



## **Anti Retroviral Treatment Support Programme**

**Eastern Cape, South Africa**

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## **Introduction**

Following its work in the Western Cape, One to One Children's Fund identified the Eastern Cape Province, one of the most deprived regions of South Africa, as an area of priority to support the provision of anti-retroviral treatment (ART) to children and families. With a HIV/AIDS prevalence rate of approximately 30% in 2004, the Eastern Cape Provincial Department of Health accredited 48 sites to roll-out anti-retroviral therapy, but did not have an integrated service providing prevention, treatment, support and care for these children and their mothers/caregivers.

Since 2004, One to One Children's Fund has been supporting an ART programme at Dora Nginza Hospital in Port Elizabeth and at Uitenhage Provincial Hospital in Uitenhage in the Eastern Cape Province, with our local partner Small Projects Foundation (SPF).

## **Project Overview**

One to One Children's Fund is supporting the ART Support Programme through the provision of three nurses/counsellors and outreach vehicles to monitor the children and their families within their communities. One to One CF also supports the Expert Patient Programme, the training of volunteers and has developed, in collaboration with SPF, a sustainable domestic agricultural programme to address the nutrition problems of HIV infected children in the Eastern Cape. In addition, the ART Support Programme includes a football programme, with a football club called the One to One Future Stars, which combines football with HIV prevention and education.

The One to One Project Coordinator, Sister Nonkosi Ndalasi, who is also one of the nurses employed by the programme, is in charge of all the outreach activities in the province. Sister Ndalasi has become an indispensable element of the Port Elizabeth Hospital services, acting as a mentor for medical staff at Uitenhage and Dora Nginza hospitals, coordinating the outreach services and provides training to Expert Patient Volunteers (EPVs) and lay counsellors. She also manages the gardening and nutrition initiatives and networks with other organisations.

Cheeky Mlamli Zinto works with Sr Ndalasi on the outreach activities from Dora Nginza hospital. Mr Zinto is a nurse and works hand in hand with the social workers, tracing defaulters and providing counselling to patients. He is in charge of the adolescent programme which began in mid-2008 in Dora Nginza Hospital. This programme offers specialised treatment and a support group for HIV infected adolescents.

In November 2007, approximately 750 children were receiving ART in the Dora Nginza and Uitenhage hospitals. In December 2008, 1075 children were on ART at the two hospitals – an increase of 43% over the period. Reports from August 2009 indicate that 1189 children are now ART patients, another large increase.



Sr Nonkosi Ndalasi with Warrington

The One to One outreach nurses' team organise support groups to follow up on ART patients, build patients' morale and ensure adherence to the ART pill-taking regimen. Moreover, by means of an active recruitment and training agenda, the programme developed a network of community healthcare volunteers and Expert Patients who do home visits, counselling support, prevention of mother-to-child transmission (PMTCT) and referral of patients to the clinics.

Home visits, carried out by nurses, counsellors, Expert Patients Volunteers (EPVs) and community health workers, are an important component of community outreach. These visits are made to trace defaulters, provide health and adherence counselling, and identify HIV positive people and encourage them to go to the clinic. Home gardens are also suggested in home visits to promote nutritional well-being.

All components of this programme are intrinsically linked through the One to One outreach nurses who carry out tracking, ongoing adherence counselling, lay counselling and EPV training (in conjunction with SPF), as well as the provision of vegetable gardens and seedlings, gardening and nutrition training. They also administer the provision of children's food supplements.

### **The Outreach activities / Community outreach programme**

The programme provides a major outreach effort into the communities of the province to identify, refer and treat many more children and their caretakers, promote knowledge and understanding about HIV/AIDS, raise awareness in the the community about the social services available, and encourage good nutrition and self-sufficiency.

- **The Gardening Programme**

The main objective of the Gardening Programme is to use local gardens and agriculture projects in the hospitals to feed patients, improve their overall health, fight malnutrition and other chronic diseases, and train patients (caregivers and children) to cultivate crops.



Food garden in Port Elizabeth

As part of the ART Support Programme, the gardening project started with the provision of gardening kits and training to HIV patients in Dora Nginza and Uitenhage hospitals. The project consists of growing community gardens, training children and their caregivers in gardening skills and distributing seedlings and gardening kits to enable them to grow their own vegetables. Counsellors, nurses, EPVs and community care workers are actively involved in this project.

The gardening initiative encourages people to be self-sufficient and enables families to boost children's intake in vitamins, increasing the standard of nutrition and generating an income by selling the vegetables they grow.

With the support of Small Projects Foundation and the South African Ministry of Agriculture, approximately 50 bags of different seed crops are distributed per month (each bag carries about five hundred seedlings) to all caregivers of paediatric ARV patients, approximately 930 families, and in 20 schools in Port Elizabeth and Uitenhage, where children started their own food gardens. Seedlings were also provided for two large community gardens.

In the period November 2007 to October 2008, SPF trained 100 HIV infected children in Dora Nginza and 20 adults in Uitenhage, as well as 200 children from 20 different schools to create and maintain their own gardens. A further 50 caregivers were trained to further develop this project. In parallel, Sr Ndalasi was trained in gardening by the South African Institute for Entrepreneurship (SAIE) and is now able to train children, caregivers and community volunteers in gardening skills. The objective of the project is also to coach EPVs and/or community workers in gardening and agriculture programmes to develop a pool of local experts able to support discharged patients or families with children suffering from malnutrition and/or chronic diseases through home visits and technical advice. To date, in the ART Support Programme, one Expert Patient has been specifically trained to support Sr Ndalasi with the gardening activities in her area.

Already, as our project nurses in the Eastern Cape report, “gardens are growing everywhere in the community, on school grounds and where land is made available for community gardens.” There are vegetable gardens at Mzamomhle Special School, community gardens in Nelson Mandela Bay, Sithembile community food garden at Kwanobuhle in Uitenhage and the gardens from the Siwa Street Gardening project. In the latter project, 25 children were trained to grow their own gardens and continue to engage in gardening. They are now training and mentoring over 100 other children in their community and are making a positive impact in the lives of their communities.



Some of the Siwa Street Gardeners



Children collecting grass to make



Sithembile Food Garden

Through the efforts of One to One Project Coordinator and SPF, food gardens have been built in the following sites: Dora Nginza Hospital, Uitenhage Hospital, Orsmond TB Hospital in Uitenhage, Zwile clinic and St Barnabas VCT community based centre.

In her reports, Sr Ndalasi continually emphasizes the significance of such agriculture and nutrition programmes in the Eastern Cape. The biggest challenge is often to find adequate plots of land to start new food gardens for the communities, as well as time and more resources to respond to the many requests from HIV patients and their families to be trained in the development of small gardens. Her current priority is to approach more schools and churches to start garden initiatives on their grounds as examples for families.

In Port Elizabeth, a building will be made available by the local community organisation and the One to One Project Coordinator is planning to start a model garden and a training centre for local community volunteers.

- **One to One Future Stars Football Club**

Cheeky Mlamli Zinto manages the One to One Future stars Football club, providing HIV education, counselling and football training to about 30 youth every week. The club, formerly named One to One United before its growth spurt this year, is comprised of both HIV positive and non HIV positive members.



One to One Future Stars football club

Through this programme, the children benefit from the football equipment, transport to the soccer field and training every Saturday by a professional from Grassroot Soccer, an organisation using the popularity of football in the fight against HIV/AIDS. The trainer, Siya Ntabeni, uses soccer activities and games to provide youth with comprehensive HIV prevention and life skills education, as well as reduce stigma surrounding HIV/AIDS.

In November, One to One Children's Fund, Grassroot Soccer and Small Projects Foundation organized a voluntary counselling and testing football tournament called "Kick Aids". This event was a success. Many organisations, including the Department of Health, took part in the HIV/AIDS testing and education, about 1,000 people attended the tournament, and 158 were tested of which 9 were HIV positive.

The One to One Future Football Stars is successful not only because of the important and comprehensive lessons about HIV and life it provides, but also for the great enthusiasm it has fostered in the children and those who run the programme. In his August 2009 report, Cheeky proudly reported of one of the teams, "The under-nines (...) won their game with flying colors, they beat their opponents two-nil (...) they were very excited and so am I."

- **VCT (Voluntary Counselling and Testing) Center**

A key component needed in prevention is to get young and pregnant women to go for voluntary counselling and testing. This has led to the initiation in December 2007 of a community based voluntary counselling and testing centre providing medical services within the community at a local church (St Barnabas Presbyterian Church). This service allows mothers and their children as well as young women to be tested and referred directly for treatment without the fear of stigma, disclosure or discrimination.

### **Volunteers**

Life-saving Anti Retroviral drugs are now funded by the provincial government of the Eastern Cape, but hospitals remain largely under-resourced and the shortage of medical staff represents a crucial challenge to provide essential care for HIV infected children and mothers in this rural area. To alleviate this shortage of professional staff, Expert Patients and Community Health Workers have been recruited and trained.

- **Expert Patient Volunteers**

Expert Patient Volunteers are HIV positive mothers and fathers trained to provide improved care and support to children in the clinics and to teach and support peer caregivers in the community to meet the medical, physical, emotional and psychosocial needs of the children.

Working in Uitenhage and Dora Nginza hospitals, there are currently four Expert Patients, two at each site.

#### **Their work**

The EPVs assist with various activities such as routine tasks (weighing and scaling the child, counting the pills), health talks, adherence counselling, taking care of the children at the clinics, tracking defaulters, doing home visits and door to door campaign, encouraging VCT to care givers, doing play therapy, marketing the ART Clinics in the community and providing support for the children and their families. EPVs receive a stipend of 500 Rands per month (GBP 32) for their service to children and their family, which represents a valuable income for families in this impoverished province of South Africa.

One EPV has been nominated with Mr Zinto to lead the adolescent programme which commenced at Dora Nginza Hospital, and another one from Uitenhage Hospital has been specifically trained in gardening skills.

#### **Their training**

In 2009, the EPVs have already completed the following courses:

- HIV/AIDS Management
- Adherence Counseling
- TB Management

- Palliative Care

In this same year, they are registered to attend:

- Voluntary Counselling and Testing (10 days)
- Prevention of Mother to Child Transmission course (5 days)
- VCT/PMTCT
- Square Metre Gardening and Nutrition.

Training workshops are organised with our local partner SPF, in collaboration with the Foundation for Professional Development (FPD). Training seminars are organised on a regular basis for newly recruited community health workers and more experienced volunteers.

The EPVs were also involved in all the in-service trainings in the Paediatric Wellness clinic such as the training in nutrition and gardening skills provided by Sr Ndalasi.



Training session held by Sister Nonkosi

Three of the former EPVs have been promoted to Lay Counsellors and have been replaced by new EPVs. This demonstrates that the One to One Children's Fund programme is contributing to building capacity of hospitals in the Eastern Cape by training EPVs who are capable of becoming competent non-medical staff to care for HIV infected children in the region.

The Expert Patient Programme is sustainable and cost effective because it:

- Taps into the experiences and expertise of people living with HIV / AIDS
- Provides a comparatively straight forward model to provide non-threatening peer support at a community level
- Employs committed individuals with first hand in depth of knowledge of the local community
- Provides support which can be tailored to the specific needs of each local area
- Enables the EPs themselves to 'win back' self respect and status
- Liberates doctors and nurses and other front line practitioners to deliver vital medical and clinical support

- **Community Health Workers**

One to One Children's Fund supports SPF to train and mentor volunteer community health workers (CHW) as part of the ART support programme in the townships of Port Elizabeth. 52 CHWs have been recruited by SPF and received comprehensive accredited training courses for the piloting of an integrated TB/HIV Outreach Programme in four townships in Port Elizabeth.

The training incorporates the following courses:

- Gardening and nutrition
- VCT and PMTCT
- Home Based Care
- TB/DOTS
- Adherence, counselling and tracing
- Peer Education

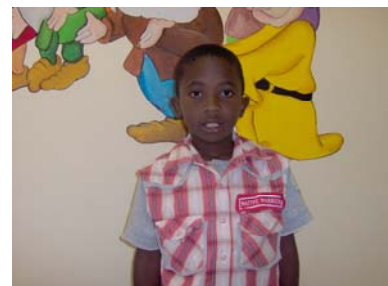
Each training module, which normally last between 1 to 2 weeks, is followed by a practical initiation of new skills in the community under supervision of clinic medical staff.

These care workers now provide a continuum of care for families living with HIV and TB in three townships in Port Elizabeth and one township in Uitenhage. Sister Ndalasi and Mr Zinto have been involved in the provision of training and getting this pilot project going.

Over time, these CHWs will accumulate enough credits (from these assessed skills training modules) to qualify for a nationally recognised qualification as Ancillary Health Care Worker Level 1.

### **Monitoring of Activities and Outcomes**

It is One to One Children's Fund's policy to closely monitor and evaluate all its projects. SPF, Sister Nonkosi Ndalasi and nurse Cheeky Mlamli Zinto send quarterly written reports to update One to One Children's Fund in the UK on their activities. Project partners are in regular contact to discuss the progress made and next steps to be taken by the project team. A representative of One to One Children's Fund UK visits the project around twice a year.



The training of EPVs and other volunteers has been very successful this year. Our local project partner, SPF, has noticed a significant increase in the number of community based workers wishing to become more involved to improve their standard of living especially for those infected and/or affected by HIV/AIDS. Medical care staff and youth come forward to be recruited and trained as community based workers to learn important skills to fight HIV/AIDS in the Eastern Cape improve nutrition and, in the mid-term, work towards poverty alleviation.

Moreover, thousands of people directly benefits from the gardening programme as more and more families are trained to grow their own food garden, but also as entire local communities can gain essential agriculture skills in the community gardens on hospital and church grounds and children learn to grow vegetables at schools around the province. This programme has shown that medical care staff can improve the nutritional status of their children living with HIV and their own well-being as well as cultivating vegetables to provide an extra income to their household.

### **Sustaining and Developing the One to One ART Support Programme**

- **Development of an Adolescent Centre**

Another noteworthy issue is the care of adolescents infected by HIV. It was discovered that when children are moved from the paediatric ward to the adult ward they feel misplaced. This is due to the change in environment and leads them to become withdrawn. There is a real need to develop the adolescent programme to help youth in this transition by providing them with targeted care and treatment. Nurse Zinto and one EPV at Dora Nginza paediatric clinic are in charge of this programme. The 10-14 years old children form a support group and the sessions have already started.

It is believed essential that adolescents have their own space within the adult ward so they continue to adhere to their treatment and feel comfortable in visiting the clinic to receive counselling and seek advice from the medical staff or their peers. The One to One project team would ideally like to establish an adolescent clinic for the province, continue to receive specific training on adolescent care and train CHWs and EPVs to support the medical teams in this task.

- **Reinforce the gardening project**

The Gardening project is an essential sustainable development plan. The knowledge of gardening heritage in Africa has been eroded by the importation of intensive farming practices and by the decimation of an entire generation infected by HIV and other diseases. The Gardening project, through its training activities, would ensure that the vital knowledge of gardening continues to be passed from generation to generation – especially important for those children now heading households.

Moreover, Africa needs to focus on a new feeding model suiting both society and land. The gardening project will provide independent food security for the clinic, the people trained and their family as they could feed themselves and manage their own resources more sustainably.

The Gardening Project offers tangible and sustainable benefits for future change and growth where it is most urgently needed. We strongly agree with Sister Nonkosi's words when she writes of the gardening project, "The phrase that says a person should be given a fishing rod and taught to fish rather than give him a fish [applies here]." For this reason One to One Children's Fund would like to prioritise its nutrition and gardening initiatives across Africa and the Paediatric AIDS Treatment for Africa (PATA) network of clinics, and wishes to reinforce the gardening programme in the Eastern Cape, supporting the creation of yet more food gardens in 2010 and the provision of comprehensive training courses for HIV patients in gardening skills as well as on soil improvement and space-saving techniques for small-plot owners and tenants.



Boy speaker from the gardening project

One to One Children's Fund would also like to rollout the ART Support Programme to further develop the capacity of the Port Elizabeth Hospital Services and undertake the care of HIV infected children and their families in all hospitals across the Eastern Cape Province within the next two years. Sustainability will be achieved through the training and support of hospital staff and volunteers, the information provided to children, adolescents and adults on HIV/AIDS related issues and interventions of community

volunteers - all of which contribute to reducing the stigma around infected patients and to improving patients' health and morale. Hospital Services in the region could therefore provide comprehensive healthcare programmes, including gardening and training.

