith-Based initiative. *J Health Care Poor Underserved.* 2009, 20(4):1111-1123.

[15] Breslau ES, Weiss ES, Williams A, Burness A, Kepka D. The Implementation Road: Engaging Community Partnerships in Evidence-Based Cancer Control. *Health Promot Pract*. 2014: April 3.

[16] Goytia EJ, Lounsbury DW, McCabe MS, Weiss ES, Newcomer M, Nelson DJ, Brennessel D, Rapkin BD, Kemeny MM. Establishing a general medical outpatient clinic for cancer survivors in a public city hospital setting. *J Gen Intern Med*. 2009; October, Supplement.

[17] Park ER, Weiss ES, and Moy B. Recruiting and enrolling minority patients to cancer clinical trials. *Commun Oncol.* 2007; 4:1-4.

Scalability and Sustainability. This program is designed to build community capacity, so that peer-to-peer support activities can be sustained. LLS will continue to fund local support groups established through this initiative and will continue to work with Atlanta and D.C. churches through our local chapters to facilitate access to resources. Upon successful execution of this program, we will seek additional funding from a variety of sources to expand to other areas of the U.S. An ultimate goal is to create a sustainable and scalable program to improve access to care and quality of life for all blood cancer patients and their families in the black community.

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[18] Shen MJ, Binz-Scharf M, D'Agostino T, Blakeney N, Weiss E, Michaels M, Patel S, McKee M.D, Bylund CL. A mixed methods examination of communication between oncologists and primary care providers among primary care physicians in underserved communities. *Cancer*. 2015: 121(6): 908-915.

[19] Weiss ES, Jurow Stevenson A, Erb-Downward J, Combs S, Sabino E, Michel T, Kemeny M., Ackley-Kazdal T, Garcia-Febo L, O'Connor, M, Rapkin B. Sustaining local partnerships to address health disparities in times of economic instability. *J Health Care Poor Underserved*. 2012;23(4):1527-1535.

[20] Weiss ES, Taber S, Breslau E, Lillie SE, Li Y. The Role of Leadership and Management in Six Southern Public Health Partnerships: A Study of Member Involvement and Satisfaction. *Health Educ Behav*. 2010;37(5):737-752.