

Medical aid for a million women

Fixing fistula in the developing world

Dr Hillary Mabeya / Kate Grant / Pauline Latham MP / Kenji Yasukawa



BY THE NUMBERS

What is fistula?

An obstetric fistula is a hole in the birth canal that develops during an obstructed labour. It leads to incontinence and social isolation. It occurs among women who become pregnant at a young age and who don't have access to healthcare, largely in developing countries.

4 in 10

More than 40% of women in developing countries give birth without a midwife or doctor present. Some 6% of maternal deaths are caused by obstructed labour.

1 million

women suffer from untreated obstetric fistula in Asia and sub-Saharan Africa. Over 6,000 new cases occur each year in these regions.

80-95%

of vaginal fistulae can be closed surgically. With proper treatment, fistula patients have a good chance of returning to a normal life.

\$586

is typically enough to provide one woman with restorative surgery and post-operative care.



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Putting an end to preventable suffering

Astellas CEO Kenji Yasukawa reflects on the positive work being done by Fistula Foundation's ACTION ON FISTULA™ programme in Kenya



Travelling to Kenya to see the work done by ACTION ON FISTULA™ and coming face-to-face with women, who having suffered with obstetric fistula, were given a new lease of life following treatment, was a very humbling experience. ACTION ON FISTULA is the world's first integrated country-wide network for fistula treatment and the results have been beyond our expectations. To date, ACTION ON FISTULA has provided life-changing surgery to 3,666 women in Kenya.

Obstetric fistula has been nearly eradicated in the developed world as complications like this mainly arise due to a lack of medical support, such as adequate and timely emergency obstetric care during labour. This is why it is the world's underprivileged women who are most affected. Astellas was keen to support this programme in rolling out treatment more widely.

The prevalence of non-communicable diseases (NCDs) is increasing, but NCDs are largely preventable. In the case of obstetric fistula, a gynaecological NCD, for instance, it can be prevented if women are provided with effective and timely emergency care when complications arise. The obstacles to fistula treatment in Kenya include the taboo and stigma associated with the condition and the lack of education, trained obstetric fistula surgeons and access to medical facilities. In addition, most women suffering with obstetric fistula live in rural communities, and are not close to medical facilities, meaning transportation to the hospital is scarce and expensive.

The key for ACTION ON FISTULA has

been to create a nationwide treatment network across Kenya. The programme's model addresses the varied obstacles in the fight against fistula and the network allows surgeons, outreach workers, and hospitals to share resources and information to treat even more women, at the highest level of care.

The programme also aims to improve the existing infrastructure in Kenya by: training specialist fistula surgeons, training and empowering Community Health Workers and conducting outreach activities across the country to identify and bring women at risk in for treatment. By 2020 the programme hopes to extend its treatment network from six to eight treatment centres and train an additional six surgeons and ten fistula nurses. Additionally, ACTION ON FISTULA aims to establish 20 support groups to help recovering fistula patients with psychosocial assistance, economic empowerment and income-generating activities.

Great progress has been made in Kenya, but there is some way to go. Both Fistula Foundation and Astellas are committed to ending suffering from fistula, but our commitment alone is not enough to eradicate fistula completely. This is why Fistula Foundation is seeking additional support from other organisations and philanthropists to ensure sustainable access to fistula treatment in the future.

ACTION ON FISTULA was conceived, built and is run by Fistula Foundation. It was started in 2014 by a grant given to Fistula Foundation from an affiliate of Astellas Pharma Inc., Astellas Pharma Europe Ltd. Fistula Foundation and Astellas jointly funded Phase One of the programme, 2014-2017. Astellas is funding approximately 25 per cent of the second phase of the programme running from 2017-2020. By 2020, ACTION ON FISTULA wants to help more than 4,500 women to access fistula treatment. In order for ACTION ON FISTULA to continue this proven, life-changing work beyond 2020, additional financial support is critical. Anyone interested should contact Fistula Foundation via www.fistulafoundation.org.

Dr Hillary Mabeya, Kenya's leading fistula surgeon, and Kate Grant, CEO of Fistula Foundation, explain why Kenya provides a model for effective treatment

Kenya: building a system that works

In 2011, Dr Hillary Mabeya rented a house in the town of Eldoret, in western Kenya. “It was a small house,” remembers Dr Mabeya, “an old house that we rented out. And we just turned it into a small hospital. We converted it into an operating room and, initially, five beds, which we increased to about 20 beds.” When other surgeons visited, Dr Mabeya would spend around six weeks teaching them to perform the delicate and complicated surgery required to correct a fistula. “We worked in that facility for five years and in that time, we did more than 1,500 operations.”

For those 1,500 women, the operations were life-changing. Mabeya explains that when a woman is in labour for a long time – up to three or four days or longer – “the baby gets lodged in the pelvic area, and this causes pressure on the bladder and the rectum”. Under pressure, those tissues lose blood supply, die and

eventually slough off, leaving a hole or holes through which urine or stool may pass into the vagina. Untreated, women that suffer from fistula must endure permanent incontinence. In rural areas of the developing world, where running water and fresh clothes may not be available, these women are often ostracised from society, unable to work or to be close to their families. The stress of this condition, which Mabeya describes as “psychological torture”, can last for decades.

Kate Grant, CEO of Fistula Foundation, describes fistula as a systems failure. “The system that has failed is an emergency obstetric care system,” she explains, “so, why don't women get fistula in the UK and US? Well, they don't stay in labour for three or four days or more. They're usually in a hospital, and if their labour is obstructed or not progressing, they'll get a C-section. But for too many women,

particularly in rural areas, there isn't a system. People ask why they don't get to a hospital; too often there's no road, there's no ambulance, and there's likely nobody at the rural clinic who can do a C-section.”

Most of Kenya's poor live in rural areas and while poverty is on the decline in Kenya, more than a third of the population lives on less than \$1.90 per day. “You're working with people who are often so poor that the cost of transportation can be a huge barrier, even when that transportation is just a bus ticket,” says Grant. “Plus, with women that are incontinent, even just the act of getting on public transport when they're leaking waste is a big challenge in itself. If you're going to go to that trouble, you want to make sure that what's on the other end is worth all that effort.”

For this reason, it's very important that fistula surgery is successful first



Dr Mabeya trains a surgeon in the complex procedure needed to cure fistula

time around. “It's a very complex procedure,” explains Dr Mabeya, because, unlike a cut or a break in the tissue, a fistula is an area from which tissue has been lost, so “there is no tissue for you to grab and repair that hole which is left”. Mabeya says his success rate on first surgery is now up to 85 per cent, but if a woman has previously been operated upon, this drops to around 60 per cent.

Kate Grant explains that this is why Fistula Foundation avoids what's sometimes called the “camp model” of treatment, which is used for fistula

“I would love to close this clinic one day”

surgery in many countries, in which “a surgeon flies in, surgeries are done, and the surgeon leaves. That's wonderful in a way, in that you can get surgery to women that otherwise wouldn't get it. But in terms of trying to establish a countrywide treatment programme, the ‘camp model’ is extremely limited.” The delicate, deeply personal nature of fistula, says Grant, means that a woman suffering from it is best served by well-trained surgeons in permanent hospitals, where “she's able to get treatment much closer to the date she's diagnosed”. This is the model Fistula Foundation has spent almost five years building in Kenya: “a network of hospitals, robust outreach programmes with community groups that get out into the hinterlands to let women know that surgery exists, and a training component, to train surgeons. It's a multifaceted programme, but the key point is that it's countrywide, it's 12 months a year, and

it's building on both physical infrastructure, in the form of hospitals, as well as technical infrastructure, with training of doctors and nurses.”

In October 2016, Dr Mabeya joined crowds of supporters, donors, doctors and former patients to celebrate the opening of the largest of these hospitals, the Gynocare Women's and Fistula Hospital in Eldoret. The new hospital has “almost 100 beds”, he says, and “per year, we do about 400 to 450 operations; the average per month is about 40.” Since 2014, Mabeya has trained six surgeons who now work in Kenya, two who work in Zambia and one who works in Uganda.

Kate Grant says that Kenya is today “the best example we know” of a system working to treat and prevent fistula in the developing world. “The Kenya model is powerful. We exported the same model to Zambia and we're seeing success there, on a smaller scale, because it's a smaller country. We're exploring doing the same kind of programme in Nepal. It's exciting.”

Both Grant and Mabeya acknowledge that there are still considerable challenges to overcome, in building infrastructure, and in persuading governments to support their work. “Whether you're in Liverpool or Lusaka,” says Grant, “politicians respond to people that have power. Incontinent women in a poor part of a poor country, whose reason for getting this injury is the root cause of their powerlessness – that group is not going to be getting the attention of health ministers.” But Dr Mabeya has seen how his patients return to normal life and to work, benefiting their society and their local economy. “The first fistula hospital,” he reflects, “was in New York, in the 19th century”, but fistula surgery became almost entirely a thing of the past in the United States more than a century ago. One day, Dr Mabeya says, “I believe that our hospital can do something else - to give women a timely delivery and a C-section if they need one. I would love to close this clinic one day, not to do fistula surgery, but to do safe motherhood.”

Treating a new kind of pandemic



A fistula operation being performed in Kathmandu, Nepal

The health of the developing world is changing. The *New Statesman* asked **Pauline Latham MP** what governments, businesses, doctors and patients can do to address the new threats to fragile health systems

Fistula is not something that can be “caught”. It is not an infection, but a condition that becomes more likely when a person is subject to certain conditions – a pregnancy early in life, poor nutrition and a lack of emergency obstetric care. These conditions are often economic and social, and as economies and societies change, they affect the health of the population. As societies in the developing world become more urbanised, factors such as car use, tobacco use, long working hours and changes in diet begin to affect the population’s health, with non-communicable conditions such as heart disease, cancer, diabetes, chronic respiratory disease and mental illness becoming more prevalent. Overall, people are living longer and becoming healthier, but the new landscape is one in which chronic, non-communicable conditions weigh heavily on the health systems of the developing world. NCDs killed more than 30 million people in low- and middle-income countries in

2015. Almost half (48 per cent) of these were under the age of 70.

The UN’s 2030 Sustainable Development Goal on Health aims to reduce premature mortality from NCDs by a third, and programmes such as Access Accelerated have taken up the challenge.

Pauline Latham MP sits on the International Development Committee and chairs the All-Party Parliamentary Group on Population, Development and Reproductive Health. Latham says that for fistula, as for other NCDs, education and early access to diagnosis and treatment are the factors most likely to improve people’s quality of life and chance of recovery. “Education, and the availability of surgery very quickly”, says Latham, help both fistula sufferers and the communities in which they live to “recognise that it is just a symptom – and that people need help, not ostracism”. The education needed to help prevent and treat other NCDs can be easier to handle; smoking causes cancer and heart disease, for example, and there are many



“People need help, not ostracism”

GEORGINA GOODWIN

international examples of how this can be limited. But in countries in which fistula is common, says Latham, “you need to do two things. One is to change the attitude to early childbirth and early marriage, and you need to stop people being raped in those countries.” The social and economic status of women in many developing countries is a factor far more ingrained and resistant to change than smoking.

But to overcome these taboos and to provide early access to treatment for fistula patients is crucial, says Latham, because while a person with diabetes or cancer can reasonably hope that their family and community will support them, a woman who suffers permanently from incontinence faces exclusion. “They are ostracised because of the smell, basically.” In Latham’s experience, this social exclusion can become permanent, even if treatment is successful. “Once they’ve been ostracised, it’s very difficult in the society that they live in for people to say

‘you’ve had your operation, you’re okay now, we’ll accept you.’ It seems to be that there’s a huge stigma attached to having a fistula, even if it’s gone, and it’s been resolved.”

One way in which the government and communities in the UK could help, says Latham, “would be through the diaspora of the various countries. We have people in the UK from, I would guess, every African country. We could work through them to get the message back that it’s okay to have this, it’s unfortunate, but you need surgery. Because they’d understand that, here, but they need to educate their families.”

Latham acknowledges, however, that the most important factor in giving people access to treatment is to make sure that the treatment is itself available, and that it is reliable. From the UK government’s perspective, Latham says: “I think the Secretary of State could take a lead in this, and try to set up more help to train doctors in developing countries. A lot of surgeons do go out and help in developing countries, and do a lot of surgeries. But maybe giving doctors a grant to go and do some time out in developing countries, so that they can train local doctors to be able to deal with it. And by doing that, by having more doctors trained to do it, there would be greater access for women in developing countries. As our economy grows and we have more money spent on international development, there could be some pilots to see if we could help developing countries with this sort of work.”

The private sector, too, has a role to play, says Latham, and in an international context their most valuable work may be in raising awareness. “The trouble is with something like [fistula], is that most people have never heard of it, in this country. There needs to be more publicity; until people in this country know what it means, it’s very difficult to get people to donate. People donate to something that resonates with them. And for many women, and for businesses run by women, it would resonate with them – if they knew what it was.”



Changing tomorrow

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