



The Expert Patient Programme

**Update Report
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Report to the Brian Murtagh Trust Fund

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Background

With the support of the Brian Murtagh Trust Fund, One to One Children's Fund is funding and co-managing the Expert Patient Programme delivered via PATA (Paediatric AIDS Treatment for Africa), a fast growing network organisation of front-line Paediatric HIV/AIDS treatment teams from across sub-Saharan Africa, responsible for the care of more than 30% of all children needing ARV's in the region.

Expert Patients are HIV positive patients 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 and their families.

One to One Children's Fund (121CF) has facilitated the Expert Patient Programme in response to the ever growing numbers of HIV /AIDS patients requiring the services of clinics with limited resources. A typical clinic takes on around 300 new patients each year, but staff teams are small and clinics do not have the money to employ extra staff to meet demand. Expert patients (EPs) are trained by the clinics themselves to carry out a variety of different tasks to support the work of doctors, nurses, pharmacists and counsellors. They are paid a small stipend for the work they do.

The Expert Patient Programme aims to:

- Use the knowledge and expertise of HIV / AIDS patients in a positive and affirming way
- Build the self esteem and confidence of the EPs themselves
- Ease the work burden of clinic teams - freeing doctors and nurses to concentrate on clinical interventions
- Expand the capacity of small, often isolated clinics to reach more patients
- Contribute by way of a modest stipend to the household income of EPs

The Work of Expert Patients

The work carried out by the Expert Patients varies depending on the needs of the clinics and their patients. Tasks carried out often include childcare, peer support education, administration, nutrition, communication, home visits and pharmacy work. Activities performed by Expert Patients vary considerably across clinics. Some examples of activities currently being carried out by Expert Patients are summarized below:

Table 1: Examples of Expert patients Activities reported by clinics

Clinic	Examples of expert patient activities
Uitenhage, South Africa	Welcoming clients and caregivers, checking heights and weight documentation, assisting the doctor when examining the patients, pill counting, checking diaries, assisting serving soup and bread to clients, sorting of old clothes and distributing to needy children, playing with children, attending and delivering health education talks and running support groups
Dora Nginza, South Africa	Retrieving files, giving educational talks, weighing children, playing with children while caregivers are at the dispensary, looking after children so that they are safe, preparing clients for ART, adherence counselling, assisting mothers with disclosure to children, ongoing adherence counselling, preparing adolescents for the adult clinic, assisting in the gardening project and defaulter tracing
Harriet Shezi, South Africa	Defaulter tracing

Newlands Clinic, Zimbabwe	Play chaperones, peer buddies, pharmacy assistants, reception duties such as filing, adolescent support group coordinators
CHUSS/ REV+, Burkina Faso	Retrieving and classifying medical charts, assisting children with ARVs, VCT, pre-ARV counselling, adherence counselling, anthropometric measurements, LTFU tracing, receiving lab sheets, visiting children in specialized departments and assisting at the pharmacy
Kakamega clinic, Kenya	Gardening, adolescent support group, inventories and adolescent training
Songea, Tanzania	Child care, nutrition education, administrative tasks, counselling, weight, height and communication with other NGOs
JCRC, Uganda	Supervision of play areas, outreach to communities, treatment support, peer support group facilitation.
Alert, Ethiopia	Adherence counselling, regular health education, growth monitoring and nutritional assessment, youth centre library and charting/ record keeping
Nyangana clinic, Namibia	Admin/ clinic flow, community/ home visits, community education and patient support, nutritional education and clinical assistance
Kalembelembe, DRC	Home visits, feeding children and palliative counselling
Mkhuzweni clinic, Swaziland	Weighing babies
Dvokolwako clinic, Swaziland	Community visits and referrals, provision of condoms and DOTS
FACES Migori, Kisumu, Rongo and Suba clinics, Kenya	Child-care, registration of patients, filing of patient charts and running errands, community visits, children's club, youth group, support group, nutrition, clinical assistance, communication and pharmacy assistance
Idas Valley IDC, Stellenbosch, South Africa	Counselling, Xhosa translator and admin
TC Newman IDC, Paarl, South Africa	Vegetable gardening
ALERT, Ethiopia	Adherence counselling and health education, growth monitoring and nutrition assessment, youth library assistance and chart management activity assistance.
Transmara clinic, Kenya	Admin / clinic flow, child care, community and home visits, patients education and support, counselling
Mbeya Referral CTC, Tanzania	Adherence counselling, weighing and height measurements, nutritional support

Training of Expert Patients

Clinics are responsible for training Expert Patients themselves. Most of the EPs are trained in the beginning only, others are trained on a monthly or weekly basis. They are also supervised in weekly supervision meetings.

For example, the Transmara District Hospital in Kenya employs seven Expert Patients who, between them, received 400 hours of training focusing on counseling, confidentiality, the use of machines, palliative care, home based care, TB/HIV, community mobilization and drug resistance.

At the TASO Mbale Clinic in Uganda, the two Expert Patients received 40 hours of training on basic nutrition, the relationship between nutrition and HIV/AIDS, effective communication, growth monitoring and also on identifying malnutrition in a community.

The four EPs at the Black Lion Clinic in Ethiopia were given 10 hours of training: 5 hours theoretical and 5 hours practical. Amongst others, these sessions were based around the discussion points of HIV as a world-wide epidemic, its transmission and prevention, prevention of mother to child transmission, infection prevention and on the set up and activities of ART clinics.

Thanks to the training and experiences that EPs have gained through the scheme, in some cases they can be promoted and hired by the clinic as lay counsellors or community health workers, or benefit from employment opportunities from other programmes. This demonstrates that the One to One Children's Fund programme is contributing to building hospitals' capacity by training EPs who are capable of becoming competent non-medical staff, and professionally care for children infected by HIV in the region.

Programme Monitoring

Monitoring and evaluating the effectiveness of the Expert Patient Programme is key to the success of the project. Clinics with EPs are required to submit quarterly performance evaluation reports to PATA and One to One Children's Fund and all clinic teams are encouraged to rigorously monitor the progress of their work in order to evaluate effectiveness of new approaches.

Impacts of the expert patient programme

The clinic reports received in October showed that the work of the Expert Patients continued to bring benefits for all those involved. Successes reported by the clinics include:

Capacity Building

Clinic teams are under-resourced and there are ever increasing demands on their services from sharply rising numbers of patients. The Expert Patient Programme provides practical solutions to specific challenges as Clinics train EPs according to their specific needs.

Expert Patients enable task-shifting to occur in clinics, which frees up the time of other more skilled staff members. For example, at Dora Nginza clinic in South Africa and at Nyangana clinic in Namibia, EPs perform duties that were previously done by nursing staff.

Expert Patients have also enabled clinics to initiate projects that they previously lacked the human resources to do. For example, at Kakamega clinic in Kenya, a demonstration garden featuring a variety of traditional vegetables is managed by the EPs. They have also started an adolescent support group.



Expert Patient tending to a garden at Bungoma Clinic, Kenya

Expert Patients have also enabled many clinics that were previously unable to do any home visits, to initiate these. At CHUSS/ REV+ clinic in Burkina Faso for example, their EPs carried out 64 visits in the period from May to August. These visits were to children newly started on ART in order to assist the children and

families as needed. Visits included helping to improve adherence through discussion of how to store ARVs, how to take them correctly, body hygiene, clothing and food.

Expert Patients assist in making clinics flow more easily through sorting folders, doing clerical work and streamlining the process at the pharmacy and the dispensary which reduces patient waiting times. In Kenya, the FACES clinics have reported that this has enabled them to manage higher volumes.

Staff within clinics expressed that they value the work that the Expert Patients do and accept the Expert Patients as part of the clinic team. In Malawi, at Zomba Central Hospital and at Mayaka and Matawale Health centres, the nurses have reported that expert patients make a very good contribution to the care of PMTCT clients.



Expert Patient measuring the height of a child at ALERT Hospital, Ethiopia



Expert Patient working in the pharmacy at FACES Clinic, Kenya

Expert patient volunteers are the pillars of the Paediatric Wellness clinic. Staff and clients value their presence” Nurse operational manager, Dora Nginza Paediatric Wellness Clinic, South Africa

Impacts on the Community

Some clinics have reported that employing expert patients gives the community a sense of community ownership. Through weekly meetings with other staff members, expert patients at the Baylor Malawi clinic have been assisted in their own lives in dealing with HIV and have benefited from being a spokesperson and role model within their communities. At the FACES clinics in Kenya, the community has reported that the Expert Patient Programme has resulted in them feeling better supported by the clinic and that they *‘feel part of the clinic’*, particularly as the programme *“has enabled the decentralization of HIV services closer to the people”* (FACES, Expert Patient supervisor).

“When we started working in the clinic it was the first meaningful thing we ever did with our lives outside from the usual church duties and activities” Claudine, Expert Patient, Uitenhage Clinic, South Africa

At the CHUSS/REV+ clinic in Burkina Faso, the Expert Patients offer counselling to children and their parents. All parents whose children have to get an HIV test receive a pre-test counselling session from the Expert Patients; after the test get another counselling, irrespective of the test result. Parents whose children have tested positive also receive counselling to get tested, particularly if they have not yet done so.

Furthermore, because Expert Patients are patients themselves, other patients in the clinic are able to identify with them.

“Our expert patients are a great resource for our new mums of exposed infants. They have so much experience and can relate to our patients. They often take the initiative to teach parents about important concepts relating to PMTCT and nutrition, such as exclusive breastfeeding and adequate nutrition for mums who are breastfeeding etc” Expert Patient supervisor, Baylor, Malawi



Expert Patient from the FACES clinics in Kenya giving HIV education

Impacts on Children

The Expert Patients Programme also brings many benefits for improving the health and well-being of children. At Songea clinic in Tanzania, expert patients identify children who need to be seen so that they get priority care and have shorter waiting times. At CHUSS/ REV+ clinic in Burkina Faso, the expert patients visit and counsel children who are in-patients in specialised departments like surgery and ophthalmology. The FACES clinics in Kenya have reported that the programme has resulted in increased attendance of children for clinic appointments, improved school performance, reduced depression, full participation in the care plan, understanding of the drugs and increased uptake of paediatric ART.



Children at the ALERT clinic in Ethiopia supervised by an Expert Patient

Expert Patients also make clinics more child-friendly for example by supervising children at play (e.g. Uitenhage Clinic). At clinics where play areas were previously neglected and equipment was damaged (e.g. JCRC, Uganda), by employing EPs, these play areas are supervised, safe and the equipment is better managed. At Baylor Clinic in Lesotho, one Expert Patient was hired to monitor the playground and to organise activities for the children as they wait for their doctor visits.



An Expert Patient supervises children using the playground at the FACES Clinic, Kenya

Staff at the Groote Schuur Clinic in South Africa have also noticed that providing a play environment for patients prior to their appointments is very important as it reduces the anxiety levels of the children. In addition to playtime supervision responsibilities, at JCRC in Uganda the Expert Patients also supervise the mid morning snack that is provided for the children.

Staff at the Baylor Children’s Foundation in Swaziland have recognised that Expert Patients are often more in touch with what is going on in the lives of the patients than the medical team. The EPs love to participate in the teen club activities which the hospital has set up, and the

EPs all helped to run the Christmas Party which the hospital was able to offer the teenagers this year.

Impacts on Expert Patients

"This experience has given them confidence and a sense of accomplishment. For example, one of our expert patients, Kuhle [name changed], has stated that she had always wanted to be a nurse and working in our clinic has fulfilled her dream in a way. Their enthusiasm is contagious and their eagerness to learn is refreshing" Expert Patient supervisor, Baylor, Malawi

The Expert Patient Programme also has a major impact on the EPs themselves. Through the training and work experience they receive they can learn and understand more about the disease and the medicine, their adherence improves, their stress levels are reduced, and they benefit from the latest information and findings about HIV / AIDS. The EPs in the TASO Mbale Clinic in Uganda were able to build their capacities through the training, which developed their self-esteem and confidence in using HIV / AIDS care packages. Furthermore, the stipend received by EPs normally contributes substantially to their family's income.



Expert Patient Taking a Child's weight at ALERT Hospital, Ethiopia

"PATA makes a lot of changes, because since my husband passed away, who was the breadwinner in my family, with the stipend I have earned from PATA, me and my children we can survive", Expert Patient, QE II, Lesotho

Expert Patient Testimony

Mary Otieno, Expert Patient, Sunshine Smiles Clinic, Gertrude's Children Hospital, 2009:

"I first came to the Sunshine Smile Clinic when bringing my daughter for treatment. Later, I was asked if I would like to volunteer for the EP programme. I agreed. Back then, life was not easy for me; I was jobless and I had a child to take care of. I had reached a point where I preferred death than felt that it would be easier to die. Before starting to work as an expert patient, I underwent counselling and later when I had gained some form of meaningful and positive understanding about my status, I embarked on learning about the day to day running of the clinic. I trained in Community based programs like HBC (home based care), peer education and customer care. I was also taught how to operate equipment used to measure weight, height and blood pressure. Though it took me a while to get used to the system, I had a good support system from the rest of the clinical staff and now really enjoy it. I now work part time in the clinic.

How has the program helped me? For one, I'm still receiving ongoing counselling. This has helped me understand my status better. Secondly, from the income I earn from my allowance, I am now able to support my family with food, shelter and other necessities. It also gives me a sense of Fulfilment to be able to be involved in the task of alleviating the HIV/AIDS burden on our children and families. Since most of us work on a part time basis, I would like to see us expert patients involved in income generating projects to supplement our incomes. Such projects would also be an avenue for us to meet, share and exchange experiences and ideas on the EP program and on HIV/AIDS in general. Sometime in the near future, I would also like to train as a nurse and receive additional professional certifications that would make me a better person and HIV health expert.

Through the EP programme, I have come to understand that HIV is no longer a killer disease. I now face life positively and the value of my family life has greatly improved because they are now aware that, even though you are HIV infected you can live a long life and fulfilled life."

Challenges

A number of challenges emerged from the October clinic reports. One issue highlighted was that there are sometimes too few Expert Patients for the work load that needs to be covered. The Newlands clinic in Zimbabwe for example, has had to extend the working hours of the EPs from the planned 3 days a week, to daily.

Even with the increase in the Expert Patient stipend, some EPs struggle financially. Clinics such as the JCRC clinic in Uganda have stipulated that EPs need to live within the vicinity of the clinic in order to reduce costs incurred from travelling long distances.

Currency fluctuations and the global economy impact severely on programmes. In Burkina Faso, where the decrease in the value of the dollar relative to the euro plays a big role in forecasting, the clinic has reduced home visits to 16 per month to manage the rising cost of transportation, despite the great need for these visits.

Monitoring and Evaluation Programme

Indicators of success include: increased capacity, improved efficiency, more child-friendly services, more accessible services, and greater adherence to the drug regime. Positive results in the above areas also indicate a reduction of stigma and discriminatory attitudes toward HIV/AIDS patients within the community.

One to One Children's Fund has initiated a pilot Monitoring and Evaluation programme of the Expert Patient Programme in 8 PATA affiliated clinics where Expert Patients have been recruited and trained.

Monitoring and Evaluation is important as it emphasizes the real impacts of the programme. It energises and reinforces the work of expert patients and it also ensures that the necessary remedial action for non performing programmes can be taken.

A five phase framework was developed:

Phase One: Assessment and Scoping

Phase Two: Monitoring and Evaluation Programme Design
Phase Three: Monitoring and Evaluation Pilot Phase
Phase Four: Monitoring and Evaluation System refinement
Phase Five: Monitoring and Evaluation System Roll Out.

Conclusion

The overarching aim of the Programme is to deliver services in the Sub-Saharan African regions highly hit by HIV/AIDS so that as many children and young people as possible can benefit from the care they deserve. Through the PATA network, the Expert Patient Programme delivers efficient support to clinics delivering paediatric HIV/AIDS treatment, stream lining services, breaking down barriers and empowering local people with real knowledge and expertise.

One to One Children's Fund hopes to continue to extend its support and funding to the Expert Patient Programme. Expert Patients currently work at 47 clinics in 14 countries; however One to One Children's Fund and PATA hope to extend the programme to 60 clinics in 2010 and 100 clinics in 2012.

One to One Children's Fund and PATA would not have been able to expand the Expert Patient programme to 47 clinics without the generous donation of the donation of the Brian Murtagh Trust Fund.

Summary of the Expert Patient Programme

Growth

Date	Number of countries	Number of clinics	Number of expert Patients Employed
June 2007	6	23	74
January 2008	11	31	104
June 2008	13	33	136
June 2009	14	47	200
January 2010	14	47	200

Coverage

Country	Number of participating clinics	Clinic names
Burkina Faso	1	CHUSS
Cameroon	1	Chantal Biya
DRC	2	CAP/ Heal Africa Kalembelembe
Ethiopia	2	Tikur Anbessa (Black Lion) Alert
Kenya	7	KNH Gertrude's FACES Suba FACES Migori FACES Kisumu Bungoma Transmara
Lesotho	2	QE II Baylor
Malawi	6	Tisungane clinic Zomba EID Zomba PMTCT Zomba Zomba Baylor
Namibia	2	Oshikuku Nyangana
Rwanda	5	PIH Kirehe PIH Rwinkwavu PIH Rukira PIH Mulindi Butaro
South Africa	11	G25 Worcester

		Paarl Idas Valley Keiskamma Dora Nginza Uitenhage Tygerburg Harriet Shezi Harriet Shezi (Zola) Harriet Shezi (Lillian Ngoyi)
Swaziland	3	Baylor Dvokolwako Emkhuzweni
Tanzania	2	Songea Mbeya
Uganda	2	Taso JCRC
Zimbabwe	1	Newlands
TOTAL	47 Clinics participating	14 Countries participating