

## MSP IMPACT-CHANGING LIVES: TREATMENT ACTION CAMPAIGN IN THE EASTERN CAPE

### “Impact on Individuals Lives”: Treatment Literacy Campaign in Eastern Cape – Increasing Access to ART and PMTCT



Yola Mtshayi receives ARVs through TAC

Yola Mtshayi is a ten-year old girl who was born with HIV. Yola’s mother passed away soon after her birth and she is now looked after by her grandmother, Lungiswa Mtshayi.

In May 2008, HLSP accompanied by Masizole Gonyela, a TAC Treatment Literacy Trainer, visited Yola and Lungiswa at their home in Queenstown to find out more about the impact Treatment Action Campaign (TAC) has had on their lives.

Lungiswa explains that before she met up with Masizole at the Masangane HIV & AIDS Centre in Queenstown, she had little awareness of HIV and AIDS and no access to ARVs. Masizole informed the family that ARV treatment was a possibility for young Yola. Lungiswa smiles when she tells us that when Yola started on ARVs her CD4 count was only 2%, but today it is a healthier 35.6%<sup>1</sup>.

“Yola knows Masizole [from TAC] as a friend”  
(Lungiswa Mtshayi)

Masizole also encouraged Lungiswa, who is unemployed, to get involved in TAC activities. She currently assists TAC with running workshops and looking after orphans in her community. She sometimes receives R200 for her work with the orphans. Over and above this, the family survives on a child support and a foster child grant, which amount to approximately R1500 per month. Despite the hardships, Lungiswa and Yola are happy. The most important thing for them is Yola’s access to ARV treatment at no cost. It means that Yola has a future.

TAC has now provided Lungiswa with materials that have enabled her to ask the doctor questions about Yola’s health and to understand any changes to her treatment regimen. With this knowledge she has been able to improve the livelihood and health of the child.

When asked if Yola knows about TAC, Lungiswa answers: “She knows Masizole as a friend”.

<sup>1</sup> Paediatric measure - CD4 cell percentage

## From patient to advocate

Further down the road lives Mpumulelo (Pumi) Okweza and her one-year-old child, Kwezi. Pumi's first husband passed away from an HIV related illness in 1998. Soon after she decided to get tested and discovered that she too was HIV positive. Her son Kwezi is HIV negative. Pumi managed to ensure her child is HIV negative through education, access to ARVs and a PMTCT programme provided by TAC.

**“Even if somebody is HIV positive they still remain a South African!”**

Pumi started her treatment in 2004 when her CD4 count was a very low 4 and by 2006 after starting the PMTCT programme; her count astonishingly went up to 531. Today, she is over 830.

“After I met TAC, I myself became a trainer and encouraged people to undergo the PMTCT programme... because I know it. It is OK for pregnant women!” says Pumi. She continues proudly, “I’m living openly with HIV and I am also a TAC activist”.

Pumi worked full-time for TAC in East London, but after Kwezi was born, she returned to her family home in Queenstown. She is currently unemployed but receives a child support grant. She lives with her brother in the family house that she grew up in.

Pumi's boyfriend and Kwezi's father, Mninawe Xelisi, is actively involved in raising their child. Mninawe tested HIV positive in 1996, but says that up until now he has not needed to take ARVs. He explains that he survives by looking after himself, taking nutritional supplements when necessary and living his life the way he wants to. Mninawe checks his CD4 count every year and tells us that he beats the symptoms by being motivated.

Both parents take Kwezi for regular checkups. They tell us that their neighbours are “amazed” that the child is negative. Pumi helps educate neighbours about the benefits of PMTCT programmes, saying: “Because of the PMTCT programme my child is negative!”



Pumi Okweza and Mninawe Xelisi: HIV positive parents

Pumi says that as HIV is increasingly destigmatised, more people in Queenstown are disclosing their status. “If they know you are HIV positive, it is easy for them to approach you and say I am also HIV positive. How can you also help me? ”.

Mninawe emphasises that TAC programmes have effected change in the area. “Even at our hospitals and in clinics you cannot go out without getting pamphlets and info about HIV and AIDS and even rights... the way we should be treated,” he explains. “We are all human beings... we all belong to South Africa. Even if somebody is HIV positive...[they] still remain a South African!”

### TREATMENT ACTION CAMPAIGN (TAC)

Founded in December 1998, TAC campaigns for access to treatment for all people with AIDS. Their efforts have resulted in many life-saving interventions, including the implementation of countrywide mother-to-child transmission prevention and antiretroviral (ARV) treatment programmes.

TAC's Treatment Literacy Programme is based on the idea that when people own knowledge – whether it is about science, laws protecting their rights, or what informs decisions about resource distribution –they are in a better position to exercise choice and claim their rights. Empowering people with the ability to take responsibility and control of their health, their medication and their society is a crucial aspect of transforming health care services and dealing effectively with the HIV and AIDS epidemics.