

# Malamulele Onward

Ongoing support for Africa's children with Cerebral Palsy

## A new organization and a new name

Following the success of the Malamulele Project, it was clear that a more formal structure needed to be set up as a vehicle to take this Project to other areas of great need. Up until now, the South African arm of the Project has been administered by the South African Neurodevelopmental Therapy Association (SANDTA). However, as SANDTA's constitution does not allow for formal fundraising activities, it was decided to set up a new organization. An added

advantage of setting up an independent organization is that it brings together a variety of stakeholders. The sustainability of taking the Malamulele vision to other settings in South Africa depends on a solid foundation built upon the support of SANDTA, the Canadian fundraisers, including the International Development and Relief Foundation (IDRF) and members of Bryanston Methodist Church.

Soul City, a South African non-governmental organiza-

tion, kindly offered to facilitate the process of creating a Section 21 Company which will administer the funds and steer the project forwards. The new organization has been named "Malamulele Onward—Ongoing support for Africa's children." This name reflects that Malamulele is where the project has its roots and that it has not stopped here. Andrew Wardle from Canada is presently designing a logo and a website for the new organization is also planned.

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## Introducing the Canadian connection

The Malamulele Pilot Project would have remained simply a vision had it not been for four remarkable women in Canada who shared the vision and raised the money needed to initiate it.

The Canadian arm of the Malamulele Project consists of three friends (Barbara Harrison, Nazreen Garda and Tara Seon), The International Development and Relief Foundation, (a NGO which provides tax receipts for Canadian contributions, and financial support for the project), and lots of

friends who actively support the project with their money and time.

Barbara was born in Johannesburg, emigrated to Canada during high school but returned to South Africa to complete her university studies. She then decided that Canada would be her permanent home. Barbara is an elementary school teacher and has worked as a self-employed Human Resources Training Specialist for many years. She is mar-

ried to a fellow South African and has two daughters aged 15 and 17. Being involved in the Malamulele Project is a family

affair, with each member of the family volunteering and contributing as needed.

Nazreen was also born in Johannesburg, and moved to Canada at the age of eight. However she has been back and forth visiting her many relatives multiple times. Being involved with the Malamulele Project has renewed Nazreen's interest in her country and she feels it will strengthen



From left : Barbara Harrison, Nazreen Garda and Tara

## The Canadian Connection— cont from pg 1

her ties with South Africa even more. Nazreen has worked for the Ontario Provincial Government for 19 years, in the Human Resources area.

Tara was born in Guyana, and has lived in Canada for many years. She has been married for almost 30 years and has two daughters aged 24 and 20. Most of her career has been in the Human Resources area, and, with her can-do attitude, she has raised funds for various charities and causes. The Malamulele Project continues to be one of the most rewarding. Tara retires at the end of 2006 to pursue other interests, including extensive traveling and volun-

teering on a variety of projects.

### How did the three Canadian “musketeers” come to be involved in this project?

Barbara explains “During Gillian Saloojee’s visit to Canada in June 2005 she told us about her dream and vision for a Malamulele Project. Inspired by the possibilities of this project and the potential impact it would have on everyone involved, without hesitation we committed to assisting with the fundraising for the initial project. There were moments of hesitation later, as we pondered how we were going to raise the money for the project, but things

fell into place quickly, and within two months the money for the project was raised. We ‘musketeers’ are now involved in further fundraising, planning and other aspects of the project. Although we live on another continent we feel very closely tied to this project, and feel that we benefit from our involvement almost as much as the children and their mothers do.”

Another member of the Canadian team is Adilla Saloojee from St. Catherine’s, about 1 hour from Toronto. Adilla is the proud mum of two year old Amani and in between a full-time job and looking after Amani, she found time to

## The Malamulele Pilot Project— a success story

A follow-up visit to Malamulele by Gillian Saloojee and Estelle Brown was made in January 2006. Twenty- six of the twenty-eight children treated in November were reassessed and their caregivers interviewed.

In addition random unannounced visits were made to the homes of two of the children to establish to what extent the equipment issued was being used and whether the child was being included in the everyday life and activity of the household. It was clear from this

trip that the pilot outreach project was a great success, and there were many heartwarming stories from the mothers. The pride that mothers felt in sharing the progress and improvement in their children was palpable. Read on in this

**The pride that the mothers felt in telling us about their children’s progress and showing us the improvements was palpable**

issue about some of these amazing stories.



*Estelle showing Xilaveko’s sister how to apply his splint during a home visit in January.*

## Xikhongela

When Xikhongela was first seen in September 2005, she was lying on the floor and could not move or roll over (*photo below*).



Now she is nearly sitting by herself!



We arrived at her home unan-

nounced and found her enjoying being outside in the sun sitting in her Shonabuggy and being the centre of attention. Her mom says she is trying to move on the floor and that dressing and undressing have become much easier because “she is not so stiff.”

# In their own words—what the mothers said

During a focus group with seven of the mothers in January 2006, they were asked for their honest opinions of the therapy intervention and what it had meant to them and their children. Here is what they had to say.

“ .....he was not able to bring both hands together, they used to be scattered around, but currently he is able to bring them together. He is able to climb the bed, even to sit on the chair, I am saying those who are still hiding their children they should come out, I am asking them to bring them outside because they are missing the gifts which we are being given. “

“.....My child was not able to roll when

asleep. When she is asleep I used to roll and change her myself, but currently she is able to roll around on her own, even sleeping on her stomach and change position and posture she can do it. She is now able to even show me many things. She can also tell me the name of the person who comes nearby. By coming for treatment, I think we got help so much. I am just saying parents who have similar children should bring them to get help. I feel pity when parents are afraid to come out with children of similar nature.”



Lilian and her son Hlulekile  
“now he can move which shows that he is alive”

“ .....Currently I want to thank because since he got assistance from November when we put him in bed at home, he could move which shows that he is alive.”

“..... the muscles were very tight, however currently they are so gentle and smooth.”

“.....I didn't know that I will ever see my child being to hold things with both her

hands. But now she is able to throw items to other friends when they are playing.“

## The figures and statistics tell the story

The children were assessed on four occasions using a variety of outcome measures: the Gross Motor Function Measure (GMFM), parent interviews and random home interviews. The GMFM is the goal standard for measuring change in motor function in children with cerebral palsy. On average, the children's scores increased by 14 points—such a high increase in GMFM scores following therapy intervention has never been previously reported. Published articles of other studies

which have used the GMFM to record improvements before and after therapy report an average increase of less than 5 points.

At the end of the week of therapy, only half the mothers could list the changes

**The increases in the children's scores of motor ability and function were statistically significant. Such big changes following therapy have previously never been reported.**

they saw in their children , saying it was “too soon” to notice any differences. However, two months later, 90% of the mothers could list all the changes they saw - these included abilities such as: she is now rolling from side to side so now she can turn herself over in bed; she can now neatly sit by herself and she is trying to move on the floor by herself; she can climb off the bed by herself; he can now hold things with both hands; he now chews nicely.

## The photos say it all .....

Remember Kuhlula .....



*See how straight he now looks when he lying on his back !*



Remember Akani ...he was learning to walk by himself with the help of a walker



Now .....he can stand up from the floor by himself without holding on; he can open his right hand; his balance is better and he can stand firmly and he can walk further by himself.



**Thanks to our recent donors:**

- **Protea Hotels for sponsoring accommodation at Mphephu Resort for the January visit to Malamulele**
- **Soul City for assistance with formalizing the organization**
- **Barbara Harrison, Nazreen Garda and Tara Seon**
- **Sean Katz, Johannesburg**
- **Baillie House, Appleby College, Oakville, Canada**
- **Borden Ladner Gervais Foundation, Toronto**
- **Hillfield Strathallan School, Hamilton, Canada**
- **International Development and Relief Foundation, Toronto, Canada**

**MALAMULELE ONWARD: OUR VISION**

Our vision is to reach out to disabled children in the most disadvantaged areas of South Africa, and further into Southern Africa. We are specifically interested in children with cerebral palsy as they have the most complex needs and problems.

We aim to:

- improve the quality of life of children with cerebral palsy and their caregivers
- support local rehabilitation staff responsible for providing services to these children and their families

*How do we do this?*

The type of outreach and support programmes depends on the local situation and what is most appropriate for the rehabilitation personnel, the mothers and the children in that area. It may include:

- intensive blocks of “hands on” therapy. This is done in conjunction with the caregivers, rehabilitation professionals and mid-level workers.
- provision of appropriate equipment such as standing boxes, buggies, splints, feeding cups and spoons. This includes training in the use and maintenance of the equipment.
- Formal five day training courses for rehabilitation personnel and/or caregivers.

Research forms an integral part of all the programmes. The aim of this research is to continually evaluate the programmes and training to find out “what works best.”

**To become a part of this exciting project.....**

If you are interested in volunteering or supporting Malamulele Onward, here’s what to do or who to contact:

**IN SOUTH AFRICA:**

**Gillian Saloojee:** gsaloojee@icon.co.za

**Estelle Brown:** ebrown@webmail.co.za

**Shelley Broughton,** Chairperson, SANDTA, edugro@pixie.co.za

**John Whitter:** johnwhi@iafrica.com

**Kobus Snyman:** Kobus.Snyman@travel.rennies.co.za

**IN CANADA**

**Barbara Harrison:** bharrison@cogeco.ca

**Nazreen Garda:** Nazreen.Garda@css.gov.on.ca

**Tara Seon:** tara.seon@enbridge.com

Donations in the form of cheques should be made payable to “IDRF– Malamulele Project “ and should be mailed to:

IDRF at 1063 McNicoll Avenue, Toronto, ON. M1W 3W6.

Alternatively, visit the IDRF website at [www.idrf.ca](http://www.idrf.ca) and make your donation online. Please make reference to: Malamulele Project in the COMMENTS box.

Receipts will be issued for donations of \$20 and above.



**THANK-YOU FOR YOUR SUPPORT!**