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26-27, back cover / Hope Tariro Trust: p. 11 (top right
and bottom right) / Kibuuka Mukisa Oscar: pp. 6, 15 /
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Museruka Emmanuel: pp. 5, 16, 17 / Mwanga & Ukweli
(Dr. Denis Mukwege Foundation): p. 20 / Phoebe Education
Fund for Orphans & Vulnerable Children (PEFO): pp. 8, 9 /
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FRONT COVER: MU-JHU Young Generation Alive youth
leaders during a planning session for HIV awareness outreach
(Uganda). Photo by Museruka Emmanuel.
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Welcome

We are enormously proud to bring you this latest Year in Review. It is filled with inspiring examples of leadership at the grassroots, leadership that is overcoming the AIDS pandemic in 15 countries in sub-Saharan Africa where the SLF supports critical work.

Leadership has become a fraught concept in the world at this moment. It is so often thought of in terms of a charismatic individual who holds the authority of an office, with a singular voice and power. What is remarkable and transformative in the response to HIV and AIDS at the community level in sub-Saharan Africa is that the collective action and determination necessary to address the pandemic has required leadership by the many. It has necessitated a coming together of young women, grandmothers and communities to consult, make decisions, act and communicate with one another – all with the purpose of devising and implementing thoughtful, humane and tremendously effective strategies. And it is our partners – the community-based organizations at the heart of the pandemic – who bring people together in healing and inclusive ways.

A new leadership has emerged, overwhelmingly demonstrated by women, who were and are the first responders in the crisis brought on by HIV and AIDS.

A new leadership has emerged, overwhelmingly demonstrated by women, who were and are the first responders in the crisis brought on by HIV and AIDS. At the epicentre of a pandemic driven by gender inequality are grandmothers, activists, young women and girls – all of them leading organizations, support groups and youth-outreach healthcare interventions. They are engaging entire communities, leading by example, and practicing a democratic and transformative leadership.

This is leadership beyond providing school supplies, job training, healthcare and counselling. It is about love, trust and compassion. It is about increasing resilience and psychosocial wellbeing. It is about family and social solidarity. It is about deeper commitments to the full protection, fulfillment and enjoyment of human rights by women and girls. It is about tens of thousands of women within...
the reach of our 125 partner organizations who are working with communities to alter the course of grief, loss and the havoc of HIV and AIDS. It is about leadership that guides everyone, with dignity and intelligence, out of the AIDS pandemic.

There is an extraordinary amount yet to be done. HIV is being transmitted to young women in alarming numbers. We know that you will join us as we move to the next chapter of the AIDS pandemic, a chapter in which young people continue to mobilize to educate and support one another through community-based programmes that engage their leadership.

And finally, at the Stephen Lewis Foundation, we are in a moment of leadership transition ourselves. We follow inspiring and expert role models in community-based organizations with whom we partner. We know that as founders move on, and new leadership emerges, it is the SLF staff and community as a whole who hold the values and ethos of the organization with the same vision and commitment as ever. Our determination and solidarity is unwavering, embedded in and guided by the profound expertise and aspirations of our African partners. We look, as they do, to the future, with hope and confidence in their abilities to overcome.

With your unwavering support, and the powerful impact of community-led programmes, we know this legion of grassroots leaders will prevail.

Ilana Landsberg-Lewis
Co-Founder, and Senior Advisor to the Board

Zahra Mohamed
Interim Executive Director

Our determination and solidarity is unwavering, embedded in and guided by the profound expertise and aspirations of our African partners.
Leadership in action

In Uganda, when Josephine Nabukenya’s mother visited an organization, MU-JHU, for a health check-up, she discovered that she and her daughter were HIV positive. She didn’t tell anyone, not even Josephine. Thinking she would soon die, she drafted a letter that Josephine later found by accident. That’s how Josephine, at age eight, discovered that both she and her mother were living with the virus. She didn’t tell her mother she knew, and she spiralled in blame, fear and isolation.

“Finally, I joined a psychosocial support group at MU-JHU, and it helped me to come to terms with being HIV positive,” Josephine says. The group was based at MU-JHU Care, a research collaboration between Makerere and Johns Hopkins universities. “The group made me realize I wasn’t the only one, and we were getting a lot of love from different doctors and counsellors. To me, the group helped me grow and actually get to the point where I could think about realizing my dream.”

Years later, Josephine attained part of her dream: she became a leader at MU-JHU. Her mother joined a group as well, participated in treatment and psychosocial support, and is thriving as a result. Josephine now works at MU-JHU with 305 children and youth who are living with HIV.

Josephine Nabukenya is an HIV advocate who’s passionate about providing better treatment and psychosocial support to people living with HIV.
“Already we have 50 school visits planned, 15 community outreaches, and a lot of activities for mutual support groups,” she says. Within the groups, new peer leaders are identified and trained on how to work with other youth who live with HIV and who face stigma and discrimination. “And we pick one of the youth in each group to be the leader of the process. We’re also doing fundraising activities with the groups, for the children who are dropping out of school, because they can’t pay for school fees or materials. The beauty of our programme is that it’s youth-led, and we have internship slots within the groups for a number of youth every year – they come on board with us, gain skills and learn how to run activities.”

Such leadership, common in our partner organizations in 15 countries, is powerful, because it involves collective action by thousands of young women like Josephine, as well as thousands of grandmothers and community members. Together, they consult, make decisions and take action – all with the singular purpose of turning the tide of HIV and AIDS in sub-Saharan Africa. This is leadership beyond individual heroes. It’s about deeper commitments to human rights and protections for women and girls. It’s about tens of thousands of women at our 125 partner organizations who are leading Africa out of the AIDS pandemic.

“Many organizations say they’re youth-led, but often that’s not true. Our activities really are youth-led. The fact that the youth who used to be with MU–JHU are now getting on board as staff and volunteers, that’s something that we should be proud of. MU–JHU and the SLF have supported us since we were little, and now we have grown up and are starting to lead this work.”

– Josephine Nabukenya, MU–JHU, Uganda

Ugandan youth look up to leaders like Josephine, the co-founder of MU–JHU Young Generation Alive, a psychosocial support group and partner of the Stephen Lewis Foundation.
Real leadership means real democracy

Around the world, many traditional leadership structures are mired in conflict and power-mongering. But in communities where our partner organizations work, leadership means determined, grassroots engagement – space to talk to one another, thoughtful checking in and genuine transparency. There’s power there, real power. When people think of leadership, they usually picture an individual, but in communities where our partners work, grandmothers lead. As part of collective responses to the AIDS pandemic, committees of grandmothers lead organizations, support groups, youth-outreach efforts and healthcare interventions. Years ago, the grandmothers became home-grown leaders, even as they were weary and worn from the tragedies they’d endured. Today, their actions and democratic processes continue to grow out of their concern and love for those around them. Increasingly and importantly, young women are assuming leadership roles in communities, alongside their grandmothers.
The organizations we support know all too well the UNAIDS statistic that 460 adolescent girls are diagnosed with HIV each day – and they’re determined to slow this trend, one community at a time.

“We have seen a big change in our grandmothers since they entered our programmes, and some of them have taken leadership training,” said a staff member at Hillcrest AIDS Centre Trust (HACT), in South Africa. “If there is a problem in the community, they mobilize, make the call for a public meeting, and invite people from outside to come in and discuss the problem they have identified. If there is someone sick in the community not being attended to, or if there is a case of abuse, it is the grandmothers who are taking the initiative.”

Last year, granddaughters and other young women continued the work of their grandmothers in sub-Saharan Africa. They didn’t have a choice; young women and girls are disproportionately affected by HIV. In 2017, in eastern and southern Africa, for example, 80% of new HIV transmissions were among teenage girls. In response, thousands of young people in programmes, such as those run by HACT, have returned to their communities to become leaders. Last year, they volunteered, became staff members, spoke out against abuse, faced off against injustice, joined local councils, and ran for public office. That’s real leadership, real democracy.

Human connection, love and trust are key to successful community outreach and holistic care interventions like those provided by Hillcrest AIDS Centre Trust (HACT) in South Africa.
The power of grassroots politics

Rights and access to healthcare in Uganda are central to the work of Mpaata (on left).
Mpaata was 77 years old when she won an election in her community in Uganda. “I'm beginning my role as Chairperson of the Older Persons Committee at the village level,” says the grandmother who worked with Phoebe Education Fund for AIDS Orphans and Vulnerable Children (PEFO), one of the Foundation’s many partners in Uganda. “This makes me proud. It’s important for grandmothers to be involved in politics, because we have pressing issues, but the government has left us behind.”

It’s this deep commitment to issues that makes running for public office a necessary next step in the collective work of grandmothers. “We’re the people who can deliver on older people’s issues,” Mpaata explains. “I’m concerned with healthcare, and a fellow granny, who was just elected to another committee, is talking about social assistance and grants for older people. We believe, if we had representatives at all the levels of government, these issues would be taken care of. We hope this is just the beginning.”

Collectively, grandmothers are leaders in community-based organizations, land councils, local governance committees and national parliaments across sub-Saharan Africa.

“This is like a dream come true. I remember when grandmothers felt hopeless, like they were nobody. Now, in the village where we work, they’re leaders. Grassroots mobilization has given grandmothers back their lives. In fact, it’s giving them even more than they had before. You see, before HIV, there was still poverty, and there was still gender inequality that was repressing their lives, keeping them down. You could hear them say things like, ‘You know the men are repressing us, we are struggling, we have no property, but we have sons and daughters.’ Most of these women were only hanging on because of their children. Then, when their children died, they had to rebuild completely different lives. So you see, this goes way beyond recovery, way beyond reclaiming what was lost. This is something brand new these women are doing. Something entirely new the world has never seen before.”

– Kenneth Mugayehwenkyi, Founder of Reach One Touch One Ministries, and Chair of the Grandmothers Consortium, in Uganda

As Chairperson of the Older Persons Committee, Mpaata is a community leader who works to amplify the voices of her peers. She helps them to claim their rights, as well as access healthcare.
Our partner organizations are saving millions of lives. They report that, thanks to the leadership and commitment of home-based care workers, the vast majority of adults and youth are taking HIV medications. This treatment adherence is important, as taking antiretroviral medication can be challenging. Many teenagers and children living with HIV need nutritious food, access to healthcare facilities, and support in taking multiple pills a day for the rest of their lives, a daunting and difficult task, especially in situations involving stigma and discrimination.

With youth leaders and home-based care, such as that offered by Hope Tariro Trust (HTT), in Zimbabwe, people overcome these challenges and barriers. HTT, a partner of the SLF, has improved the lives of more than 5,400 orphaned and vulnerable children, mainly through psychosocial support at play centres and through support to grandmothers raising children orphaned by AIDS. “Our home-based care workers are helping to keep people on treatment by closely monitoring patients with constant follow-up visits and also by offering emotional support,” says one HTT staff member.
An estimated 25 million people in sub-Saharan Africa live with HIV, more than double the number in the rest of the world, according to UNAIDS. Just over half of those individuals are adhering to successful ARV therapy. Astoundingly, however, most of our partner organizations report adherence rates above 95% – and people are thriving. These are inspiring successes, thanks to youth leaders and their elders in community-based organizations, who lead the way in renewing hope, optimism and confidence in communities where they work.

Hope Tariro Trust, an SLF partner organization in Zimbabwe, has improved the lives of more than 5,400 orphaned and vulnerable children, mainly through psychosocial support and through supporting grandmothers raising children orphaned by AIDS.
They demanded action (not charity) as a matter of social justice

In Tanzania, grandmothers are the pillars of their nation. They’ve raised a generation of grandchildren left parentless by the AIDS pandemic, and they’ve shown what love, commitment and leadership means. Last year, in a show of solidarity and with support from the Stephen Lewis Foundation, more than 200 grandmothers from Tanzania, South Africa, Uganda, Canada, Australia, the UK and the USA gathered in Arusha, Tanzania, to tell the world that they’re overburdened (typically raising four to 10 children each) and under threat (often defending their right to own land or to run a small business).

They marched through the streets and attracted media attention in an effort to put pressure on local and national leaders to prioritize pensions, childcare grants, land and property rights, protection from violence and abuse, better access to healthcare, and increased representation of older women at all levels of government. As the Tanzanian grandmothers later stated: “We face the stigma of HIV and AIDS, and as we get older our lives are valued less and less. We are speaking out now because we know that if we hide these truths, the problems will never end.” The gathering was one of a series held in recent years – in Swaziland (now eSwatini) in 2010, Uganda in 2015, and in South Africa in 2016.
In solidarity with the Tanzanian grandmothers, youth helped lead the march.

“Protect us, listen to us,” the grandmothers said in Tanzania. “We are not asking for favours. We are speaking out for our human rights. When we are well taken care of, the entire society will flourish.”

In 2018, hundreds of grandmothers from across Tanzania marched in Arusha to demand their rights.

In solidarity with the Tanzanian grandmothers, youth helped lead the march.
Women’s leadership

Hundreds of community-based organizations have partnered with us over the years. Recently, 40 of them reported that they work with 50,000 people and their families during home-based care visits. The majority of the visits, as well as the organizations themselves, are run by older women who often volunteer their time while living with HIV in their own families and communities. Since the beginning of the pandemic, they’ve shown breathtaking leadership in ensuring that people living with HIV have access to healthcare, support and information.

Mama Darlina Tyawana, South African advocate and activist with the Treatment Action Campaign (TAC), leading member of the Grandmothers Movement in South Africa.
Six areas of work

Since 2003, the Stephen Lewis Foundation has partnered with 325 community-based organizations on more than 1,800 initiatives in the 15 countries that have been hardest hit by the AIDS pandemic in Africa. We partner with grassroots organizations whose work covers six major areas of work on HIV and AIDS.
Every week, approximately 6,200 young women, aged 15–24, contract HIV.

Children, youth and HIV & AIDS

The current generation of children and youth will lead Africa out of the AIDS pandemic. Last year, the Foundation continued partnering with community-based organizations who work with millions of children and youth. HIV and AIDS has had an especially devastating effect on children in sub-Saharan Africa: 1.8 million teenagers and children were living with HIV in 2017. Women are particularly vulnerable. Every week, approximately 6,200 young women, aged 15–24, contract HIV, often because of forced marriages, gender-based violence and other situations beyond their control. Grassroots organizations support these children and youth, providing healthcare, medication, counselling, testing, awareness, education, school uniforms and food. And, since the beginning of the pandemic, the organizations have provided care for children orphaned by AIDS – much of the care led by grandmothers who developed visionary, holistic community programmes.
Nyimbwa Multi-Purpose Organization of People Living with HIV/AIDS (NYIMUPHA), in Uganda, strengthens communities through income-generating activities, micro-loans, house construction for the elderly, home-based care, education support for orphaned and vulnerable girls, and awareness-building around HIV and AIDS and sexual reproductive health rights.

**Grandmothers**

Last year, Africa’s grandmothers continued to care for millions of children orphaned by AIDS. In some countries, it’s estimated that 40-60% of orphans live in grandmother-headed households. Grandmothers have become small-business owners or farmers earning a living for their families. They mobilize and advocate for their own human rights as well – rights to pensions, healthcare, land rights and political representation. They work with governments and international agencies as community experts. They work as activists for their grandchildren’s rights. They nurture, feed and send them to school, teaching them about HIV prevention care and treatment. As one grandmother poignantly put it, “We will not raise more children for the grave.”

“Grandmothers stand with orphans, but who stands for us? We must not be left alone to raise the next generation. These orphaned children are society’s future leaders...”

From the Tanzania Grandmothers Gathering Statement, 2018
In 10 of the 15 countries where our partners work, only one doctor is available for every 10,000 people. This is where home-based care workers step in. Thousands of them support people to lead full, healthy lives, providing essential healthcare to those living with and affected by HIV and AIDS. If hunger and nutritional deficits are challenges, they provide food baskets, as well as guidance on food preparation and vegetable gardens. If stigma and discrimination are devastating people, they help to restore loving family environments and community support. If financial pressures are creating catastrophic issues, the caregivers connect families to income-generation and small-business training opportunities. Home-based care workers visit countless homes each day, travelling great distances, often on foot or by bicycle. The trust and healing they generate is immeasurable.

Across Africa, home-based care workers, such as these with mothers2mothers (Lesotho), travel long distances to reach communities. Most of them are women who volunteer their time, skills and leadership.

**Home-based care**

The trust and healing they generate is immeasurable.
Positive living

It takes great courage to openly declare one’s HIV positive status. Throughout sub-Saharan Africa, people living with HIV and AIDS – many of them women – have formed associations to increase awareness about the virus, provide leadership in addressing stigma and discrimination and educate their communities about HIV prevention, care and treatment. By their example of positive living, they encourage others to get tested, speak out and advocate for access to antiretroviral medicines and the repeal of outdated or punitive laws. The Treatment Action Campaign (TAC) of South Africa, for instance, has saved millions of lives, as it campaigns and litigates on critical issues related to healthcare, including HIV.

“Without TAC’s brilliant, principled, unswerving interventions, millions would not now be in treatment,” said Stephen Lewis, Co-Founder, and Co-Chair of the Board of the Stephen Lewis Foundation.
Sexual violence

Violence – and the threat of violence – traumatizes women and girls at every stage of life, and includes the additional threat of contracting HIV and other diseases. The Foundation partners with organizations that challenge gender-based violence and provide urgent medical care. One such partner is Panzi Hospital, led by Nobel-prize winner Dr. Denis Mukwege and his staff in the Democratic Republic of the Congo. They treat survivors of violence in three ways: medically; through psychosocial services; and by providing legal advice. Panzi staff have cared for more than 50,000 survivors of sexual violence in the past 20 years. The Foundation has many partners in other countries who provide similar, life-saving care and critical support.
LGBTQ Africa Initiative

In many parts of sub-Saharan Africa, LGBTQ communities are under attack. Of the 54 countries on the African continent, more than 30 have laws that criminalize consensual sexual relations between men, and 24 have similar laws that apply to women. LGBTQ people live with intolerable persecution – they are threatened, jailed, beaten and sometimes murdered. The Foundation partners with 16 LGBTQ organizations led by courageous and strategic activists who reach those who are marginalized and targeted, including those subjected to violence and discrimination in Uganda, Kenya, Rwanda, Tanzania and the Democratic Republic of the Congo. The 16 organizations offer access to HIV testing and counselling, as well as solidarity, legal services, healthcare, support and hope. “We have partnered with a number of donors, and the Stephen Lewis Foundation is different,” explained a leader from one of our LGBTQ partner organizations in Kenya. “You don’t tell us what to do – you give us support, and we walk together as partners, as human beings.”
WHERE WE WORK

In evaluating organizations with whom we partner, we look at priorities, such as:

- women involved in leadership roles;
- community involvement in planning and implementation;
- the organization’s governance measures solidly in place;
- and people living with HIV & AIDS represented in the organization’s staff, management and Board.
“In the past, if a woman wanted to speak at a village meeting, she would have to kneel. With home-based care education and MWEDO’s empowerment programmes, this expectation shifted. In the past, village assemblies were attended only by men, but now, women are included on the agenda and participate in meetings. Women are increasingly being invited and participating in forums as equals. This growing visibility and confidence, along with access to income through MWEDO’s income-generation groups, is encouraging women to take up other rights, such as owning land.”

– Maasai Women’s Development Organization, Tanzania
At Sophiatown Community Psychological Services, support activities for children are part of holistic approaches to addressing traumas inflicted by the AIDS pandemic.
From resilience to leadership

Life is complicated. One approach or solution (one medication, one school or one income-generation project) cannot hope to provide the answer to a community’s complex challenges. Our partner organizations take a holistic approach to addressing HIV and AIDS, focusing on the intersection between physical, financial, social, educational and emotional wellbeing.

In Kenya, for example, Kiambu People Living with HIV/AIDS (KIPEWA), works from the premise that becoming healthy is as much a “battle of the mind” as it is a physical struggle – and as much a political and economic battle as it is a social struggle. KIPEWA’s programming takes all this into consideration, and the organization is a leader in the communities where it works.

Similarly, in South Africa, innovative programming is being done by community-based organizations in the area of psychosocial care. Sophiatown Community Psychological Services (SCPS) and Ekupholeni Mental Health and Trauma Centre are two excellent examples. SCPS provides culturally relevant forms of psychosocial support and works with communities on social justice initiatives, mainly with communities affected by HIV and AIDS and bereavement, and with migrant communities affected by forced displacement, xenophobia and war. Ekupholeni, also in South Africa, offers mental-health services involving processes of healing, recovery and empowerment in communities facing HIV and AIDS and historically targeted for political violence, crime and gender-based violence.

All these partners work in areas beset by poverty and HIV, yet they deliver hope and health every day. They know that, for communities facing unimaginable struggle, being listened to and heard is key to moving from resignation to resilience – to leadership.
$118.5 million in programme spending

Direct support to over 1,800 initiatives with 325 community-based organizations in 15 African countries.

Programmes

We’re committed to getting the majority of our revenue to the organizations with whom we work. Between July 1, 2003, and December 31, 2018, the Stephen Lewis Foundation disbursed and committed a cumulative $118.5 million in programme spending, including direct support to over 1,800 initiatives with 325 community-based organizations in 15 African countries. This represents more than 82% of total expenditures over the past 15 and a half years.

Administration

Administration is essential to the success of every charitable organization. At the Foundation, costs associated with day-to-day operations and expenditures ensure we’re accountable for how funds are being allocated. We’re committed to keeping these administrative costs low through in-kind donations and pro-bono support. We’re proud to report that over the past 15 and a half years, administrative costs were 10% of our total spending.

Funds Development

In order to continue to support the innovative programming developed by our African partners, the Foundation has increased its fundraising capacity to engage supporters through a variety of recognizable initiatives, such as special events that feature the voices and work of our partners, and by encouraging monthly donations. Over the past 15 and a half years, our fundraising costs were 8% of our total expenditures.
We’re committed to keeping administrative costs low. Over the past 15 and a half years, from 2003 to 2018, admin costs were 10% of total revenue.

Want More Information?
For a copy of the Stephen Lewis Foundation’s full audited financial statements and the link to our annual Canada Revenue Agency (CRA) charity returns, please visit our website (stephenlewisfoundation.org). The Foundation’s fiscal year runs from July 1 to June 30. Our auditors are Grant Thornton LLP Chartered Accountants. The Foundation’s charitable number is 89635 4008 RR0001. If you have questions about our financial statements, please call 1-888-203-9990 (ext. 244) to speak to Esther Vise, Director of Finance.
About the Stephen Lewis Foundation

The Stephen Lewis Foundation works with community-based organizations who are turning the tide of HIV and AIDS in sub-Saharan Africa. Since 2003, we’ve partnered with 325 community-based organizations on more than 1,800 initiatives in the 15 countries that have been hardest hit by the AIDS pandemic. Most of these organizations were born of the resolve of small groups of individuals who, after witnessing the devastation of HIV and AIDS in their own lives, began to work determinedly to save their communities. Over the years, the organizations have grown and evolved to become trusted and important local institutions, and leaders in the fight against HIV and AIDS.

Staff and volunteers at the organizations help people to access healthcare, counselling and support – and restore hope in every home and community. They recognize that gender inequality is driving the AIDS pandemic in Africa, and that it’s necessary to have specialized programmes to support women and girls. They know that the best way to secure decent futures for the millions of children orphaned by AIDS is to empower the grandmothers who are caring for them. And they reach out to LGBTQ communities who struggle to survive, not only with HIV, but also with discrimination and persecution.

Our community-based partners have set for themselves the ultimate goal of restoring the resilience of the people and communities who have been hardest hit by HIV and AIDS. Their holistic programmes, which combine medical and material assistance with emotional and psychosocial support, are life changing. They’re enabling people who are living with HIV and affected by AIDS to cope with crisis, rebuild their strength and face the future with confidence.

With every Year in Review, we present the evidence that because of their dedicated, loving efforts, our partner organizations are contributing to profound changes in people’s lives.
Thank you to our donors and partner organizations

We feel privileged to stand in solidarity with community-based organizations, whose holistic programmes are life saving and life changing. The Stephen Lewis Foundation invests in their work in homes and communities, investments made in the struggle to turn the tide of HIV & AIDS. And the SLF is grateful to our supporters – the thousands of individuals, the unions, the faith groups, the schools, the private-sector partners, the foundations, and the members of the Grandmothers to Grandmothers Campaign – whose financial contributions have made this work possible. Thank you for your support and thank you, most of all, for understanding why community-based organizations matter.
Please donate now

Thanks to your generous support, the Foundation has invested $118.5 million through partnerships with more than 325 grassroots organizations in 15 countries — responsively, without needless bureaucracy, directly at the community level. Now that’s undeniable success. A grassroots-to-grassroots movement. Let’s continue.

stephenlewisfoundation.org/donate

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