



Children of Fire

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www.firechildren.org

Newsletter

Children of Fire saves government thousands

In November 2006 it was six years since we arranged for teenage burns survivor Irene Peta to have her colostomy closed. In addition to improving the quality of her life beyond anything that she could have imagined, we have along the way saved government at least R60,000 for stoma bags and tape that she would have had to have used in that time frame. Assuming that Irene would have at least a normal lifespan, the overall savings to the healthcare system will eventually be close to three quarters of a million rands without even allowing for inflation or the cost of time of healthcare professionals to help her. All that from one small charity Children of Fire. For people who are not so lucky as Irene, there is a **Stoma Support Group**: Contact Sister Fiona Gopie at Helen Joseph Hospital. (011 489 0469)

August—November 2006



Children of Fire—Africa's
first burns charity

*Top left: Actress Jane Seymour met
volunteers Marietta and Koichi*

Sizwe seizes the day in Cape Town

In late August 2006, Director Bronwen Jones went to Cape Town. Her travel companion Sizwe (5) just could not believe what he was experiencing and talked pretty well constantly for the two-hour flight. "Are we going up to Heaven?" "Can the plane swim?" "Are we going to fall down?". Mostly he was excited as he tried to work out perspective and distance, why the cars and houses were "so little", and he did not really seem to recognise the aerial view of water at all - but he did of the mountains. All the time in the Cape, Sizwe also did not seem to understand quite how far away he was from home; particularly not that he was in another city and that it was not Johannesburg.

He did get to go up to about the 19th floor in the Shell building to admire the view of Table Mountain and also to the 26th floor where Marsh Insurance let him see the huge ships in the harbour (then again he did not seem to fully comprehend the size and distance).



And when he went to the Santam building and was given a hamburger and lots of attention, he was in his element. Bronwen and Sizwe took with them 17 covered hot water

bottles (teddies, elephants, rabbits, etc) for children at the Red Cross Hospital burns unit along with some bright red toy fire engines, toy cars, a cuddly tortoise and a lovely talking doll. Thanks to Netcare Pharma-



Sizwe jumping for joy at the Strand beach near Cape Town

cists, Janet Landy of Party Design, and Dee French of Ultra Liquors, who had been the original source of some of these gifts.

And for surgeons invited to our party held for the medical fraternity in July 2006 who could not attend, they hand-delivered some doctors' party packs for Prof. Heinz Rode, Prof. Don Hudson and others... yes, there was still a little surplus from the annual Chocolate Fest and they knew the very best use for it would be in delicious thank-you parcels to those who have assisted our children over the years.

After the hospital a quick hello to Nelmarie du Toit at the Child Accident Prevention Foundation where Bronwen and Sizwe learned more about their current candle project, saw yet another safe candle

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holder design and introduced a local inventor to them.

They also saw a very useful book on Paediatric Burn Care just written by Prof. Rode and anaesthetist Jenny Thomas. It sells for about R170.

The duo also touched base with Neil Kirkwood of the SA Airforce at his new base (Children of Fire worked with him before in Hoedspruit near the Kruger Park) and Sizwe got to sit on the SAAF yellow fire truck and honk the horn. The fire fighters were given a demonstration of the Parasafe pressure stove by inventor Colin Vale. They were most impressed, even though it took a while to get started with no methylated spirits to hand.

Neil and colleagues were up to their eyeballs preparing for the imminent international air show but they expressed keen interest to be involved in both the Drakensberg and the related Kilimanjaro projects. Dragon Peaks lent us the SAAF base close to Champagne Castle and next time we hope the kids will get some flying there too...

Bronwen and Sizwe also met with Chris M at St Georges' Grammar School - giving him a poster of Kilimanjaro... which he might get to climb if he is not on a soccer tour of Argentina in June 2007!!

Christopher has grown into a tall, handsome, well-mannered boy whose teachers speak of him highly.

He is thriving at the school and was evidently well-liked. Sizwe saw the similarity between himself and teenage Christopher and talked about him for a long time afterwards.

Then it was off to the seaside for the first time, albeit in cold grey windy weather. Sizwe was scared that the waves were "coming to get" him. He thought it was a very big swimming pool.

The next day he thought all ponds and reservoirs were the sea. On his second visit to the sea he watched parasailing and wanted to join in. He was told firmly that he had to learn to swim first. He also saw huge jelly fish and dared to touch the water... just a little.

Despite some poor manners from Engen, the visit was generally a great success.

And a little repair work was started to undo the damage done to the charity by the defamatory behaviour of former school staff in mid 2006.

Then back to Joburg for yet more teacher interviewing, a visit from the Education Department and seeing British volunteer Ollie off on his travels.

We also gave 20 pillows to ward 275 at Joburg Gen and 130 extra ones to the hospital, so that different patients could be more comfortable. And a further 40 pillows to Helen Joseph Hospital, collected by Alpheus on 18th September. Thanks to our donors.

Beating bird wings and pulsing drums for Heritage Week

At end-September 2006, The Johannesburg School for Blind, Low Vision and Multiple Disability Children (Beka) presented yet another exciting Holiday Activity Week. With themes all around South African heritage, children from Beka, Katlehong School for the Blind and Deaf, as well as a group from the Joe Slovo squatter camp, went to *Aladdin* at the National Children's Theatre, learned new dances, drummed African drums, touched bird eggs and feathers from the Zoo and listened to live birds, at Monte Casino bird gardens. It was great fun.



Lindiwe Msomi from the Ekurhuleni School for the Deaf (formerly Katlehong School for Deaf and Blind)

Anele hopes to sleep with her mouth closed in 2007

Anele Nyongwana's tissue expander was sadly removed due to an infection that she probably caught when she visited her squatter camp home one weekend. There was minimal improvement to her hairline, but we will try again in future. She went on to see one of South Africa's leading surgeons, Dr.

Martin Kelly at Sunninghill Hospital. He will soon release contractures around her mouth, so that it can close properly when she is relaxed. This will also improve her oral health, as she already exhibits tooth decay from her ever-open mouth. More work to her nose, hairline and hand, as time goes on.

Zanele "Power Girl" Jeza has mouth contractures released



Zanele Jeza age three, was burned in an accident with hot homemade floor polish manufacture in her Soweto garage home. She had surgery to her mouth on 12 September 2006, releasing the contracture on her lower lip with skin borrowed from her thigh. On a phone call to Joburg Gen ward 275 to check on her recovery after the operation, Sister Nandipa Guda said: "She's fine, she's eating, I even found her running in the ward." The Occupational therapists made cool new pressure garments for her too. *Zanele here is wearing a top given by TV producer Junius Hughes' church. Thank you!*

Noisy boys have mild to moderate hearing loss

Sizwe Hlophe-Jones went for a hearing test in September and the Hearing and Balance unit at Garden City Clinic.

Thanks to Claudia and Penny. And subsequently he went to see Deon Rossouw, the Ear Nose Throat specialist, also at Garden City.

Sizwe has been booked for a contracture release to

his upper lip in early 2007. This will hopefully improve his speech (he lisps a little) but many find his skew-wiff face is part of what makes his so lovable.

After Sizwe, our next "noisy boy" Bongani Madlala went for a hearing test. High levels of antibiotics in intensive care often lead to hearing impairment in burned children. We'd like more information on this.

Medical and surgical challenge child Sicelo

In early November 2006, Sicelo Maduna (8) finally went for the first of several operations to reconstruct his nose, which was burned away as a tiny infant. The skin from the tissue expander he had been wearing under his forehead for the past 12 months, was used as a flap to cover what was missing from his nose. Some cartilage from his ear gave support. The flap seen here is still attached to Sicelo's forehead and will be separated during December 2006.



Starting Anti-retrovirals: They took his blood, examined his ears, X-rayed his chest, asked him questions, asked his caregivers questions, and explained every detail of the anti-retroviral (ARV) treatment -

now, two months after Sicelo's first dose of ARVs, giving the medication correctly and on time has become part of everyone's daily trials.

For your interest: Understand HIV, Aids and Anti-retrovirals

Anti-retrovirals have to be taken twice every day without fail, for ever. One dose is taken in the morning at a set time that does not change; one dose is taken in the evening at exactly the same time. Changing the times would encourage resistance to the ARVs.

The different tablet and capsule doses are adjusted to the body weight of the recipient. If you lose weight you change the dose. There are different regimens of anti-retrovirals. "Regimen" means com-

bination - so if a patient does not respond well to one regimen, or has developed immunity against it, he can change to another regimen. However there are only two other regimens, so every effort has to be made to make the first combination work as long as possible. This means strict compliance in taking the medication on time. The chance for resistance to medication increases if it is not taken on time, or worse, if it is missed out - even once.

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Sicelo takes Stavudine and Lamivudine (which can be replaced with 3TC— different brand but same effect) in the morning, and in addition to that, Stocrin in the evening.

Two factors are used to determine the level of infection with HIV that the patient has, and their need for ARVs: The CD4 cell count and the amount of the HI virus in one cubic millilitre of blood.

CD4 cells are part of the immune system and they fight off diseases. HIV attacks these cells and destroys them. That is why people infected with HIV are more prone to diseases and infections. In healthy people, the CD4 count is sometimes as high as 1500. ARV treatment is typically begun when the CD4 count drops to close to 200, or in children, when it is less than 15 per cent. Cases have been recorded where people had a CD4 count of 5, and survived.

Anti-retrovirals slow down the reproduction of the virus. The viral load decreases soon after the treat-

ment has begun, and the CD4 count goes up. ARVs cannot totally destroy the virus, which is why they have to be taken continuously. If the treatment is not effective, the immune system no longer functions and the patient will develop AIDS. The cause of death is a disease or infection associated with AIDS, such as tuberculosis, pneumonia or cancer.

Side effects of the ARVs include headaches, diarrhoea, nausea, vomiting, dizziness, nightmares, fever and rashes. Usually they disappear after the first two weeks.

Thanks to the advice from Dr Lynn Webber of Lancet Laboratories and Joburg Gen Virology clinic sister-in-charge Martha Mathodlana, Dr. Vuyiswa Maziko; and Dr Sheba Varughese (acting head), child carers at Children of Fire have gained a better understanding of the virus and its treatment. However, getting consistent advice on HIV and AIDS is not easy, not even in printed material. Aids helpline 0800 012 322

Phone 011 488 3218 or email Dr Sheba Varughese at varughese@medicine.wits.ac.za for more info.

Teachers on trial

Following a letter to *The Teacher* newspaper, which asked for a compassionate and skilled teacher for our school, some of the following teachers were invited on a trial at our school:

Godfrey Bopape with some 16 years teaching experience in Limpopo, has a passion for arts and culture, especially where it is done by or for the disabled. He had travelled to Burkina Faso to represent South Africa but has at least two government departments owing him money for a prolonged period of time which made his life complicated....

Yvonne Rametse just loved the children. She also has 16 years experience in a Limpopo school and is looking for a new challenge. She also met a "home boy" Mahlatsi Rapetswa and that alone might be enough to justify a move to the city...

David Madire arrived on 25 September 2006 as a helper for the Heritage Week. The next day after breakfast he left without explaining himself or even saying good bye at the offices.

John Shezi from Durban displayed eagerness and love for the children. However, after two days he started trying to persuade us to hire him straight away, claiming that he is the one and only and we might never find someone like him again. This made most of us doubt his professionalism.

Malusi Sithathu works for the Department of Labour in Pretoria, despite having a teaching diploma. It is a desk-bound job with finances and doesn't let him mix with lots of people - but he is gregarious by nature. Being wheelchair-bound due to polio as a child, Malusi required us to rethink garden accessibility at the school and various safety features like high-up bolts to keep children out of the kitchen - as they don't work for people in wheelchairs.



Malusi Sithathu surrounded by some of our children

Ira Botha from Pretoria helped at the Heritage Week in September. Just about to leave university, her enthusiasm was a delight for the entire school. The job advert is on www.firechildren.org

Interested in teaching disabled, blind, low vision and burned children? Phone 011 726 6529.

Stars in the making

Quick reaction to an email from Penguin Films secured a cameo role for our blind part-time pupil Khaya Gxekwa in the SABC 1 television series *Home Affairs*. He was filmed on campus at Wits University on September 7th 2006, playing the role of a blind student who inspired another student with his endeavours. And where did Khaya get his first acting experience? Through Children of Fire's part in the Constitutional Court's Youth Parliament programme, where the youngsters had to act out plays on rights and responsibilities. You'll have to wait until August 2007 to see him on TV though... unless some agents pick up on his budding talent and get him some other roles soon. Email firechildren@icon.co.za if you can put work his way please.

And another: We then linked an older blind adult for another acting role. And another: And our teenage burns survivor Irene Peta was recently in the Nestlé-sponsored programme on Saturday mornings.

Then James Phosa, a man whom we arranged legal help for when he was falsely accused of arson in a

squatter camp, spoke out on the issue to advise young people on *Zonke Rulz*, aired on Thursday September 28th at 15h00. Meanwhile Abigail Ximba's hands appear typing Braille at our school in the *Zonke Rulz* "Disability in School" episode aired on 12th October 2006.

Publicity for Children of Fire and for our school continues. We were mentioned in the Caxton magazine *120 years of Joburg* and wheelchair-bound teacher Malusi Sithathu was in the *Northcliff Melville Times* of September 22nd 2006 and young actor Litha Boo who volunteered twice at our Sunday Library squatter camp reading scheme was in the *Sunday Times* September 10th 2006 *Read Right* section. Burn survivor Mittah Lebaka (17) appeared with a bird of prey in the Caxton papers in November after her exciting pre-Kilimanjaro journey to the Drakensberg. Deputy Director Helene van Rhyn is in a forthcoming edition of *Fair Lady* magazine. On December 12th we're on SABC3 *3 Talk* and then there's the upcoming Junius Hughes' documentary.

Feleng meets "stoned" Fire Chief in Durban!

In October 2006 Feleng Mahamotse reached for his own small dream and got to see the sea for the first time in his life in Durban and really got into the water the next day at Ballito. The waves were rather big for a four-year-old but there was comparative safety in a rock-edged pool. He also took part in the Drakensberg recce, getting to touch the nose of a Shetland pony wandering in a meadow. Upon seeing a zebra he exclaimed: "Look! Giraffe!" Teenage UMashesha volunteer Tristan helped out at a head on collision on Van Reenen's pass, using part of the broken car parts



to splint an injured man's leg. The crash, in which all three people survived, had a surreal atmosphere as out of the low lying cloud walked a man also trying to help - the spitting image of the "Mad Dog" assassin in television soapie *Isidingo*. It might indeed have been Mad Dog but then was not the time to ask. The two most injured people seem not to have been wearing their seatbelts. When checking for injuries it was alarming to see one of them missing a foot - but he assured us, no, he had lost that in a

previous (motorcycle) crash. The trip also included chatting to Durban fire chief Mark Tewater who regaled us with a story of squatter camp crowds

sometimes getting upset when fires are not doused sufficiently quickly. At one troubled community, Mark joined his fire fighters one evening to work alongside them. The anxious crowd started to throw small stones. This was summed up in an internal email where someone wrote "And the chief was stoned."

Not knowing the context, Mark was surprised to be summoned to Council offices to explain his behaviour, for seemingly taking drugs on duty! They quickly saw the funny side when they realised the real meaning of the words. But of course it is never funny if the emergency services face even minor assault when helping others. We also arranged linen supplies for the disaster recovery services in Durban. Feleng went to the grand

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marbled Albert Luthuli Hospital and handed out 72 toys to children in plastics and in paediatric burns. We were lent a penthouse flat in Marine Parade and our trip did not end without more drama: Tristan and Bronwen were revising their work schedule, Feleng was fast asleep, when on Thursday night the shouted word "Fire!" made everyone in the 35-storey building



A car where UMashsha helped with First Aid. Wear your seatbelt please!

jump to their feet. Flames shot out from the opening of the lift, right next to a pair of gas tanks. Tristan was busy running up and down the stairs, ushering people out and using small extinguishers to keep the fire from spreading until the fire brigade arrived. Feleng slept through the whole event but was a visual aid the next morning for Otis Lift servicing staff clearly needing to learn

Setswetla's riverside blaze—water pumps an option?

The moon smiled an absurd crescent grin as the well-fed black and tan dog sat forlorn, looking out across the shallow river towards the RDP housing the other side. Behind, all the shacks were crumpled and torn, ravaged yet again by fire.

Some of the surnames, Tsonga-speakers we had helped at the same place only a year ago, were starting to become familiar on lists of recipients of disaster recovery supplies.

The ash was still warm, smoking. The people gave up raking through grey flaky underfelt for retrievable possessions - it was simply too dark to see. They just threw hard or sharp objects toward the river in the hope for at least a piece of level ground to sleep under the stars that night.

Some fifty families were affected. Most households were headed by young men and not all had returned from work by the time we left. They will have heard on the news about the fire and prayed in vain that it was not them, this time. There were no really old people and while there were babies on backs, there were few older children.

All residents were happy to receive Children of Fire's disaster recovery bags with some clothes, a

pillow, some food, toothbrushes, toothpaste, soap powder, soap, safety candles holders, pens, juice, cups, saucepans and more. They were also given blankets by the charity and a few blankets from the local ward councillor as well.

We had considered providing fire-fighting water pumps to place in the Juskei river the last time we were here, but there is insufficient sense of community to guarantee that such equipment would not be stolen or vandalised.

So our water tanks are still close by in Setswetla, Alexandra and have been used to good purpose to extinguish fires around them. When there is firmer leadership in the fire brigade, their refilling will be guaranteed. The community that night were bitter about the emergency services. They said that so far as they could tell, the fire had started in the middle of the day, when unsupervised children had been cooking for themselves and a stove had fallen. The residents alleged that the fire brigade took a full hour to arrive, by which time the damage was done. It is estimated that 204 people were affected in total. We subsequently helped residents affected by another fire on London Road near 3rd Avenue, in Alexandra Township.

Dr Quinn comes to school

November 7th 2006 was an exciting day at the Johannesburg School for Blind, Low Vision and Multiple Disability Children, as TV's famous "Dr Quinn" came to school. British-born actress Jane Seymour, her beautiful daughter Katy, American guests and lots of senior people from the Dis-Chem Foundation came to visit our school - and gave the children some tactile drawing pads, bubble bath and other treats. We hope that they become long term

friends. The Dis-Chem Foundation has been helping to fund teaching staff at the school. Thanks!



Thank You

Thanks to **A1 Bee Removals** (011 763 1002 / 472 4458 admin1@A1pest.co.za) for removing the bees that decided to settle under the bird bath at our school in November. Thanks to **Region 4 Environmental Health** for responding to the bees that settled in the exterior wall of a nearby building in October. Now that's enough guys - please go and make your honey somewhere else.

Thanks to **Jamie Els** who readily made a new prosthetic nose for Dorah, after her old one was lost *again* - this time thrown away by a well-meaning domestic worker at a volunteer's home.

Thanks to Roy from **R and R signs** for making us another sign to discourage passers-by from giving our children sweets! Bees and sweets don't go together.

Thanks to **Hirsch's Homestores** for obtaining another second hand washing machine after the valiant endeavours of **Greenside Plumbing** to fix the first one... and to **Ernie Brough's** team for raising a tap and plumbing in a machine; and to **Troy O'Mant** and colleagues to try to fix the next washing machine problem (children will always play with knobs, dials, etc)

Thanks to **Louis Rutstein** for delivering more magazines, books and puzzles to prison on September 12th, 2006.

Thanks to **Slam Pool Care** (tel: 011 493 0330) for fixing our pool pump and the leak and keeping our pool sparkling blue.

Thanks for transport help from **Richard Walls**, **Thabo Lekgau**, **Desmond Blow**, **Tamzin Williams** and her Dad **Barry**, **Ian McLean**, **Peter Harris**, **Michelle Germond**, **Helene van Rhyn**.

Thanks to **Zanele Molefe** for helping so willingly with *Heritage Week* preparations at the school and for **Imelda Matlala** for arranging a special bird lesson from Johannesburg Zoo. Thanks to **Rea Le Roux** and **Sumari Fourie** for dance and song classes; and **Per Herbertsson** for attention deficit disorder expertise.

Thanks to **Bowman Gilfillan**; **Webber Wentzel** **Bowens** and **Routledge Modise Moss Morris** for always being on hand when legal advice is needed.

And of course, thanks to all the doctors, surgeons, anaesthetists, ophthalmologists, hearing specialists, etc that we work with day to day. We could not do without you!

In 2007 teenage burns survivors from across Africa will raise awareness about burns in their historic climb of Kilimanjaro.
Contact us if you sponsor them or help in any way.

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Children of Fire

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