

## Film

### At high risk: becoming a mother in the Peruvian Andes

The Quechua people, part of Peru's 2.5 million indigenous population, live in the southern Andes and Peru at the highest altitude of any people in the Americas. Indigenous peoples' lives are governed by the traditions of their ancestors, and never more so than during pregnancy and childbirth. Yet such traditions can sometimes exist in opposition to the practice of orthodox medicine. Indeed, the barrier of beliefs between indigenous people and health professionals is partly to blame for the unacceptably high rate of maternal and infant mortality among Andean people. In a bid to better understand—and hopefully to begin to overcome—these barriers, Rebecca Rivas lived in some of the most inaccessible regions of the southern Andes and observed indigenous women throughout their pregnancies. *At Highest Risk: Maternal Health Care in the Peruvian Andes* is the result of this project, which was supported by a 12-month Fulbright grant.

Judyth Aguero Vega, whom Rivas met in the town of Ccapacmarca, Peru, is the focus of Rivas' intimate documentary. An educated and successful woman, Judyth respects the traditional medicine practised by her mother and ancestors, but opts

for western medical care during her pregnancy. Yet this decision does not stop Judyth from observing Quechua customs as much as is possible. We see her receiving a traditional herbal body wrap as part of her prenatal care, to strengthen her bones. The practitioner, a woman from the community, refuses payment saying that "you can't buy these things".

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At 8 months' gestation Judyth moves to Cusco, where she will stay with her sister to be near the hospital where she plans to give birth. This modern hospital in Peru's capital offers a stark contrast to the mud hut where Judyth has spent the first few months of her pregnancy. Between clinical appointments and shots of high-tech equipment, we see Judyth's sister discussing their mother's instructions for her labour care—hot chocolate is to be given when the contractions start (to warm the body), a special belt is to be worn during labour to relieve the

pain, and Judyth must not wash for 1 month after the birth. Judyth copes surprisingly well with these mixed messages and gives birth to a healthy baby boy. After the child's birth, Rivas interviews the doctors involved in Judyth's care. It is telling to see how surprised they seem when they are asked to keep the placenta so that it can be buried and are told that the child's meconium will be smeared on the mother's face as her "pregnancy freckle marks".

Alongside Judyth's story, the film offers insights into the public-health initiatives under way in Peru to try to improve rates of maternal mortality. The Peruvian Government has received praise for its success: in 1996, the maternal mortality rate was 265 per 100 000 livebirths; in 2000, this rate had been reduced to 185 per 100 000 livebirths. The initiatives include the introduction of antenatal waiting houses, voluntary sterilisation campaigns, and integration of modern and traditional birthing methods.

All women must report to a waiting house at 7 or 8 months' gestation where they will remain until after the birth of the child. This policy ensures that health professionals can treat any complications during the birth and take care of the newborn baby. The statistics are good—the house seen in Rivas' documentary has not had a maternal death in 2 years. However, Rivas shows some less enthusiastic responses from the indigenous women who talk of feeling "lonely" and finding the waiting centres "boring". In the community, horror stories of these clinics abound: claims of "babies being ripped out", mothers "bleeding everywhere", and doctors demanding payment for their services (all care at these centres is meant to be free). Local women also seem to resent the fact that there is a fine for giving birth outside of these clinics, and Rivas records stories about



**At Highest Risk: Maternal Health Care in the Peruvian Andes**

Written and produced by Rebecca Rivas. Inner Mission Productions, 2006. On release at selected venues in the USA from September, 2006. <http://www.athigherisk.com/mambo2>



Rebecca Rivas has published an article about her maternal health project with Andean women in Peru, see *MIDIRS Midwifery Digest* 2006; 16: 46–50.

families being forced to bury their stillborn children to avoid a fine that they cannot afford.

A similar picture emerges about the well-intended sterilisation campaigns. The Peruvian Government set up an initiative of voluntary sterilisation in 1985 to reduce the high rate of maternal deaths. The initiative included monthly quotas for doctors to meet, and as a result some of the Andean women who feature in Rivas' film say they were bribed by doctors to agree to have the operations against their will. These women tell Rivas how they no longer feel strong enough to help their families with work in the fields.

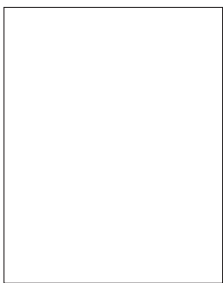
Local birthing centres have also been set up in rural areas to incorporate traditional beliefs with modern health care and create an environment where women feel safe and comfortable. Most Quechuan houses have a large rope hanging from the ceiling for the women to pull themselves up on during labour. These ropes have been installed in the centres, and every care is taken to make the atmosphere as much like the women's homes as possible. So far only 25 hospitals in Peru combine treatments in this way, but it is a positive start. Rivas shows how the women and health-care staff welcome this integrated approach.

Judyth may seem an unusual choice as the focus of the documentary. The doctors in Cusco remark that insured patients like her are generally more educated and less bound by traditional beliefs than other women. Presumably, Rivas chose her because she represents how western and traditional medicine can be successfully integrated. Judyth's experience, so perceptively documented by Rivas, proves that this partnership is possible and offers hope for the future of maternal health in Peru.

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Love, Labor, Loss: a Documentary Film on Obstetric Fistula  
Produced and directed by Lisa Russell. Governess Films.



Fistula Pilgrims  
Written, produced, and directed by Nancy Durrell McKenna for Safehands for Mothers and the International Federation of Obstetrics and Gynaecology.

Renew The Campaign to End Fistula  
<http://www.endfistula.org/index.htm>

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## In brief

### Film *Fistula in the frame*

In a corrugated iron shack in the outskirts of the village, they find a young woman. Hands and feet bound together, hips contracted, muscles wasted. A miasma of stale, black air swathes her rigid skeleton. Her eyes betray a solitary tear as she agonisingly recollects a labour through which she saw the sun rise and set seven times. The nauseating stench of the faeces and urine that bathes her sheets makes her flinch. "If I stay still it will all dry up", she thinks. If only the world were so kind.

Such is the image conjured up by a recent international film-based campaign that strives to end the plight of more than 2 million women worldwide with obstetric fistula. For a women living in the west, fistula is something that has been consigned to the past. The possibility that, during labour, her baby's head could bore a hole through her own vagina and bladder so that she would be left perpetually leaking urine or faeces is unimaginable. But for many women in developing countries obstetric fistula is a reality: the result of prolonged labour without medical

intervention during which the baby is usually stillborn. Albeit virtually eradicated in the western world during the 18th century, this silent epidemic marginalises women throughout Africa, Asia, and the Arab region, stripping them of their inherent entitlement to safe motherhood.

As part of a collection of advocacy documentaries for Renew The Campaign to End Fistula, film makers Nancy Durrell McKenna and Lisa Russell have used this powerful medium to instigate reform. *Fistula Pilgrims* and *Love, Labor, Loss* offer compelling insights into needless suffering of pregnant women in Africa.

The focus of *Fistula Pilgrims* is Telanish, one of the 9000 Ethiopian girls subjected to a life of shame and misery because of fistula. Betrothed at the age of 10 years, pregnant at 11, and mother to a stillborn baby at 12, her life seems to be over before it has begun. Resigned to the fact that medical care is financially and geographically inaccessible, Telanish's future is bleak.

Has history not taught us that a key antidote to such stigma is

international collaboration? *Love, Labor, Loss* is undeniable testament to this in its depiction of a fistula repair compound spearheaded by local people in Niger and safeguarded by foreign medical expertise. The film follows the moving stories of five west African women who find medical care and solace from a life of neglect at the compound. But the life-changing work at the compound is impeded by insufficient resources and its temporary nature means that the health of most women with fistula in Niger remains fragile.

This exploration of Africa's growing maternal health crisis powerfully communicates its lucient aims: to raise the marital age; stop the medical brain drain from developing countries; and to increase access to health care for mothers. By putting fistula in the frame these films help to end the silence about what the United Nations has called "one of the top ten most underreported stories the world should know about".

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## Profile

### Mulu Muleta: Ethiopian surgeon working to end fistula

Working for 16 years with impoverished fistula patients in Ethiopia has made Mulu Muleta a world renowned fistula surgeon and a passionate supporter of the global campaign to end fistula. The moving tales of young girls and women who are abandoned by their husbands and ostracised by their families because of fistula have strengthened her resolve to contribute to the eradication of obstetric fistula. "Recently, we carried out a national survey on public perceptions about fistula. We found that many people, especially in rural areas, think fistula is a curse, or a punishment for sinning. They think it cannot be treated", she says.

Muleta says fistula is an issue in almost every developing country where emergency obstetric care is scarce. In Ethiopia, fistula is most prevalent in rural communities where access to health-care facilities is difficult because of the mountainous terrain with poor, often non-existent, roads. Moreover, the custom of early marriages in some parts of the country exacerbates the problem.

"Every fistula patient is different and comes with unique heart-breaking problems. Often they are young peasant girls, who have been in labour for days, sometimes even a week, had a stillbirth, got divorced, and are made outcasts", Muleta told *The Lancet*. "One very young girl was denied a seat on a bus and forced to buy a bucket in which to collect the leaking urine. She came to our hospital after a 2-day trip, which she made while seated on that bucket." Such heart-rending stories and Muleta's ability to transform these damaged lives are the motivation for her work as medical director of The Addis Ababa Fistula Hospital. "We get job satisfaction that is why we are sticking to this work. Seeing patients coming here desperate, and after treatment going away with lovely smiling faces is truly gratifying", she says.

The Addis Ababa Fistula Hospital, which is supported by Hamlin Fistula Research and Welfare Trust, is one of the few hospitals in the world that specialises in fistula surgery. The hospital's five surgeons treat more than 1200 patients every year, all free of charge. More than 24 000 women have been cured at the hospital since it was founded in 1974.

Yet only a small proportion of the estimated 8000-9000 women that suffer an obstetric fistula in Ethiopia every year are treated at the hospital. Two of the hospital's rural outreach centres are functional, but poverty, a shortage of trained personnel, and inadequate road and health infrastructure hamper their efforts to reach more women in isolated areas. Furthermore, according to Muleta, most doctors do not want to specialise in fistula surgery: "Very often they get disappointed when they do difficult work for little pay. But you can't make money by treating fistula patients because they are the poorest of the poor."

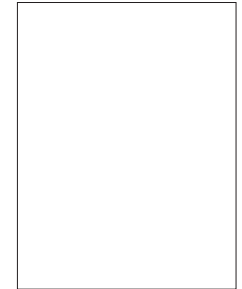
Muleta's passion for her work was evident early on in her medical career. After qualifying in medicine at the Gondar College of Medical Sciences in northern Ethiopia, she specialised in obstetrics and gynaecology at Addis Ababa University Medical School. She met the Australian founders of the hospital, Reginald and Catherine Hamlin, during this training, since it is a requirement for obstetrics and gynaecology residents in Ethiopia to be attached to the hospital to learn skills in fistula repair. Muleta, who completed a master's degree in disease control in Antwerp, Belgium, in 2000, did her stint at the hospital more than 16 years ago. Reginald Hamlin must have been impressed with her, because he asked Muleta to join their team when she graduated in 1990. She has been a dedicated fistula surgeon at the hospital ever since.

Alongside this work, Muleta, a 45-year-old mother of two boys, has been involved in campaigns to end domestic violence against women and other cultural practices that oppress women, such as forcing young girls into marriage. A consultant obstetrician and gynaecologist for the Organisation of African Unity in Addis Ababa, she is also a member of various international organisations, including The International Federation of Gynecology and Obstetrics.

Under Muleta's directorship, The Addis Ababa Fistula Hospital is becoming a model for other African countries, and has been involved in treating patients from Uganda, Sierra Leone, Kenya, and Sudan, where facilities for fistula surgery are scarce. The hospital team has also trained 100 surgeons who have gone back to their own countries to set up health centres. "The Fistula hospital in Ethiopia is a success story for Africa. Fistula is a big problem in Ethiopia because we have so many young brides, yet there are few people like Dr Muleta working to alleviate the problem", says Emrakeb Assefa, co-founder of the Ethiopian Women's Media Association.

In recent years the Ethiopian public's knowledge of fistula has grown thanks to the work of Muleta and her colleagues and support lent to the campaign to end fistula by the United Nations Children's Fund and the United Nations Population Fund. Muleta is optimistic about future efforts to tackle fistula in her country. "The government is taking the issue seriously now. At the policy level women's issues are a priority for the government, and there is work to improve maternal health. Regional and federal government is talking about fistula, and they are giving us land so that we can build regional fistula centres", Muleta said.

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For more about the work of The Addis Ababa Fistula Hospital and the Hamlin Fistula Research and Welfare Trust see <http://www.fistulatrust.org/about.html>



## Vernon M Ingram

Molecular biologist who uncovered the molecular basis of sickle cell anaemia. He was born in Breslau, Germany on May 19, 1924, and died after a fall in Boston, MA, USA, on Aug 17, 2006, aged 82 years.

Vernon Ingram, who discovered in the 1950s that a single amino acid substitution caused sickle cell anaemia, was an irrepressible experimentalist whose research continued at full speed until his sudden death. "What kept his heart beating was his passion for science", said his friend and colleague Graham Walker, professor of biology at the Massachusetts Institute of Technology (MIT), Cambridge, MA, USA. "He was just relentlessly interested in the next experiment. It was a small blessing he never had to close his lab."

Ingram's most celebrated experiments were done in 1957 when he worked at the Cavendish Laboratory, Cambridge University, Cambridge, UK, under the leadership of Max Perutz. Working in a well equipped former bicycle shed in the laboratory's courtyard, Ingram became interested in the haemoglobin molecule, especially the variant present in people with sickle cell anaemia. His interest was piqued by the arrival in the laboratory of Tony Allison, who had previously shown that people who carried a single copy of the gene for sickle cell were resistant to malaria. Using samples of haemoglobin brought by Allison, Ingram began exploring the molecule. Ingram subjected the molecule to a fingerprinting technique he had devised that characterised peptides according to their position on a two-dimensional map, using a combination of electrophoresis and partition

chromatography. With Allison's samples, and samples from unrelated patients with sickle-cell anaemia, Ingram discovered that the misshapen haemoglobin was the result of a change in a single peptide. A couple of years later, he and his co-workers showed the change was a substitution from glutamic acid to valine at position 6 of the  $\beta$ -chain.

This remarkable discovery helped cement the idea that one change in the gene should produce one change in the protein and led to Ingram being called "the father of molecular medicine". "It really was an absolutely brilliant confirmation that the model which people had about the role of what DNA was all about was true", said Tony Stretton, who worked with Ingram from 1957 as his graduate student. "The thing that really struck me was the delight he took in doing the experiments", says Stretton, now a professor at the University of Wisconsin-Madison, USA. "He was very inventive." The discovery also had implications for the prenatal diagnosis of the disease, and led Ingram and his colleagues to go on to investigate other abnormal haemoglobins and develop a broader picture of the evolution of the molecule.

Ingram escaped Germany with his family to the UK in 1938. His experimental impulse was evident from an early age. "I knew from the age of 10 that I was interested in science, in how things work", he told the *Proceedings of the National Academy of Sciences* in 2004. After high school he worked as a chemist while studying for a part-time degree in chemistry at Birkbeck College, London, UK. He graduated in 1945 and earned his PhD in organic chemistry in 1949. He then spent time in the USA, but after a fellowship at the Rockefeller Foundation and 2 years in Joseph Fruton's laboratory at Yale University working on peptide chemistry, he began looking for a job back in the UK. He wrote 32 letters without success, before he heard that Perutz was looking for a protein biochemist. By September, 1952, he had landed the job and within a few years had made the sickle-cell anaemia discovery. It was "one of the absolutely seminal discoveries in the history of molecular biology", says Walker. But Ingram, with characteristic modesty, would often attribute it to serendipity.

In 1958, Ingram became an assistant professor at MIT, which he liked so much that he remained there for the rest of his life, researching thalassaemia and then neurological disorders. At MIT, Ingram also began teaching, which became another passion. On one occasion he gave an undergraduate class some advice on taking up a career in science. "He said, you want to look for a crowded lab", remembers Walker. "Because that meant there was something interesting going on." Ingram was elected a Fellow of the UK's Royal Society in 1970 and was elected to the US National Academy of Sciences in 2002. He is survived by his wife, Elizabeth Hendee, and his son Peter and his daughter Jennifer from his first marriage.

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