



Kidzpositive

www.kidzpositive.org

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2009 NEWSLETTER

Kidzpositive in 2009

Dr. Paul Roux

We continue to grow and prosper. Thanks to a five-year donation from an anonymous Philanthropy, we remain able to manage USAID PEPFAR funds that support paediatric services at Groote Schuur and Somerset Hospitals, adult medical and psychiatric services at Groote Schuur and GF Jooste hospitals.

We now support services delivering antiretroviral therapy, at three sites, to a total of more than 1000 children. The clinical care team is doing excellent and very hard work. A high rate of retention in care and low incidence of drug resistance attest to their dedication.

Our adolescent service is rapidly increasing in numbers and growing its quality of care. Young people attending the monthly adolescent clinic s receive care and support from a team directed by Diane Gray. Phumla Tyosi, Jenny Gray and Nuruneesa Lalkhen form the mainstay of psychological support and we have been able to learn a great deal from Barbara Kaim who visited Cape Town to teach ATICC and ourselves about the use of the TARSC 'Auntie Stella' life skills training instrument. We are developing a partnership with the Desmond Tutu HIV Foundation and took part in the first PATA forum held in November, where the care of adolescents with HIV was on the agenda. The Ratanga Junction outing for our youth and the Earthbox project are highlights, which are described elsewhere in this newsletter. We gratefully acknowledge financial support from the Rotary Club of Claremont for our Auntie Stella and Earthbox projects. All those people whizzing around the Cape Peninsula to complete the Argus Pick and Pay Cycle Tour are also doing it for our patients and their families.

The Positive Beadwork Project is definitely a jewel in the Kidzpositive crown. Thanks to generous funding from Sidaction (www.sidaction.org) and AREVA (www.areva.com) we continue to support income generation enterprises in Paarl and are confident of assisting in the development of other sites in Knysna and at False Bay Hospital. Laura Koopman, who has been completing her studies at the Hanze University of applied science, Groningen in the Netherlands helped us to write a Dutch marketing plan for Kidzpositive and the Beadwork Project: Now we need to find a way to implement it.

It was heart-warming and a great finale to this reporting period when the graduating 'Class of 2009' from the Faculty of Health Sciences at the University of Cape Town honoured Kidzpositive as their designated charity at their final year dinner on November 10th. We recognise the work of our founding Board member Dr Lauraine Vivian in this, because it was she who first introduced Kidzpositive and its work to this class.



Day 1 Positive Beadz False Bay Hospital

Jane Dunn

After months of planning and meetings our team of ten women finally came together for its first day of training with Sylvia Rasmeni from Positive Beadwork. There was a palpable sense of anticipation and excitement in the air as these women began their journey at Positive Beadz. From learning to thread the loom, the team then began the very frustrating task of learning to thread the needles! For most, including myself, trying to put the fraying thread through the needles, with their impossibly tiny eyes, was cause for loud exclamations and hoots of laughter! What stood out the most for me was that not a single woman gave up. This was to set the tone for the rest of the day and by the end of the session, three women had already completed their first few, beautiful South African flag pins!

There is a lot of focus in the media on the sadness associated with HIV/AIDS. The Positive Beadz team wants to create a different focus, by showing the community through their beadwork that they are living well on ARV's, facing their challenges, taking responsibility for their own lives, caring for their children with total commitment and constantly working to change the negative attitudes prevalent among the communities that stigmatise them and their children.

The 9th of October 2009 will always be remembered as a day of friendship, smiles, laughter, triumph and hope for the future.

Our Christmas wish:

A HUGE ORDER for FBH in 2010

Email jane.dunn@netactive.co.za





Clinic update *Di Gray*

The clinical service has continued to be a busy and rewarding aspect of the Kidzpositive project. The growing number of children requiring antiretroviral therapy has led to rapidly expanding clinic numbers. This means very busy clinics and a lot of thanks goes to all the dedicated team members who make sure that the care delivered is of the same excellent standard as always. Our team is made up of nurses (Sr Susan Isaacs and Sr Fatima Noor), counselors (Pumla Tyulu, Lindi Madasi, Charlene Mfundisi, Sabrina Jeffries, Vivian Tshingane), administration staff (Jenine Vermeulen, Zurina Isaacs, Sylvia Ncethani), psychologists (Nuruneesa Lalken, Jenny Gray), a physiotherapist (Tania Salie), an occupational therapist (Naema Razack), pharmacists (Asa Jaffer, Michelle Brown), doctors (Dayle Zieff, Thania Hisham, Diane Gray), data-plus team (Lucia Matshoba, Lil Hobbs) and our leaders (Paul Roux and Ronelle DeVilliers). Everyone plays their crucial part in preparing, providing and maintaining the clinical service.

Currently we serve three paediatric antiretroviral clinics with a total of 1050 current patients in care. Two clinics are held at local primary health care facilities (Mitchells Plain and Crossroads) and the 3rd based at G26, Groote Schuur Hospital. We have enrolled 319 new children enrolled in care since October 2008. The average age of new enrolments is getting younger, which is very encouraging. Evidence is now clear that the sooner HIV-infected children can start ARVS the better their outcome from both AIDS related illnesses and non-AIDS related events. The 'CHER' study has unequivocally

shown that HIV infected infants should be put onto antiretroviral therapy as soon as possible. This early initiation of highly active antiretroviral therapy (HAART) has the potential to reduce mortality by 75% in HIV infected infants. Another aspect of care in our clinics is the identification and management of late effects of long term HAART exposure. Over 50% of children in our clinics have been on HAART for longer than 4yrs and are doing extremely well. Some now have to deal with late effects of the treatment such as body shape changes, blood sugar problems and bone density effects. However, overall it is most encouraging to see how many of our children are living lives free of sickness and participating in the excitement of life along with their peers.

CURRENT CLINICAL PROJECTS

Disclosure to a child

HIV infection in a family affects not only the infected parent and/or child but also siblings, families and communities. Many families are obliged to cope with the loss of family members and the stress of managing strict health care routines despite extremely limited resources. The stigma of HIV continues to provide a huge barrier to disclosure in many situations. One of our current projects is designed to examine how and when carers disclose the diagnosis to their HIV-infected children. We know this to be very stressful to families and our clinics need to support the process of disclosure. Together with other paediatric HIV clinical teams we will be working on a team approach to family disclosure – a challenging but essential issue.

Cellphone messaging

We have embarked on a joint project with Cell-Life, a not for profit organisation which uses cellphone technology to improve the lives of people living with HIV. The project is using text messages to remind patients of appointments. Messages are sent a week before and the day before an appointment. Patients who do not attend appointments are contacted by a counselor and given new appointments. The project will also allow patients to contact the clinic free of charge to change appointments or consult a member of the team. Another aspect of the project will be to set up a MXIT communication network for adolescents and possibly other clinic members. This is an inexpensive way for adolescents to communicate without fear of unwanted disclosure to their peers.



Lifeskills magazine

We have used ExtraTime, a life-skills educational tool created by Grassroots soccer, as a school life-skills tool in randomly selected classes in a school in Ocean View, Cape Town. This project showed a high baseline HIV related knowledge in adolescent children attending this school. It also showed a significant increase in HIV related knowledge when compared to children who received alternative life-skills lessons.



Research

Our clinical team is engaged in a number of research projects that are aimed at identifying and limiting the toxicity of the life-saving anti-retroviral therapy we have to use.

positive
heroes+



Kidzpositive



2 Positive messages of hope and inspiration

Ronelle de Villiers

Two South African organisations, both dedicated to improving the quality of life of patients living with HIV/AIDS, got together this past year....

Positive Heroes (www.positiveheroes.org.za) vision is to reduce fear, misinformation, stigma and discrimination that surround HIV. The charity raises the profile of South Africans living positively with HIV. People from a wide variety of communities and walks of life both urban and rural, encourage others to manage their HIV infection and live full, rewarding lives.

Kidzpositive is a Non-Profit Organisation which raises support for the daily needs of

children and families affected by HIV/AIDS.

Two inspiring events held this past year:

1. A Christmas party celebration at Mitchell's Plain Paediatric ARV Clinic- Cooldrinks! Snacks! Party hats and.....TOYS!

Brett Anderson, one of the Positive Heroes shared a moving and inspiring story of his personal journey with HIV. His message was that life is about choices, that HIV is an illness that can be managed, and that we can all choose to live full and rewarding lives with a positive attitude.

2. A Teddy bear's Picnic! We thank a group of ladies in the United

Kingdom who gave of their time to knit beautiful items for others to treasure. Their generous donation of loveable teddies via Positive Heroes and Kidzpositive has enriched the lives of many children who are being treated for HIV and AIDS at Groote Schuur Hospital.





Adolescent Update *Lil Hobbs*

The 18th July 2009 was a celebratory day for all South Africans. It was Nelson Mandela's 91st birthday. Kidzpositive collaborated with the Desmond Tutu HIV Foundation in taking a group of adolescents from the respective clinics to Ratanga Junction for a fun-filled day of games, rides, bonding and celebrating. Thanks to the Siyasanda Foundation, who organized the day, over 100 excited teenagers piled into buses early on this Saturday morning.

Dedicated volunteers from all walks of life provided supervision and care for small groups of adolescents whilst riding the rides. Lunch was shared together as a large group, with music and singing, followed by a talent contest. Mandela's rainbow nation was in full swing with the mingling and celebrating of young and old, HIV positive and negative, black and white, rich and poor – a true testimony of how far South Africa has come in our sprouting democracy.

One wonders how many of the children who participated in the Adolescent Fun Day would have been alive today if it had not been for starting their ARV treatment over the past 6 years. Consistent palliative care in the form of regular medical check-ups, ARV therapy and counseling have helped to provide ongoing quality of life for many of the adolescents attending our clinics. We are grateful for the benefits of treatment and the efforts of NGOs and volunteers, which have had profound effects on the wellbeing of our young patients.

We at Kidzpositive continue to learn the value of our adolescent patients in experiencing care-free days as a group, in socializing and to have the opportunity to be youthful. In essence through these activities we aim to provide a space in which – be it for just an hour – youth can meet and forget the burdens of their everyday lives.

The 1st October presented itself as the perfect opportunity to initiate the Earth Box to our group of adolescents at Kidzpositive.

'Earth Box – an award-winning, innovative gardening system which regardless of space, water and resources can provide individuals and communities with consistent and cost effective supply of nutrient rich food and the possibility of generating income from selling a surplus'



Summer is nearing and the time for planting is upon us. Reaping the benefits of caring for one's food garden is bound to produce an array of tasty vegetables and salads for family's meal times. James Millar, a UCT medical student, through an interactive presentation on the Earth Box concept, fueled the enthusiasm of 11 of our adolescents in receiving and caring for their own Earth Boxes at home. International Day of Climate Change is planned globally for the 24th October this year; fittingly we decided to roll out the Earth Boxes to the group of adolescents on the day. Boxes were hand delivered to the respective adolescent houses. Chard, tomatoes and beans were planted and left to grow and flourish under the watchful, nurturing eye of the proud young gardeners.

We hope that this project will continue to flourish, aiming to instill within groups of active and energetic teenagers the process of caring for themselves as they care and tend for their Earth Boxes. Through commitment to an activity, an end result of health, wellbeing and positive outcomes can be achieved. We feel that this is a valuable lesson that needs to be learnt by youth, looking forward to the exciting future of their lives.

Another exciting activity is happening at the clinic as a result of the arrival of 'Auntie Stella' in Cape Town.

'Auntie Stella – is a printed pack of 40 letters between teenagers and an "agony aunt." Drawing from experiences and stories of young people in Southern and Eastern Africa the letters deal with all kinds of personal, emotional and social issues affecting young women's and men's lives and their sexual health and relationships with peers, partners, family and society.'

Barbara Kaim of the Training and Resource Centre (TARSC), who has been integral in developing and implementing Auntie Stella in Zimbabwe and neighboring countries, trained 11 Counsellor Trainers at the Western Cape AIDS Training Information and Counselling Centre (ATICC). The aim is that that through 'training trainers' they will in turn train counsellors in using Auntie Stella as an interactive tool in working through 42 sensitive life skills issues faced by youth (including 11 AIDS-specific questions).

It is expected that young people between the ages of 12 – 19 will find it easier to talk about matters that worry about them in a constructive, non-threatening and activity based manner. The tool has been used in other African contexts and proven highly successful in implementation. The aim is that this tool will provide an opportunity for the youth attending our clinics to engage with these materials in a safe space with trained counsellors. Teaming with the Desmond Tutu Foundation, Kidzpositive aims in the future to assist ATICC in rolling out the process of implementation and of evaluating the intervention.



A blast on the Vuvuzela for Kidzpositive!

Kate Gray

Positive Beadwork is on the brink of securing a bite of the 2010 World Cup marketing opportunities. The project will be teaming up with the Iziko Lo Lwazi community project in Hout Bay to provide the decorative panels that will be worked into thousands of vuvuzelas that are being beaded for the World Cup. This has come about because of the special skills in using the beadloom for which the women of our project are well known. This work will provide an opportunity for the mothers to earn a little extra over the Christmas period – usually a lean time for income generation via the project. We hope it will all come to fruition and that there will really be a reason to shout LADUMA!

Another goal scored by the project this year is the production of a beautiful 8 page brochure to showcase Positive

origins of the project, the schools' initiative and heartfelt comments from the mothers.

Our friends at Ballarat Grammar have notched up another 'first' – the year 11s had the idea of providing each mother with a 'winter' hamper – something to brighten up a cold winter day. The initial request for us to make up hampers was impractical to implement but a happy solution was found in that we bought a R100 food voucher for each mother. This was presented in a colourful card sent over from Australia each with a hand written message to the mother from the pupils. It all came as a complete surprise and there was much excitement.

We held a workshop in April, which has resulted in a 'shake-up' and new vitality.

these positions of responsibility – especially when it came to some of our big orders of the year – an urgent order for 2500 beaded pens for a local conference and more recently an order for 10 000 special AIDS pins. New vitality has also been injected into the project with the appointment of Cindy Tyrrell as assistant co-ordinator – her empathy with the mothers and enthusiasm for the project is a tonic for us all.



POSITIVE BEADWORK IS ON THE BRINK OF SECURING A BITE OF THE 2010 WORLD CUP MARKETING OPPORTUNITIES.

Beadwork. This attractive and informative booklet was made possible through an award by the Impumelelo Awards Trust. We are grateful to Cornel de Kock who visited us, freely gave of his time and talents, related easily to the women and took the photos that capture the essence and spirit of the project. Besides presenting our products and photos of the mothers at work, the colourful brochure also provides information on the

Sylvia Rasimeni has been appointed product developer and trainer, with particular focus on new mothers. We really want to encourage these vulnerable mothers who can benefit most from the project. Monelwa Canda is the new floor manager. She supervises orders going out each week and quality assessment of finished work. Both these mothers have been with the project since its inception in 2002 and it is great to have them in



The role of Expert Patients

Lil Hobbs

Paediatric AIDS Treatment for Africa (PATA) sponsors two Expert Patients at our Wednesday and Thursday clinics at Groote Schuur Hospital. The term Expert Patient is not a new one. Since June 2007 PATA has been funding a pilot expert patient programme in 20 Southern African clinics. The aim is to facilitate task shifting within clinics to reduce the stress of the clinical team. This idea complements Kidzpositive's entrepreneurial approach to improving quality of health care delivered in the Public Service.

The expert patient may be deployed in many ways: From helping with childcare whilst patients wait to be seen, to taking folders to the pharmacy, to providing clinical assistance and support to new patients and their caregivers.

Expert patients are extremely helpful. Mothers who are part of our Beadwork group are able to sit in the waiting room and complete their orders, safe in the knowledge that their children are with an Expert Patient who is not only watching over them but stimulating their play and interactions. Children are surrounded with a variety of toys, with drawing materials and posters. Expert patients read stories, sing songs and play games with the children. We feel that this is a valuable space for our young patients to play, interact and learn whilst waiting to be seen by our nurses and doctors.

Our experienced expert patients can provide valuable advice and mentorship to patients newly entering our service, on how to get your child to take regular medication, where to find the counselors,

where to meet the support group, where to pick up medication and where to make your next appointment. This care assists newcomers who may be overwhelmed and uncertain at their first clinic visit.

We continue to add value to the Expert Patient programme through monitoring and evaluating their progress. Expert Patients are eager to add to their skills and enhance the service that they provide. Expert Patients are currently being assisted in developing 'play plans' for clinic days.

Thank you to our funders, partners, staff and supporters for their commitment to us and the work that we strive to do.