

## PROPOSAL TO MERGE PINK-4-EVER AND THE R.E.D. ALLIANCE

### Historical Context:

In 2008 John Miller established Pink-4-Ever after the death of his oldest sister to breast cancer and during the fight to survive breast cancer of his younger sister, Nadia. He witnessed the impact breast cancer had on his sisters, his family and the community. He also recognized a lack of awareness and support in local traditional organizations and decided to create a movement among the minority community to dispel myths about breast cancer and to create an environment where “it’s okay to talk about it (breast cancer).” John and family members chose the name Pink-4-Ever to reflect the lifelong impact of a breast cancer diagnosis and treatment and of living as a survivor. In creating a breast cancer awareness minority community movement, Pink-4-Ever has maintained a long-standing relationship with the faith-based community—conducting educational programs at churches, participating in health fairs and offering support to families touched by breast cancer. Pink-4-Ever established an emergency assistance fund to provide financial help to women in treatment, particularly women who sometimes have difficulty accessing and receiving help from other community agencies.

Since 2008 Pink-4-Ever has grown its programming to include: screening mammography assistance; Sisters Inspired to Stand (S.I.S.)--the support and empowerment group for breast cancer survivors and caregivers; and establishing the Junior Ambassadors Initiative, a group of high school and college students who are trained to share breast health information and self-advocacy messages with their peers and to positively promote the Pink-4-Ever mission. Nadia Miller has served as the president of Pink-4-Ever since 2013. Nadia represented Pink-4-Ever when a group of breast cancer stakeholders were brought together in 2015 in response to the public revelation of the breast cancer disparity problem for Black women in Indianapolis.

The revelation about breast cancer disparities for Black women in Indianapolis came from an Avon Foundation research study finding there were high rates of breast cancer mortality for Black women in many U.S. cities. Indianapolis ranked 10<sup>th</sup> out of the 50 largest U.S. cities in breast cancer mortality among Black women. When the Avon Foundation study findings were released in 2015, Dr. Robert Goulet was serving on the board of directors of Susan G. Komen Central Indiana. Dr. Goulet was instrumental in getting Komen to convene a coalition of stakeholders to try to collectively address the mortality disparity in Indianapolis. These stakeholders included representatives from the faith-based community, hospitals, research/academic institutions, advocacy/service organizations and insurers. Lisa Hayes, a breast cancer survivor who was the director of Women’s Health at Gennesaret Free Clinic and also involved in breast cancer advocacy around the community, was one of the stakeholders invited to the convening meeting.

Trying to form a coalition of stakeholders into a mission-driven, productive organization proved to be a challenge, but after months of meetings the group reached consensus on two things: 1) to name the organization the R.E.D. (Reaching to End Disparities) Alliance and 2) to launch its work by partnering with churches to train breast health advocates to serve in their congregations. The decision to have R.E.D. in the organization name was a deliberate attempt

to distinguish the organization from some of the materialistic pink branding that had become associated with breast cancer and to symbolize (through the color red) the urgent need to address the high death rates for Black women. The stakeholders also recognized the need for more research to obtain more information about breast cancer issues in the Indianapolis Black community.

Lisa and Nadia created a breast health advocate training curriculum, recruited partner churches and conducted the first advocate training in August 2015. They worked with other Alliance members to create a survey to elicit data and information on topics including: breast health/breast cancer knowledge; access to screening services; healthcare coverage; individual or family breast cancer impact; and lifestyle behaviors (smoking, nutrition, exercise, etc.). The newly-trained breast health advocates were tasked with distributing surveys in their churches. Using the Pink-4-Ever “Pink Sunday” model, in October 2015 the advocates shared breast cancer awareness information and talked about the mortality disparity during Sunday church services and also facilitated the completion of over 700 surveys. In subsequent months interns compiled the survey data. The Alliance used the data to provide partner churches with a church profile and recommendations on actions they could take to address the issues identified for their congregation members. The recommendations centered on actions to help church members improve their overall health and decrease their breast cancer risk, such as offering exercise or healthy cooking classes, connecting members with smoking cessation resources and holding breast health education workshops. The Alliance also provided a resource guide for churches to connect with other community organizations and individuals to help them implement programs in their churches.

In 2016 interest in continuing to build the Alliance waned for some of the original stakeholders and Komen Central Indiana was non-committal about supporting the Alliance financially or otherwise for the long-term. However, a small group including Lisa, Nadia, NaKeita Boyd and Pastor David Greene, remained committed to the effort and became a steering committee to lead the Alliance. Also in 2016 Lisa and Nadia re-visited an idea they had first come up with in 2015—to hold a Breast Health Summit, particularly targeting Black women to attend, to provide expert-led workshops, health screenings, connections for breast health services and a culturally-friendly environment to discuss and seek solutions for the breast cancer disparities in Indianapolis. They also viewed the Summit as an opportunity to re-engage the original stakeholders and/or to garner new supporters for the Alliance mission to address disparities. Lisa led the effort to get Summit sponsors and was able to secure enough funding for the Alliance to host the first **Stay Alert, Stay Alive Breast Health Summit** in February 2017. The Summit sponsors included some of the original stakeholder organizations, as well as new supporters, like the Catherine Peachey Fund. The Summit also had a diversity of participants, including community members, health professionals, government representatives and cancer advocates. The success of the Summit propelled the steering committee to seek to establish the Alliance as a 501(c)(3) organization. In designing the organizational structure and goals, the steering committee used the Chicago Breast Cancer Task Force (now Equal Hope) as a model. The Alliance was granted 501(c)(3) status in July 2017. The primary distinction between the Alliance and other local cancer organizations was and continues to be centering its work on utilizing research data, from its own research initiatives and partnerships or from other published research to more specifically identify the reasons for the breast cancer

disparities in Indianapolis. And then to work collaboratively with other stakeholders to implement interventions that lead to better breast cancer outcomes for Black women.

The first research partnership the Alliance formed was with Silvia Bigatti with the IU Fairbanks School of Public Health, who was conducting a study about the breast cancer treatment experiences of Black women in Indianapolis. Lisa assisted Silvia with recruiting and enrolling study participants and conducting participant final interviews. Information from that study, along with information women shared at a series of community town hall meetings the Alliance conducted after the 2017 Breast Health Summit, revealed that many Black women felt they would have had a better experience if they had more social support at the time of their diagnosis and during their treatment. Around the same time Pink-4-Ever was creating S.I.S. and Nadia and Lisa saw another opportunity for the Alliance and Pink-4-Ever to collaborate. S.I.S. now functions as a joint initiative of the two organizations. The Alliance has also had partnerships with researchers at IU School of Medicine/IU Simon Cancer Center researchers, Purdue University/Regenstrief Institute, IU School of Nursing and the Komen Tissue Bank. The Alliance plan to expand its Breast Health Advocate program in 2021 is a response to research showing breast cancer disparities are caused, in part, by delays Black women experience between abnormal screening mammograms and diagnostic tests, delays in starting treatment and treatment abandonment. Breast health advocates can help Black women navigate the health care system to receive more timely services and support. The American Cancer Society has made a verbal commitment to the Alliance to help fund the expansion of the Breast Health Advocate program.

A common thread between the histories of Pink-4-Ever and the R.E.D. Alliance is Nadia and Lisa. Since their own breast cancer experiences they have both dedicated their lives to advocacy and supporting women from screening through diagnosis, treatment and survivorship. They advocated along separate paths, occasionally crossing each other, until their paths converged in 2015. In many spaces across the community—faith-based institutions, academia, healthcare, cancer support organizations—Lisa and Nadia are the face of Black breast cancer advocacy and survivorship.

### **Factors Supporting Merger:**

- Mission Congruence
- Strength of Existing Partnership (S.I.S., Pink Sundays, IU School of Medicine/Simon Cancer Center Partnership)
- Opportunity for Leveraging Resources (human, physical and financial)
- Alleviate Public Confusion and Divided Loyalties
- Capability to Address Breast Health Needs Across Continuum of Care for Black Women
- We're better together

