

# The Campaign to End Fistula: 10 Years On



Campaign  to End Fistula





# Obstetric Fistula: A Neglected Crisis that Affects Millions of Women and Girls Worldwide



Obstetric fistula not only causes pain and suffering, but it often results in stillborn births and the added indignity of incontinence and disability. A woman with obstetric fistula spends each day surviving, not “living”.

To end this disease, we need to ensure universal access to the three most cost-effective interventions that can prevent maternal deaths and childbirth injuries like fistula: family planning; a trained health professional with midwifery skills at every birth; and timely access to high quality emergency obstetric and newborn care. We also need to make sure that the more than 2 million women and girls currently suffering with fistula in silence have access to high quality surgical treatment to repair the condition.

It's also critical that we tackle the underlying societal drivers of fistula, including poverty, socioeconomic and gender inequality, child marriage and early childbearing, and marginalization and lack of access to education.

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Cover: Dhaka Medical College Hospital, Bangladesh.

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This page: Fistula survivor at Babbar Ruga Fistula Hospital in Katsina, Nigeria.

© Dr. Gloria Esegbona

Help stop the suffering  
of women living with  
one of the most dreadful  
childbirth conditions.

Make a donation today [click here](#).

While funding for the overall strengthening of maternal/newborn health systems has increased in a push to meet Millennium Development Goal 5 – which especially supports the prevention element of a holistic fistula response – the challenge of putting an end to obstetric fistula continues to require vastly intensified efforts at the regional, national and international levels. These efforts must include gender and socioeconomic equality, empowerment of women and girls, and promotion and protection of their human rights.<sup>1</sup> To accelerate progress, substantial additional resources need to be forthcoming and the existing case backlog must be addressed through increased funding that supports treatment, rehabilitation and reintegration of women and girls affected by obstetric fistula.

**The UNFPA-led global Campaign to End Fistula works to bring awareness to the devastating childbirth injury that affects more than 2 million women and girls in developing countries.**

Join the Campaign to End Fistula in its world-changing mission and help women worldwide by sending a gift of \$35, \$50, \$100, \$500 – or as much as your heart dictates.



**\$10** helps feed a recovering fistula patient for two weeks

A simple lunch for patients at Dhaka Medical College Hospital, Bangladesh.

© GMB Akash/Panos Pictures

<sup>1</sup> The United Nations Secretary-General Report, “Supporting Efforts to End Obstetric Fistula.” See more at [endfistula.org](http://endfistula.org)



**\$60** pays for a life-saving Caesarean section to prevent the occurrence of fistula

**\$75** pays for transportation from home to hospital and back, which enables poor women and girls from very remote provinces to access life-transforming surgery

**\$150** provides a small business starter loan to a recovered fistula patient and helps break the cycle of poverty and vulnerability that renders women and girls susceptible to fistula in the first place

**\$400** pays for a fistula repair surgery

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A recovering fistula patient learns to use a knitting machine at Kwali Rehabilitation Centre in Kano, Nigeria, which teaches women basic skills such as literacy, knitting and sewing.

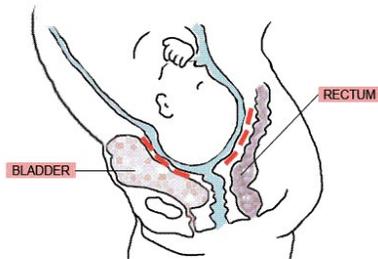
© Lucian Read/WpN/On behalf of UNFPA

“The persistence of fistula is a result of human rights denied and a reflection of human rights abuse. It reflects chronic health inequities and health-care system constraints, as well as wider challenges, such as gender and socioeconomic inequality, child marriage and early child bearing, all of which can undermine the lives of women and girls and interfere with their enjoyment of their basic human rights.”

- Babatunde Osotimehin  
Executive Director, UNFPA

# What is obstetric fistula?

Obstetric fistula – a hole between the bladder and the vagina or the rectum, or both – is a childbirth injury caused by prolonged, obstructed labour without timely emergency medical intervention such as Caesarean section. The baby rarely survives such labour.



In unrelieved obstructed labour, the prolonged pressure between the baby's head and the mother's pelvis cuts off the blood flow in these structures (highlighted in red), which results in a hole or, in medical terms, a "fistula", i.e., an abnormal communication between two hollow organs, one being the vagina and the other the bladder or rectum (or both). This leaves the woman unable to hold urine and, sometimes, bowel content.

## Amani's Story

Amani is a pregnant adolescent who is expecting her first child. Her story is an example of the kind of obstacles many women and girls face from the moment they go into labour.

Tragically, Amani's experience occurs all too often to some of the poorest, most vulnerable and remotely located women and girls. When faced with life-threatening childbirth complications, those without access to emergency care will likely suffer from serious injury, infection, disease or death. Obstetric fistula is one of the most devastating of all possible maternal injuries, and although exact prevalence rates are not known, it is generally accepted that at least 2 million women and girls in developing countries live with obstetric fistula.<sup>2</sup>

The infographic was produced for the Campaign to End Fistula in partnership with Johnson & Johnson. [Click here](#) to learn more and download Pathway to Ending Obstetric Fistula Infographic.

<sup>2</sup> [who.int](http://who.int)



# Why does obstetric fistula still exist?

Although obstetric fistula is a devastating medical condition, in most cases it is both preventable and treatable - which is why it has all but disappeared in wealthier countries. The persistence of obstetric fistula reflects the failure of health systems to provide accessible and equitable sexual and reproductive health services, including universal access to family planning, skilled birth attendance, and referral to emergency obstetric and newborn care when needed. The condition also persists because of broader human rights violations

facing women and girls such as poverty, socioeconomic and gender inequality, early marriage, early child bearing and lack of schooling, all of which impede well-being and opportunities. The average cost of fistula treatment - including surgery, post-operative care and rehabilitation - is approximately \$400. Yet millions of women and girls are unable to receive this care for a lack of available services by skilled, trained, expert obstetric fistula surgeons, and when services do exist, many are not aware of them or cannot afford access to those services.

*"I lived for a year with fistula. I just stayed at home with my mum. Sometimes I could see her crying. No one wanted to be around me. My in-laws abandoned me. They didn't want to pay for an operation to fix me. All I could do was stay home. I couldn't go outside just in case I urinated on myself. When I went outside people would laugh at me, pointing. It was like a prison. I sometimes felt it would be better if I died and just be quiet somewhere else."*

- Rebecca Mambweni  
Democratic Republic of the Congo



Rebecca Mambweni was just 23 when she went through days of agonizing labour. She pulled through but her baby did not, and as a result of the injuries sustained during labour, Rebecca began leaking urine. After receiving surgical treatment and social reintegration services, she is now employed and optimistic about her future. Rebecca hopes to one day open a beauty salon.

© Robin Hammond/Panos/DRC

# History of the Campaign to End Fistula

*"In the last decade, the Campaign to End Fistula has dramatically strengthened the visibility of obstetric fistula by increasing collaboration and coordination among doctors, hospitals, advocates and governments. This leadership has worked to inject data into a field where little existed before, and has helped at a global level to distribute government and private resources where women with fistula need them most."*

– Kate Grant  
CEO of the Fistula Foundation

The Campaign to End Fistula is an initiative led and coordinated by the United Nations Population Fund (UNFPA), with the goal of making fistula as rare in developing countries as it is in developed ones. The Campaign was launched with partners in 2003 in response to a multi-country study that revealed a critical need to lower the incidence of fistula, to treat a growing backlog of cases, and to raise awareness of this severely neglected health and human rights tragedy. The Campaign to End Fistula brings together hundreds of partner agencies at the global, national and community levels and is present in over 50 countries across Africa, Asia, the Arab States and Latin America.<sup>3</sup> The diverse scope and reach of its partners, that range from human rights organizations, research and medical institutions and surgeons to other health care providers and donors, has enabled the Campaign to initiate innovative joint projects, forward-thinking strategic direction, heightened advocacy and knowledge generation about obstetric fistula.

The Campaign to End Fistula focuses on three key areas of intervention: prevention, treatment and social reintegration.

It also helps raise awareness about gaps in maternal/newborn health services and underlying drivers such as socioeconomic, gender and other forms of inequality. As a result, more comprehensive services are now offered for fistula prevention and treatment, and thousands of the poorest, most vulnerable women and girls have regained hope and dignity.

By providing a snapshot of various initiatives developed over the last 10 years, this publication highlights some of the achievements made possible through the Campaign to End Fistula and its partner agencies. Of note, during a decade of activities the Campaign has drawn the attention of policymakers, health officials, affected communities and individuals, as well as the general public to the issue of fistula.

## Campaign to End Fistula celebrated as a good practice to achieve the MDGs

In 2010, the United Nations Development Group MDG Policy Network featured the Campaign to End Fistula as one of the few initiatives in its MDG Good Practices document. Some of the successes highlighted include the Campaign's "innovative and comprehensive approach, combining programmatic, technical and advocacy interventions" as well as its "commitment to reinforcing south-south cooperation to promote the sharing of knowledge and skills, treatment and training, the development and implementation of national media and communication approaches, and the integration of best practices".

<sup>3</sup> The Campaign to End Fistula includes over 90 partner agencies at the global level. The full list can be found in Annex.

# What has the Campaign achieved over the past 10 years?

*“The Campaign to End Fistula in the last decade along with other health care providers has highlighted the role of midwives as a first reference for women suffering from obstetric fistula. The Campaign involved midwives as key players in fistula prevention, screening, raising awareness and timely referral for treatment, and thus has [facilitated] reintegrating women and girls as productive members back to the families and societies.”*

– Pashtoon Azfar, Regional Midwife Adviser Asia for the International Confederation of Midwives (ICM)<sup>4</sup>

Over the past decade the Campaign to End Fistula has quadrupled in size and has significantly impacted the lives of thousands of women and girls and their communities. UNFPA alone has directly supported 35,000 women and girls with access to fistula surgical treatment and care, while Campaign partners like EngenderHealth (22,000 women and girls), Hamlin Fistula Ethiopia (18,500), Amref Health Africa operating in Tanzania (9,500) and Fistula Foundation (8,500) have supported thousands of others. Despite these successes, an estimated 2 million are still in need of treatment services and further resources, while recognition is critically necessary to ensure that fistula is finally eliminated and the health and well-being of these women and girls is restored.

## Campaign to End Fistula Countries<sup>5</sup>



## Number of people receiving services by a selected number of Campaign to End Fistula partner agencies<sup>6</sup>

	In 2012	Since 2003
Women who received fistula repair operations	25,000	131,000
Women who received social reintegration services	9,500	35,000
Health professionals (including doctors and non-physician clinicians) trained in fistula care	3,000	16,500

<sup>4</sup> Read about Ms. Azfar’s work at [nytimes.com](http://nytimes.com)

<sup>5</sup> Campaign to End Fistula countries map is available at [endfistula.org](http://endfistula.org)

<sup>6</sup> Table provides a snapshot of overall figures from 2012 and since the Campaign began in 2003; however, these figures are likely much higher as the table does not include data from all Campaign partners. Indeed, figures reflect self-reported data from 48 partner agencies (57% of total). In some cases, data has not been consistently collected for each of the four indicators over the last 10 years.

# Selected Achievements

1

Increased capacity for prevention, treatment and social reintegration

2

Harnessing the power and potential of technology

# Increased capacity for prevention, treatment and social reintegration

Shortly after the Campaign to End Fistula was launched in 2003, it was estimated that at the current capacity rate it would take 400 years to clear the backlog of patients and that the unmet need for surgical treatment could be as high as 99 per cent.<sup>7</sup> Though more recent figures are not available, Campaign to End Fistula partner agencies have made great strides in preventing the occurrence of fistula cases and improving treatment capacity. Following are samples of these efforts within the Campaign's three main focus areas: prevention, treatment and social reintegration.

## Prevention: Groundbreaking initiatives prevent maternal deaths and injuries

A healthy woman means healthier infants, children, families, communities and societies. Prevention is a core strategy for eliminating obstetric fistula and saving the lives of the women, girls and newborns that die each year from complications of pregnancy and childbirth. Over the past 10 years, the Campaign to End Fistula has supported partners that work to prevent obstetric fistula from occurring in the first place and to prevent its reoccurrence in survivors during their subsequent pregnancies. Some of these initiatives include:

- ▶ In 2008, UNFPA and the International Confederation of Midwives (ICM) launched the global Midwifery Programme with the goal of improving skilled attendance at all births in low-resource countries. The joint programme now operates in 30 countries and has embarked on a number of initiatives to improve midwifery education and training; strengthen and establish midwifery associations; and advocate for increased investment in midwifery services. As a direct result of the programme, more than 10,000 midwives have been trained and 175 midwifery schools have received books, clinical training, equipment and supplies.
- ▶ The Government of Niger and Health and Development International (HDI) have made tremendous strides in preventing obstetric fistula and reducing maternal mortality through its Rapid Maternal Mortality and Obstetric Fistula Prevention project in the country, which began in 2008. Within the initial pilot area (approximately 100,000 people), total birth-related maternal mortality has decreased by 85 per cent and the number of stillborn births or babies that die within three days has decreased by 62 per cent. Since July 2009, only one case of obstetric fistula has occurred, compared with the World Health Organization's (WHO) estimate of 24-48 new fistula cases. Some of the strategies that contribute to this success include close collaboration and strong community engagement; monthly data collection and analysis; and case investigation of all fistula occurrences and maternal deaths. HDI and its partners plan to expand the programme to other areas of Niger and other countries with unacceptably high incidences of maternal death and obstetric fistula.

<sup>7</sup> Browning A., Patel TL. FIGO initiative for the prevention and treatment of vaginal fistula. *Int J Gynecol Obstet* 2004; 86(2): 317-22. Quoted in S. Ahmed, S.A. Holtz, "Social and economic consequences of obstetric fistula: Life changed forever?". *International Journal of Gynecology and Obstetrics* (2007) 99, S10-S15.

## New resources developed for fistula treatment

Although prevention is the ultimate means of eliminating obstetric fistula, for women and girls living with the condition treatment is critically important as it enables them to reclaim their lives, hopes and dignity. Tragically, the demand for treatment still far exceeds its current availability for women and girls around the world. The Campaign, therefore, has prioritized increased access to fistula treatment by upgrading health facilities and training health personnel.

- ▶ In 2013, UNFPA, Jhpiego, WHO and Intel launched three interactive multimedia e-learning midwifery training modules to strengthen key life saving skills of midwives and other frontline health workers on pre-eclampsia/eclampsia, post-partum hemorrhage and obstructed labour. The latter three causes alone account for 50 per cent of maternal mortality cases, and these training tools can play a significant role in improving maternal health outcomes.

- ▶ To fulfill the urgent need for physicians trained in fistula care, the International Federation of Gynecology and Obstetrics (FIGO), EngenderHealth, the International Society of Obstetric Surgeons (ISOFS), the Royal College of Obstetricians and Gynaecologists and UNFPA developed the Competency-Based Fistula Surgery Training Manual. The first standard training manual of its kind, its

purpose is to enable physicians to acquire the knowledge, professional skills and attitudes needed to prevent obstetric fistula and provide surgical, medical and psychosocial care to women and girls with the condition. A select group of senior fistula surgeons in Africa and Asia have also been trained in how to use the manual and are now training other surgeons in order to improve surgical outcomes.

- ▶ To provide fistula surgeons and health care teams with much needed medical supplies, a UNFPA and ISOFS collaboration created two complementary kits of specialized medical instruments and supplies for fistula repair surgery. The kits were developed to ensure that the highest quality and specialized materials are made available and delivered directly to expert fistula surgeons and health care teams. Since launched at the end of 2012, 16 countries have ordered over 725 kits.



Fistula surgeons inspect the new fistula repair kits on display at the 2012 International Obstetric Fistula Working Group (IOFWG) meeting.

© UNFPA

## Social reintegration: Empowering fistula survivors and helping prevent future cases

Experience shows that healing fistula requires more than surgical intervention since many women and girls living with the condition have endured tremendous psychological and social trauma. Furthermore, while most cases can be treated, a very small percentage will be deemed inoperable. Previously, very few countries supported social reintegration services for those with fistula but with support and technical guidance from the Campaign to End Fistula, 58 per cent of supported countries now provide these services along with prevention and treatment.

▶ Fistula Foundation Nigeria empowers fistula survivors and women and girls with inoperable and incurable cases (who are often abandoned by their families and cast out of their communities) by providing counseling, professional training, extensive post-operative follow-up, and involving patients' families and communities in sensitization activities. The programme helps fistula patients regain their autonomy and dignity so that they may better reintegrate into their communities and support themselves.

▶ The Liberia Fistula Project is a joint initiative between the Liberian Ministry of Health and Social Welfare and UNFPA, with financial support from Zonta International. The project provides life skills, adult literacy and business management training with specific skill-building lessons in tailoring, soap making, tie-and-dye, cosmetology and pastry making. At the end of their training, fistula survivors are given starter kits in line with the skills they have acquired – and \$100 to begin their new lives. The project also provides prevention and treatment services and has helped over 1,000 fistula patients receive surgical repair since its inception in 2008.

▶ Since 2001 the Association for the Rehabilitation and Re-orientation of Women for Development (TERREWODE) in Uganda has worked to develop a vibrant, grass roots network of diverse volunteers, including fistula survivors, community-based women's groups, medical staff, journalists, law enforcement officers and school communities. As a result of their advocacy and awareness-raising efforts, more than 800 women suffering from fistula in eastern Uganda have received treatment, counseling and social reintegration services, and the number of hospitals that offer fistula surgical treatment has expanded from zero to eight.



Rohima and Banu met at Dhaka Medical College Hospital, Bangladesh, and have become close friends.

# Harnessing the power and potential of technology

As technology becomes more readily available, groundbreaking initiatives across the globe, including in the most remote and challenging contexts, are harnessing its power to change the landscape and the future of women and girls who suffer from fistula and to aid in its prevention.

► In Western Kenya, DRI uses mapping technology and geographic information system (GIS) tools to help explain the spatial distribution and key characteristics of women receiving fistula treatment.

The map helps identify where there may be clusters of patients, where additional outreach may be required, and where additional resources that address underlying causes of obstetric fistula may be needed.

## Mapping technologies help visualize solutions

► Launched by Direct Relief International (DRI), UNFPA and the Fistula Foundation, the pioneering Global Fistula Map (see [globalfistulamap.org](http://globalfistulamap.org)) provides the first and only snapshot of the state of fistula treatment capacity around the world. As of 2013, the map highlights over 230 health facilities that provide fistula repair surgery in 42 countries. Its purpose includes visualization so donors and advocacy organizations may understand where financial and other resources are most needed, and helping public health researchers answer questions related to the supply and demand for fistula treatment.

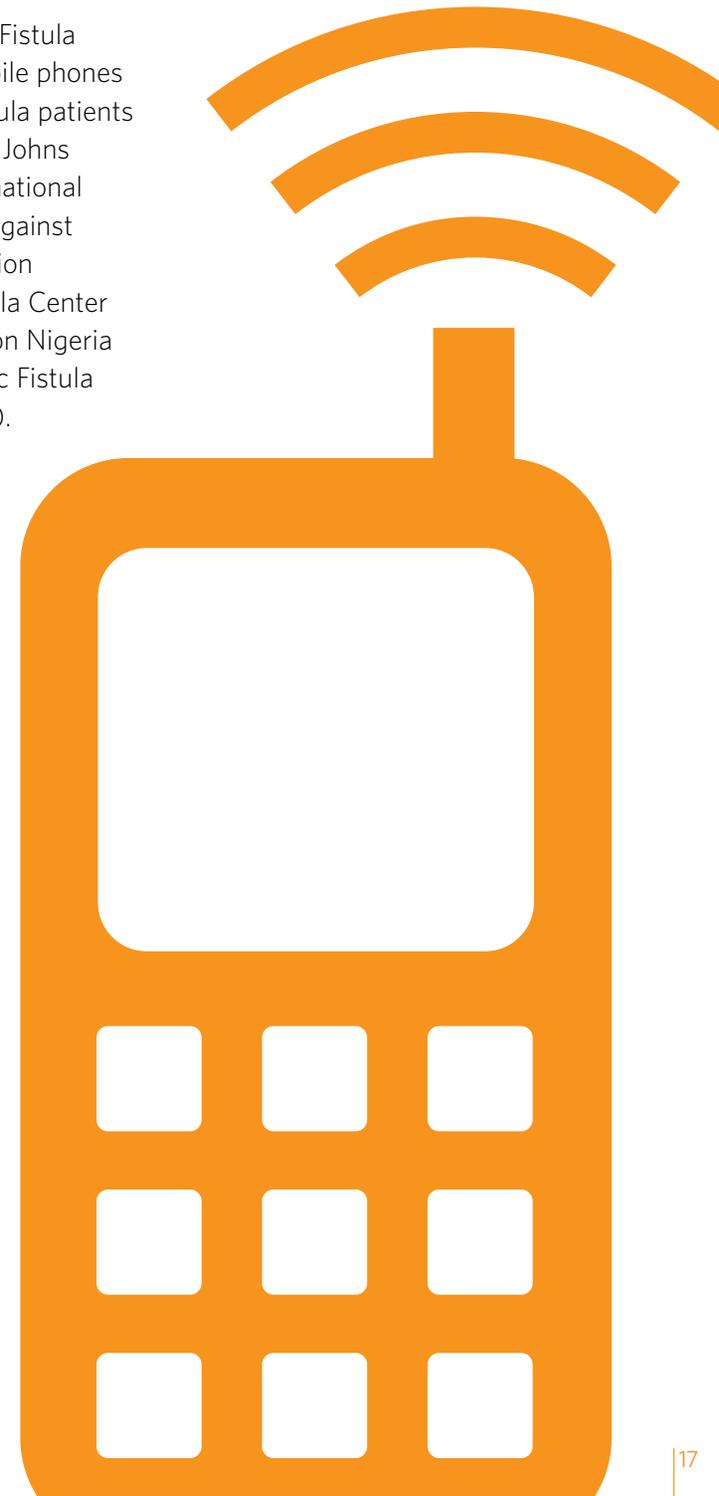


## Mobile phones expand access to care for the poorest and most remote women and girls

▶ In 2009, Comprehensive Community Based Rehabilitation (CCBRT) in Tanzania partnered with UNFPA and Vodacom to initiate an innovative project that uses the M-PESA mobile phone money transfer service to help women and girls access fistula repair surgery. Although CCBRT provides fistula surgery free of charge, many women and girls reported that they were unable to reach a hospital due to the high cost of transportation. Using mobile-to-mobile banking technology, funds can now be transferred to fistula patients to cover this cost. Since the project began, the number of women that received fistula treatment nearly doubled from 268 in 2010 to 500 in 2012. Through community outreach and the use of electronic media including mobile phone messaging, the Pakistan National Forum on Women's Health has also more than doubled the number of fistula patients treated.

- ▶ CCBRT in Tanzania, Médecins Sans Frontières Belgium in Benin, Dr. Abbo's National Fistula Center in Sudan, the Aberdeen Women's Centre in Sierra Leone and the Children's Surgical Centre in Cambodia have all set up toll-free hotlines that provide women and girls with fistula information and care options. In Sierra Leone, 361 patients were referred to the Aberdeen Women's Centre and 248 patients were treated within the first year of the hotline's launch.
- ▶ Fistula Foundation Nigeria, Health and Development International (HDI), Healing Hands of Joy and Family Care International use mobile phones to help coordinate health service treatments and transportation, including referrals, for fistula patients. HDI considers mobile phone use a critical contributing factor in the impressive results their prevention initiative saw within a short period of time.

- ▶ Several Campaign to End Fistula partner agencies use mobile phones to help follow up with fistula patients after treatment, including Johns Hopkins University, International Nepal Fellowship, Hope Against Fistula Support Organization (Uganda), Gynocare Fistula Center (Kenya), Fistula Foundation Nigeria and the National Obstetric Fistula Centre Abakaliki (Nigeria).



## All-terrain motorbikes connect women in hard-to-reach areas with prevention and treatment services

In Senegal, Women and Health Alliance International (WAHA) and the Fistula Foundation use all-terrain motorbike ambulances to aid in the prevention and treatment of obstetric fistula. Motorbikes are low cost yet effective vehicles that can quickly transport women and girls to medical treatment services in areas with unpaved roads. The programme piloted in 2010 and in its first year, requests for and use of motorbike ambulances for pregnancy and childbirth emergencies and transportation for fistula care increased by more than six fold, while the number of skilled attendants at birth increased by 40 per cent. WAHA now deploys 57 motorbike ambulances throughout Senegal, 15 in Somalia, 26 in Niger, 10 in Kenya and 52 in Ethiopia. In the near future, WAHA plans to deploy 26 more in Chad, for a total of 429 motorbike ambulances across 20 countries.



WAHA and Fistula Foundation all-terrain motorbike ambulances.

# Advocacy and Awareness Raising

Campaign to End Fistula partner agencies, fistula survivors, national champions and global activists have all been instrumental in increasing the visibility and awareness of fistula.

# First International Day to End Obstetric Fistula marked globally

In December 2012, the Third Committee of the United Nations General Assembly passed a resolution that called for renewed focus and urgent additional resources for fistula. It also designated the 23rd of May as the International Day to End Obstetric Fistula, to be observed annually beginning in 2013 as a way to significantly raise awareness and intensify actions towards ending obstetric fistula. To mark the first international day, the Campaign helped organize and support activities in over 30 countries around the world. The day was launched on the African continent in the Democratic Republic of the Congo with the United Nations Secretary-General, the UNFPA Executive Director and the President of the World Bank among those who visited patients who had received or were awaiting fistula repair surgery at the HEAL Africa Hospital.

*"We must invest in the people who have suffered so much. We must invest in women and girls. Today is the first International Day to End Obstetric Fistula. Many women and girls at this hospital [HEAL Africa Hospital] suffer from fistula...In pain, and often unable to control bladder and bowels, they are disabled and often shunned by society."*

- Ban Ki-moon, United Nations Secretary-General



United Nations Secretary-General Ban Ki-moon and UNFPA Executive Director Babatunde Osotimehin visit a fistula ward in the Democratic Republic of the Congo on the first International Day to End Obstetric Fistula, 2013.

© UN Photo/Eskinder Debebe

In New York, UNFPA organized an event that featured high-level guests, including actress, singer and Virgin Unite ambassador Natalie Imbruglia; Ambassador and Vice President of the United Nations General Assembly A.K. Abdul Momen; and United States Congresswoman Carolyn Maloney. Artists representing fistula-affected countries also performed at the event, including singers from Senegal who premiered a new song about the issue. A highlight of the event was the powerful testimony of Beriha Reda, a fistula survivor from Ethiopia who now works as a safe motherhood ambassador at Healing Hands of Joy.



Gillian Slinger, coordinator of the Campaign to End Fistula, presents flowers to fistula survivor Beriha Reda from Healing Hands of Joy after she delivered her powerful testimony at the high-level launch event in New York.

© Whitney Kidder/Paper Moon Photography



Senegal's Baay Bia is joined by other artists in a performance of his original song about obstetric fistula at the high-level launch event in New York.

© Whitney Kidder/Paper Moon Photography

# Advocacy tools expand outreach to new audiences

While the issue of obstetric fistula is still unrecognized in many parts of the world, Campaign to End Fistula partners are finding new and innovative ways to raise its profile both globally and locally. For example:

- ▶ In 2013 the Fistula Foundation became part of the new Facebook-based Half the Sky Movement: The Game, a game that highlights issues, including fistula, that impact women in the developing world. Players are asked to complete tasks and unlock real-life donations, including donations from Campaign to End Fistula partner Johnson & Johnson. This platform draws visibility, action and funding for fistula repair surgeries for women and girls around the world.
- ▶ Operation Obstetric Fistula utilizes the Global Fistula Map to identify areas that are most in need of fistula surgical repair services. Their Obstetric Fistula Treatment Expansion Network (OFTEN) connects donors with fistula

surgeons working in some of the world's most under-served areas. Funds are unrestricted, which gives surgeons the flexibility to identify their greatest needs in exchange for patient record verification. This streamlined approach allows donors to understand exactly where their money is being spent. So far, the programme is operational in Malawi and has plans to expand into Madagascar.

- ▶ UNFPA has partnered with various public and private agencies to expand knowledge about fistula via social media. For example, with support from Virgin Unite Ambassador Natalie Imbruglia, the Draw Shop contributed a video to the Campaign to End Fistula that launched at the international day event in New York. Its whiteboard animation delivers a powerful and clear message about obstetric fistula and what people can do to help eliminate the condition globally.



Animation developed by the Draw Shop tells how you can change a life today. Narrated by Natalie Imbruglia. [Click here](#) to see the animated End Fistula video.

# Fistula survivors advocate for prevention, treatment and social reintegration

*"Because I know what it feels like, a woman leaking urine, the trauma that is attached to the condition... I decided I'll not just sit back and let other women suffer in silence, just the way I suffered in silence."*

– Sarah Omega, Kenya

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After surviving the ordeal of fistula and regaining her place in society, Sarah Omega became an advocate for the Campaign to End Fistula and is now Outreach Manager in Western Kenya for One by One's Let's End Fistula initiative.

© David Rosse/Panos/Kenya



Fistula survivors are important sources of knowledge and expertise and play a unique and powerful role in the global movement to end obstetric fistula.

Their insights have already made a real difference in strengthening health services and helping other women have healthy, safe deliveries and, when necessary, receive treatment for obstetric fistula.

- ▶ Campaign partner One by One in Kenya has developed a network of fistula survivors and community volunteers to educate their own communities about fistula, find and bring fistula patients in for care, and provide reintegration support for women when they return home following treatment. In 15 months, 1,553 education sessions conducted through this network reached over 125,000 people living in rural areas.
- ▶ Similarly, in Ethiopia, Healing Hands of Joy's Safe Motherhood Ambassador programme provides counseling, economic support, micro-loans, literacy training and maternal health training to fistula survivors. Graduates then monitor and register pregnant women in their village and report to trained health workers. Thanks to this programme, over 1,000 safe, skilled, fistula-free deliveries were made in rural Ethiopia between July 2012 and February 2013.



One by One community outreach programme.

© Charlie Ainslie

# Research activities broaden knowledge about obstetric fistula

Solid, reliable data on fistula is scarce, scattered and difficult to obtain, but a number of Campaign to End Fistula partners are conducting research to better understand the burden and needs of women and girls suffering from fistula, as well as the effectiveness of treatment options. For example:

▶ Johns Hopkins University, together with WHO, the MacArthur Foundation and UNFPA, is conducting a multi-country study to examine post-operative prognosis, improvements in quality of life, and social reintegration and rehabilitation of fistula patients after surgical treatment. The study's results are intended to help with advocacy efforts and improve the appropriateness, cost effectiveness and feasibility of programmes and national strategies for treatment, prevention and rehabilitation for fistula patients, including training of fistula surgeons.

▶ The Geneva Foundation for Medical Education and Research (GFMER) has developed an online database to collect information about fistula patients. The database represents the first systematic data collection tool and is aimed at improving our understanding of the pre- and post-operative profile of fistula patients so that more appropriate and effective preventative measures may be designed. In 2011, a "digital pen" that facilitates the conversion of patient data into a database was developed. An iPad app will also be developed to facilitate better patient follow-up.

▶ In Kenya, One by One is using digital pens to collect in-patient and post-treatment follow-up data for monitoring, evaluation and research purposes at a relatively low cost.

▶ EngenderHealth's Fistula Care programme has conducted numerous research projects, including determinants of post-operative outcomes of fistula surgical treatment, costs of fistula services in Nigeria and Ethiopia, a five-country review of Caesarean section records and a feasibility study on conducting community-based fistula screening processes. This research has increased and improved the much-needed evidence base for fistula prevention and treatment.



# The Way Forward

While remarkable progress has been made over the last 10 years, the number of yet-to-be-treated women and girls remains enormous, underscoring the urgent need to significantly scale up effective prevention, treatment and reintegration services. The United Nations Secretary-General's Report, "Supporting Efforts to End Obstetric Fistula," recognized this need, stating that while there is global consensus on the key interventions required for ending fistula, intensified political commitment and financial mobilization are essential for accelerating progress.<sup>8</sup>

The Campaign to End Fistula is committed to moving forward by strengthening strategic activities, broadening reach, leveraging partnerships, raising visibility and improving performance. UNFPA is proud and grateful to be one of many Campaign partners helping to achieve these ends. The successes achieved so far are a direct reflection of the dedication of its partner agencies, the selfless medical professionals, committed advocates, skilled trainers and brave and resilient fistula survivors. Too many of the world's most disadvantaged and vulnerable women and girls have suffered this preventable and treatable condition in silence. Too many women are dying in childbirth needlessly. It is time to put an end to maternal death and disability.

Together,  
we can end  
obstetric fistula.

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<sup>8</sup> United Nations General Assembly, *Report of the Secretary-General on Supporting Efforts to End Obstetric Fistula*, 6 August 2012, A/67/258, available at [un.org](http://un.org)

# Annex

## Partners in the Campaign to End Fistula

1. Aden Hospital (Yemen)
2. Amref Health Africa
3. American College of Nurse-Midwives
4. Babbar Ruga Fistula Hospital (Nigeria)
5. Bangladesh Medical Association
6. Bill & Melinda Gates Institute for Population Reproductive Health
7. Bugando Medical Center (Tanzania)
8. CARE
9. Comprehensive Community Based Rehabilitation (Tanzania)
10. Centers for Disease Control and Prevention (CDC)
11. Centre Mère-Enfant (Chad)
12. Centre National de Référence en Fistule Obstétricale (Niger)
13. Centre National de Santé de la Reproduction et du Traitement des Fistules (Chad)
14. Columbia University's Averting Maternal Death and Disability Program (AMDD)
15. Cure International Hospital of Kabul (Afghanistan)
16. Direct Relief International
17. Dr. Abbo's National Fistula and Urogynaecology Center (Sudan)
18. East Central and Southern Africa Association of Obstetrical and Gynecological Societies
19. EngenderHealth
20. Equilibres and Populations
21. Eritrea Women's Project
22. Family Care International
23. Fistula e.V
24. Fistula Foundation
25. Fistula Foundation (Nigeria)
26. Friends of UNFPA
27. Geneva Foundation for Medical Education and Research
28. Girls' Globe
29. Governess Films
30. Gynocare Fistula Center (Kenya)
31. Hamlin Fistula (Ethiopia)
32. Healing Hands of Joy (Ethiopia)
33. Health and Development International (HDI)
34. Health Poverty Action (Sierra Leone)
35. Hope Again Fistula Support Organization (Uganda)
36. Human Rights Watch
37. Institut de Formation et de Recherche en Urologie et Santé de la Famille (IFRU-SF), (Senegal)
38. International Confederation of Midwives
39. International Continence Society
40. International Federation of Gynecology and Obstetrics (FIGO)
41. International Forum of Research Donors
42. International Nepal Fellowship
43. International Planned Parenthood Federation
44. International Society of Obstetric Fistula Surgeons (ISOFS)
45. International Urogynecological Association (IUGA)
46. International Women's Health Coalition
47. Islamic Development Bank
48. Johnson & Johnson
49. Johns Hopkins Bloomberg School of Public Health
50. Kupona Foundation
51. Lake Tanganyika Floating Health Clinic
52. Ligue d'Initiative et de Recherche Active Pour la Santé et l'Education de la Femme (LIRASEF), (Cameroon)
53. London School of Hygiene and Tropical Medicine
54. Maputo Central Hospital (Mozambique)
55. Médecins du Monde
56. Médecins Sans Frontières
57. Mercy Ships
58. Moi University (Kenya)
59. Monze Hospital (Zambia)
60. Mulago Hospital/Medical School (Uganda)
61. National Obstetric Fistula Centre, Abakiliki (Nigeria)
62. Obstetrical and Gynecological Society of Bangladesh
63. One by One
64. Operation Fistula
65. Pakistan National Forum on Women's Health
66. Pan African Urology Surgeon's Association (PAUSA)
67. Population Media Center
68. Psychology Beyond Borders
69. Regional Prevention of Maternal Mortality Network (Ghana)
70. Royal College of Obstetricians and Gynaecologists (RCOG)
71. Sana'a Hospital (Yemen)
72. Selian Fistula Project (Tanzania)
73. Société Africaine des Gynécologues-Obstétriciens (SAGO)
74. Société Internationale d'Urologie
75. Solidarité Femmes Africaines (SOLFA)
76. Association for the Re-orientation and Rehabilitation of Women for Development (TERREWODE), (Uganda)
77. Uganda Childbirth Injury Fund
78. United Nations Population Fund (UNFPA)
79. United States Agency for International Development
80. University of Aberdeen
81. University Teaching Hospital of Yaoundé (Cameroon)
82. Virgin Unite
83. White Ribbon Alliance
84. Women and Health Alliance International (WAHA)
85. Women's Health Organization International
86. Women's Hope International
87. Women's Missionary Society of the African Methodist Episcopal Church
88. World Health Organization
89. World Vision
90. Worldwide Fistula Fund
91. Zonta International