



**CHILDRENS HOSPICE**



## Iris House Children's Hospice

Legal Status and registration number:	126-228 NPO
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### 1.1 Initiation & Background

Iris House Children's Hospice has seen many successes since its inception in 2011, and has positive changes in the lives of Iris House children and families with special needs. Our community based respite care sessions have always been a core part of what we do at Iris House. These respite care sessions are provided in order to relieve a parent or parents for up to four hours in the comfort of their own home. With the growth of our care team, we have been able to expand these services and are now able to care for over 1200 individuals in 26 communities, which include children with disabilities and their families who are in desperate need of our services. In addition to these important community based respite care sessions, our hospice continues to provide safe and fun respite care sessions to many of our children. Each session is headed by a lead (senior carer) and the creatives lead by a Playmaker. We place emphasis on the ability of the children and not their disability, and thus structure the day around the unique ability of each individual attending the session. This positive approach to caring for children with special needs allows us to provide One2One stimulation, love and care. We are extremely proud of the quality of these sessions and with the addition of our full time registered nurse in 2017 will see further improvement in this regard.

The Iris House care team now consists of 30 carers, 17 of which were employed in 2016 alone. In an effort to provide the best quality care to our families, and to develop the skills of our carers, we have made sure that 11 of our carers have completed their level one First Aid Course and 5 senior carers have gone further and completed their level three First Aid Course. Understanding the importance of quality care for all, we have partnered with Frsanterkraal to provide ongoing practical training for 50 students within our hospice setting. Giving them valuable "hands on" experience that will have far reaching positive effects in their communities.

Other exciting projects include the creation of a sustainable food garden, which will grow in 2017 as we embark on a joint project with Urban Harvest and sponsored by Checkers. Using a food garden as a model, we aim to train and equip 20 parents of special needs children from underprivileged areas to enable them to grow their own vegetables and herbs at home. Other project improvements to our sensory garden, the training of our therapy horses, launch of our sensory story telling project, Imagination Station, and the building of our new reception area as well as the construction of our outdoor play area.



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Quality Care for the Child - Supporting the Family

At Iris House supporting the family is as important as providing quality care for the child, it is because of this understanding of the unique challenges faced by parents of special needs children that we place emphasis on the wellbeing of the parents. Our parents are very special people and at Iris House we do everything possible to support them. One of the ways in which we do so is by running support groups that create a safe platform that enable parents to share common challenges, forge new friendships, and grow their own support network. These support groups are hosted in Mfuleni, Khayelitsha and the Northern suburbs on a monthly basis, and as another special way to support our amazing parents we have hosted numerous Mom and Dad treats and projects.

Events such as our Easter Egg Hunt, Run.WalknRoll – 5km, and Iris House Ball, help to raise much needed funds to assist us in continuing our work, but also help to create awareness about issues and challenges faced by people with special needs, but more importantly their abilities and potential. These events have brought together over 500 parents and family members of special needs children and young adults, and have been the catalyst for many friendships. Currently hosting end of year Christmas family parties, we continue to bring together these families with festive cheer and of course generous gifts.

## 2 Objectives and Scope

### 2.1 Organizational Objective

Iris House is a totally unique model of children hospice and respite care encompassing a holistic approach to free quality care for the whole family, Iris House Children's Hospice provides life-changing support for families in their own homes in the form of community sits, and in the hospice, itself where we provide a place in which children are encouraged to reach their full potential however limited that may be. Understanding that raising a child with special needs is a full-time job, that comes with a variety of emotional and financial stresses. We purpose to support families through the provision of these and other holistic services, and make a tangible change in their lives,

With over 350 registered children, whose symptoms range from severe epilepsy, cerebral palsy, autism being nonverbal, curvature of the spine, being fed via feeding tubes and low quality of life. Our mission is to provide free qualified, professional care and therapies to these children and their families by helping improving their quality of life through an a holistic approach. Our approach highlights the need to support the whole family, training and supporting parents, siblings and extended family members as well as by providing direct hands on care for the affected child.

This approach has seen many successes, and continues to effect tangible positive change in the lives of children and families affected by disability. It is this successful approach that has resulted in our respite care model being adopted by national government in 2015. We pride ourselves on shifting the focus from end of life, to quality of life. Our approach to respite care is two pronged, and is provided both at the child's home by our care team and at our hospice in Bellville. Our community care at a child's home can cover large areas due to its flexible strategy which includes training parents and members of each community to provide quality care. We currently provide care in 26 areas in the greater Cape Town and Saldanha area, which importantly include areas in desperate need, such as Khayelitsha and Mfuleni on the Cape Flats.



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We have noted an alarming rate of child abuse and neglect of special needs children; many are not being removed because there is no one who will take them. We find this situation totally unacceptable. In 2016 we committed to working with existing safe houses and foster homes, training their carers, equipping and supporting them to be able to include special needs children at risk in their facilities. We are also planning to open our own safe house on the grounds of Stikland close to our hospice where children will be fully assessed before going into care at a trained facility

Iris House receives a grant from the Western Cape Department of Social Development. Which covers 41% of our expenses, but this is simply not enough. Understanding this we raise the balance needed to continue and expand our work ourselves. Making our fundraising events calendar extremely busy with fundraisers happening every month. Highlights include our Christmas in July dinner dance, The Iris House Ball and Run, Walkn'Roll 5km All Ability Family Day. Other income generators include our online E shop, online monthly debit orders and email marketing to ensure our sustainability. This is not an easy task, but with hard work and dedication, we have maintained a positive cash balance.

The increasing demand for our services, and our obligation to help families in desperate need of assistance has created the need for increased funding. If granted, funding will greatly assist in the continuation and expansion of our service. Funding for our operational costs will ensure that we are able to continue to provide respite care service to over 333 Children, and their over 900 family members, but also to further improve their quality of life by increasing their frequency of individualized care and support services. Additionally, funding our operational costs, will allow us to reach more children and families from disadvantaged and under resourced communities. Furthermore, funding for the expansion of our work in the form of increased care sessions, increased training and capacity building for new carers, and in particular the start of our overnight Hospice sessions will help to significantly increase the wellbeing of our children and families. The increase of our sessions is also increasingly necessary, as two government facilities that offer respite care have been closed down. Making us the only organisation providing respite care to children and families affected by disability in the Western Cape.

Our work is necessary, and has been proven to change lives. It is for this reason that we have endeavored to expand and grow whilst not compromising on quality care for the child and family, but also to go beyond just care and support through transferring important skills to our parents that increase employability, and even employ these parents ourselves. We will continue to do so, as is our responsibility, but hope that your organization too recognizes the necessity of our services as well as the necessity for increased funding. As we look back at the tangible change we have affected we can't but be amazed at the growth of our organisation and the lives touched. For as our families grow in strength so too do we. We are excited about the life changing projects on the horizon, and know that with your support the possibilities for growth and impact in 2017 and beyond are limitless.

## 2.2 Purpose

The purpose of the project is to provide holistic, loving, professional Community based, Hospice based respite, overnight and end of life care for special needs children with life threatening illness and or life limiting conditions in the Western Cape, and to provide holistic support for their families. In doing so, tangibly improve the quality of life for children and families affected by disability. Additionally, we seek to further improve the lives of children and families affected through the creation of employment opportunities for parents of special needs children



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## 2.3 Outcomes

### Activity:

#### Community Based Respite Care

##### Results:

The results of this particular activity is far reaching and core to our mission of providing quality, free and individualized care to children and families affected by life limiting and life threatening conditions. The positive results on the emotional, and physical wellbeing of the child being cared for are plentiful. With increased emotional and attitudinal wellness through play therapy being one of the highlights. In addition to the tangible effects on the child, positive emotional, psychological and physical wellbeing effects on the parent/caregiver are achieved through the provision of a break and safe, secure and loving environment for their children.

The current Community Based Respite Care programme caters for over 30 families a month by providing families with individualized quality respite care in their own homes. Families request community care sits based on their need, and we provide them with our services for free.

##### Monitoring and Evaluation:

The results of the project's (hospice based respite care) positive effects on both children and families affected by life limiting and life threatening conditions are recorded through parent feedback forms and survey's managed by the organization's Social Worker and Hospice Manager. Parent Surveys, feedback forms, hospice session log as recorded by carers and Hospice Manager and verified by parents, as well as the Social Worker's Report.

### Activity:

#### Hospice Based Respite Care

##### Results:

The results of this particular activity is far reaching and core to our mission of providing quality, free and individualized care to children and families affected by life limiting and life threatening conditions. During these sessions children are provided with play-therapy, equine therapy, and sensory input via our beautiful sensory room and sensory garden. With each visit, the child receives individualized therapy and care, and families are provided with food hampers, basic hygienic necessities and nappies. The positive results on the emotional, and physical wellbeing of the child being cared for are plentiful. With increased emotional and attitudinal wellness through play therapy being one of the highlights. In addition to the tangible effects on the child, positive emotional, psychological and physical wellbeing effects on the parent/caregiver are achieved through the provision of a break and safe, secure and loving environment for their children.

The current Hospice Based Respite Care programme only allows for three days, with a maximum of 6 children per session in which the respite care takes place. Improvements that will result from increased funding and resources include the increase of the hospice based respite care sessions to 5 times a week, with more children per session, each with their own carer and individualized care and play plan.

##### Monitoring and Evaluation:

The results of the project's (hospice based respite care) positive effects on both children and families affected by life limiting and life threatening conditions are recorded through parent feedback forms and survey's managed by the organization's Social Worker and Hospice Manager. Parent Surveys, feedback forms, hospice session log as recorded by carers and Hospice Manager and verified by parents, as well as the Social Worker's Report.



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**Activity:**

**Overnight Respite Care**

**Results:**

The results of this particular activity is far reaching and core to our mission of providing quality, free and individualized care to children and families affected by life limiting and life threatening conditions. The positive results on the emotional, and physical wellbeing of the child being cared for overnight are plentiful. With increased emotional and attitudinal wellness through play therapy being one of the highlights. In addition to the tangible effects on the child, positive emotional, psychological and physical wellbeing effects on the parent/caregiver are achieved through the provision of a break and safe, secure and loving environment for their children.

Current overnight hospice based respite care sessions only occur once a month with a maximum of 4 children per session. Improvements as a result of increased funding will allow for these sessions to be extended to up to 4 times a month

**Monitoring and Evaluation:**

The results of the project's (hospice based respite care) positive effects on both children and families affected by life limiting and life threatening conditions are recorded through parent feedback forms and survey's managed by the organisation's Social Worker and Hospice Manager. Parent Surveys, feedback forms , hospice session log as recorded by carers and Hospice Manager and verified by parents, as well as the Social Worker's Report.

**Activity:**

**Grocery and Equipment Donation**

**Results:**

The provision of life sustaining/improving equipment that families would otherwise not be able to afford directly results in the enhancement of the physical wellbeing, and medical wellbeing of children affected by life limiting and life threatening conditions.

The continued and consistent donation and provision groceries to our families are in many cases essential to their survival. Many of the families suffer tremendous financial strain and rely on Iris House grocery donations to help feed their family.

**Monitoring and Evaluation:**

Currently every family who attends a hospice based respite care session leaves with groceries, additionally any family who requests help gets groceries, equipment and other essentials delivered to their homes. Improvements resultant from increased funding will allow the grocery donation to grow to allow for all families in need to receive weekly grocery donations.

Achievements and results for this activity is monitored through the recording of every donation through a donation form completed by the parents themselves and verified by the Hospice Manager and administrative team.

The donations as recorded on these forms are stored and accurately kept on file. Family donation forms as completed by the parents and verified by the Hospice Manager.



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Activity:

Parent Support Services

**Results:**

Emotionally, physically, and practically supporting parents of children affected by a disability is an essential part of our service.

Parent Support Services include monthly support groups, weekly massage therapy offerings, professional counselling in partnership with Vision Medical Suites. These services positively effect the well being of parents, improving the quality of life for the entire family.

Improvements to the provision of parent support services will include the increase in frequency of parent support and care events as well as the expansion of services to include stress management courses, and other practical life skills workshops.

**Monitoring and Evaluation:**

The results of the project's Parent Support Services positive effects on both children and families affected by life limiting and life threatening conditions are recorded through parent feedback forms and survey's managed by the organization's Social worker and Hospice Manager. Parent Surveys, feedback forms , Parent support group log as recorded by support group facilitator as well as the Social Worker's Report.

Activity:

Equine Therapy

**Results:**

Our horses provide equine therapy on two days a week under our equine trainer's supervision. Most our children are none verbal, but this is not a barrier for our horses. They readily engage in "conversation" with our children, moments of magic are plentiful as the children interact at their own pace with the horses. It is well documented that riding assists children with Cerebral Palsy with building muscle tone and with children who are on the Autism scale horse riding helps with behavioral issues and confidence. As we continue with therapy and advance to hippo therapy we hope to positively affect the lives of all of our children with equine therapy.

**Monitoring and Evaluation:**

Our horse trainer Alan Lockwood has worked with Malan du Toit and operates his own equine training program. Alan has been key to both Divia and Viltalgo's ongoing training to work with special needs children. Alan has a strong passion for horses and has an extremely humane approach to training. Both horses have responded extremely well to his work with them. Sue van der Linde (Founder and CEO of Iris House) herself a rider for many years in her youth, is under Alan's guidance working with Viltago and Alan is riding Diva. Alan visits the horses three times per week: Monday – Wednesday and Fridays for an hour session. Each session is based on the horses capability and aims to build confidence.

Both Alan and Sue monitor and manage the Equine Therapy programme. Monitoring and evaluation of this programme will be done through the reporting of our horse trainer Alan, and as we develop a relationship with the South African Disabled Riders Association, we hope to have them take over monitoring and evaluation.



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Activity:

**Carer Training and development workshops**

**Results:**

Developing and training our 35 carers, which include parents of children with disabilities are important to the organization. The tangible effects of this programme within the projects include the upward mobility in the financial situation (improved economic opportunity) of our carers through upskilling and skills transfer, increased employability of our carers resultant of an increased knowledge and skills base.

Improvements to this portion of the project will include increased training and development workshops, increased evaluation systems to improve the amount of carers being developed, an improved mentorship programme, the introduction of formal training offerings, and assistance to access formal training offerings.

**Monitoring and Evaluation:**

The Carer training and development programme is guided by our training and development policies. Which provides for a framework in which training and development is monitored through the quarterly appraisal process, headed by the Care Team Manager with guidance from the CEO.

Training sign in sheets/logs, quarterly staff appraisals well as the annual training and development report as reported by the CEO.

Activity:

**Subsistence Farming/Gardening Workshops**

**Results:**

A recent introduction to our hospice offerings, the subsistence farming workshops is important in transferring skills to our parents, thus providing them with alternative means of income generation as well as the tools necessary for self sufficiency in relation to food.

With 15 mothers participating in the program in March 2017, improvements will include the increase in amount of parents participating in the workshops, as well as an increased amount of equipment and seed donations. The goal is to have 50 mothers from previously disadvantaged areas such as Khayelitsha and Mfuleni participate, successfully implement skills learnt, and themselves transferring these skills to other mothers in their community.

**Monitoring and Evaluation:**

As this particular programme is in partnership with Urban Harvest, they will oversee the monitoring and evaluation of the project to ensure the training, transfer of skills and provision of subsistence farming equipment is successful and sustainable.

Regular workshop participant feedback forms as well as the monitoring and evaluation report from Urban Harvest.



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**Activity:**

**New Carer Training and Certification**

**Results:**

The transfer of skills and development of new carers helps to further our goals of providing care and support to families affected by a disability. To date we have trained over 200 individuals, equipping them with the necessary skills to provide high quality care to children affected by life limited and life threatening conditions. This is particularly important, to the parents of these children, who also participate in the carers training course, and are employed as carers, providing them with an opportunity to generate increased income.

Through increased funding and additional resources, we plan for further formalize this training, and expand the programme to help train over a hundred new quality carers a year

**Monitoring and Evaluation**

The training of new carers is accurately recorded, and their practical training after completing the theoretical portion of the course is monitored by our Care Team Manager.

Carer training log and Care Team Manager's New Care Training completion report.

**Activity:**

**Imagination Station**

**Results:**

Recently launched, Imagination Station, our sensory storytelling initiative uses the Arts as a medium to develop communication skills, increase confidence, improve tolerance of stimuli, increase level of personalization of care, increase capacity to demonstrate learning of children with life-limiting and life-threatening conditions. Additionally, this project will be used to create employment opportunities for unemployed youth and young adults in the specialised area of sensory storytelling, special needs playmaking, and by extension in the arts

The broad outcome for the Imagination Station Project is:

- Increased development, interaction and engagement for children with special needs through specialized arts programmes.

The Target Outcomes for the Imagination Station are:

1. Develop and execute targeted and specialized individual arts sensory programme in the hospice and the community, for 333 registered children.
2. Employ, develop and train 3 project interns for specialized individual arts sensory programme, thereby creating employment, earning capacity building and life skills opportunities for unemployed vulnerable youths.
3. Build the capacity, through specialized sensory story telling workshops of 30 existing Iris House Children's Hospice carers, increasing earning and skills development opportunities.
4. Build the capacity, through specialized sensory story telling workshops of carers and staff of external organizations working with vulnerable, life-threatened, and life-limited individuals, increasing earning and skills development opportunities.
5. Initiate research and evaluation with the focus of highlighting positive affects of arts programmes on children with special needs.

**Monitoring and Evaluation:**

The results of the project's Parent Support Services positive effects on both children and families affected by life limiting and life threatening conditions are recorded through parent feedback forms and survey's managed by the organization's administrative staff. Parent Surveys, feedback forms , hospice session log as recorded by carers and Hospice Manager and verified by parents

## 2.4 Beneficiaries

With the national disability prevalence rate at 7.5% there is an ever increasing need for structures to support individuals and families affected by disability. Our aim is to create a support structure for our families both in the community by way of community sits and at our new hospice premises. Our vision is not that of traditional Hospice. We aim to provide a place where children are encouraged to reach their full potential, however limited that may be. We aim to make Iris House a place where children can attend day sessions, overnight care and short respite periods, a home away from home,

Beneficiaries of the project are children and families affected by life-limiting and life-threatening conditions. As a children's Hospice a large majority of the individuals affect by disability that we care for are under the age of 18. But our care extends far beyond just the individual, but rather the family as a whole. A majority of the children and families that we care for suffer great economic hardships, as a result of the disability affecting the family. Our care therefore is provided to a large amount of families living in previously disadvantaged communities, where already tough economic conditions are exacerbated by medical and other bills related to caring for a child with disability.

A detailed group of project beneficiaries include

Children with disabilities: 274

Adults with Disabilities: 59

People living with HIV/AIDS: 4

Children (Siblings): 183

Youths (Siblings): 142

Women: 333

By virtue of providing a wholistic support structure and the creation of a supportive community of individuals and families affected by disabilities, beneficiaries are actively engaged in the project by benefiting from hospice respite sessions, individualized care, grocery and equipment donation, and other support services. In addition to participation through benefit, many of our part time employed carers are themselves mothers of children affected by disability, and are therefore both active participants as well as beneficiaries of the project, through the accessing of our support servoces as well as the generation of income.

## 2.5 Sustainability

As an NPO providing free services to an incredibly vulnerable group, all of our projects are reliant on the generous support from government which is only partial. Understanding that we are not fully funded, our fundraising team has worked tirelessly to ensure the financial sustainability of our organization. As we continue to grow and effect greater tangible change, we have amped up our efforts to raise funds in house through our own fundraising events. This will continue, and will allow us to become more and more self sustaining.



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<p>Administration:</p>	<p>Since the inception of the organization, administration has been critical to ensuring that care services are effectively and efficiently to those in need. Formerly Managed by the Director of Administration, the administrative systems of the organization continue. With administrative interns and long term volunteers assisting to make sure that the system continues to work and improve. All staff are also trained in basic administration and are given specific administrative roles to ensure that the team operates cohesively. And will continue to operate in the same fashion even if one were to leave. To safeguard systems from being lost, all administrative roles, responsibilities, guidelines and documents are safely stored on a protected google docs account.</p>
<p>Finance:</p>	<p>In order to secure and sustain funding and the financial health of the organization, various steps have been put into place. Although external sources of funding is critically important in the NPO space, Every effort has been made to ensure that the organization remains as self-sufficient as possible without an over reliance on such funding. To make sure of this, a permanent committee of fundraisers has been set up and guide the organization's fundraising strategy. This strategy includes the hosting of top class fundraising events which help to raise a significant amount of funds. Annual fundraising plans are also put into place so as to ensure sustainability.</p>
<p>Human Resource Development:</p>	<p>So as to ensure the constant development of our staff, we have developed and implemented a training and development policy, which helps to ensure cultural and professional development through experiential learning and working with professional international volunteers. Additional this policy puts development on top of the agenda during quarterly staff appraisals. A staff mentoring system has also been put into place to ensure the constant development and monitoring of progress in this regard occurs.</p>
<p>Programme (Organisational &amp; Project core purpose; Product):</p>	<p>In order to ensure the sustainability of our programme, a variety of steps have been put into place to ensure that the programme is not only sustained but continues to grow. This is evident in the consistent growth of our organization since its inception in 2011. Central to ensuring the programme is sustained is the maintenance of quality care, this is ensured by hosting quarterly recruitment an training of new carers. Carers are hand selected and undergo theoretical and practical training to ensure they maintain the quality care our organization is now known for. By increasing the pool of quality carers and by ensuring existing carers develop into senior carers through our training and development plan, we can ensure that we not only maintain the quality service we provide, but continue to grow and expand this service.</p>
<p>Public Relations / Marketing:</p>	<p>Public Relations and Marketing is important in ensuring that our work is not only recognized but that the stories of those with special needs are heard and listened to. It is therefore important that we maintain and improve on our public relations plan, through partnerships with local media. Through the development of good working relationships, we have a network of local media that we can call on to share our vision, mission and stories with. Additionally we have impressively built up our social media following, and understand the importance of maintaining this. Staff trained are therefore trained on social media marketing.</p>



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## 2.6 Budget

### BUDGET OF INCOME for 2016/2017 financial year

Source		Amount in Rands
Subsidy and/or grant from Government Departments:	Dept. of Social Development	1, 428, 000
Donations		400, 000
Fees for Services paid by beneficiaries		0
Fundraising and/or Events		600,000
<b>TOTAL:</b>		<b>R 2, 428, 000</b>

### BUDGET OF EXPENDITURE 2016/2017 Financial year

<u>Item</u>	<u>Amount in Rands</u>
Accounting/bookkeeping fees	55, 104
Audit fees	7, 800
Bank charges	9, 867
Cleaning and laundry	20, 000
Clothing (for beneficiaries)	14, 000
Food	15, 400
Personnel salaries	2, 108, 097
Personnel training and development	37, 472
Post and telecommunications	12, 400
Rent	1, 200
Security	12, 420
Stationery & Printing	35, 454
Stipends	36, 000
Maintenance and repairs to vehicle/s and equipment	32, 720
Water, electricity and rates	7, 800
Insurance	54, 000
Staff Welfare	2, 200



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Subscriptions	1, 400
Transport and Freight	2, 600
Repairs to Hospice Building	36, 000
<b><u>TOTAL</u></b>	<b><u>R 2, 501, 934</u></b>

## 2.7 Management Committee

Names	Identity Number	Role on the Board	Background and Experience
Susan I van der Linde	6310050291084	CEO, Founder,Chairperson	B.Com, Senior Management in retail industry, QVC in special needs care, years of special needs advocacy and care experience, social media marketing consultant.
Zaahir Abdurahman	8602225189088	Director	Entrepreneur
Kathleen A M Gentz	4903320054089	Director	Philanthropist
Carol Charline Petersen	7205090231083	Director	Years in administrative management, care and now in Social Work
Irina Mink	951629233	Director	Photographer

## 2.8 Auditors

Haumann Rodger Chartered Accountants  
 Registration No. 2008/008838/21  
 Contact Person: Bianca Venter  
 Telephone: 021 913 8152  
 Fax: 0866804020  
 Email: bianca@haumann.co.za



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