

# MOTIVATION FOR FUNDING

For

# S A PREEMIES



## Contact Details

Name: Adele Benvie

Mobile: 083 454 0273

Email: [info@sapreemies.za.org](mailto:info@sapreemies.za.org)

**SA PREEMIES ASSOCIATION**

**Detailed Business Plan**

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**SA PREEMIES ASSOCIATION**



# SA PREEMIES ASSOCIATION

## Detailed Business Plan

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### 1. COMPANY STRUCTURE

SA Premies is a non-profit organization, duly incorporated as an Association under article 21 of the Companies Act.

SA Premies have eight members, whom we refer to as “Shareholders”. The “Shareholders” appoints a Board of Directors to run the Company.

Please refer to **Addendum “A”** for a breakdown of “Shareholders” and the current Board of Directors.

#### 1.1 MISSION

SA Premies Association is the **ONE** Company people need to contact for **support**, **information**, **advice** and **products** pertaining to premature birth and babies in South Africa, from birth to when needed.

#### 1.2 VISION

- i. To inform the general public what it entails having and caring for a premature baby and what can be done from all sides to better the situation for the baby and parents, as well as preventative measures that can be taken.
- ii. To inform parents and all other involved of the importance of Kangaroo Mother Care (KMC) while in hospital and during the initial home period.
- iii. To inform parents about the importance of Early Intervention (EI)
- iv. To accommodate all in their preferred language.
- v. To inform all about the rights of the premature child and its parents.
- vi. To reach out to less privileged parents of premature babies who do not have access to the specialist services required to help them to develop their children to their best potential.

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## 2. EXECUTION OF MISSION

SA Premies Association is the **ONE** Company people need to contact for **support**, **information**, **advice** and **products** pertaining to premature birth and babies in South Africa, from birth to when needed.

The Support Director of S A Premies is currently collating data to establish how the support is distributed across the various demographic groups of South Africa. Once this information is available, it will be put into this document.

### 2.1 SUPPORT

**"The strength of a premature infant portrays the courage of a hero."**

The birth of a premature infant is a journey few are aware of unless they are faced with the overwhelming experience. The joy of giving birth is often coupled with fear, guilt, loneliness and anger. A helpless infant confronts every part of your belief system and challenges every aspect of your life.

After eleven years as a NICU nurse, I thought I would be somewhat prepared for the premature birth of our daughter Mackenzie, born 3 1/2 months early, and weighing only 1 pound, 12 ounces; but I was immediately humbled. I quickly learned how little I understood about caring for a preemie. Although I had support from families and friends and the medical knowledge from my career, I found little resources that I needed to care for my preemie after she was discharged from the NICU.

Now that my daughter has grown out of many of her complications of prematurity, I have been able to work at helping other preemie parents. I hope this website will bring knowledge and emotional support to both parents of premature infants and the health professionals who care for them. I have also co-authored the book, "Your Premature Baby and Child" (Berkley, 1999), which is a comprehensive handbook for preemie parents that gives critical information regarding the first five years of their preemie's life.

Resource: <http://premature-infant.com/index.cfm>

#### 2.1.1 Reasons

When having a premature child, you embark on a roller coaster ride. Professional personnel strive to help and support the parents of a premature baby, but in many cases it's only those that have travelled the road that can fully comprehend the emotional ups and downs.

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When faced with the Neo-Natal Intensive Care (NICU), many a parent feel overwhelmed by all the equipment, regulations and other associated with pre-term birth.



Once at home, they are faced with new challenges, in the NICU, the staff is around to help if alarms sounded, but at home it's you and only you. Please refer to our web page, [www.sapremies.za.org](http://www.sapremies.za.org), for some of the parents stories.



Wynand at age 7 months

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(He was born at 24 weeks, 540 grams)

### 2.1.2 How do SA Preemies provide Support

We strive to provide support, encouragement and assistance to parents, family, friends and Nursing Staff dealing with babies born premature in South Africa. Support is currently given via ***one of the following methods:***

#### i. Support Groups

Our vision is to have a support group in every town that has NNICUs in close proximity, ideally in every hospital that has a NNICU. It is envisaged that the support groups will meet twice a month during the day for perhaps 90 minutes or so. We will supply total support for the groups, i.e. topics to share, ideas, themes, event ideas, preemie information, etc. We are going to put the fun back into parenting and have lots of fun at the groups as well as be an emotional support to those in the group.

#### ii. 24 hour telephone support

At a share call number, which is accessible 24 hours every day of the week, parents can speak to me or my personal assistant. We try to calm parents, give needed information and supply them with applicable advice. If we are unable to speak the *callers preferred language*, we will do our utmost best to find a *support parent speaking the preferred language*, and getting that parent to phone the parent in need to provide support.

#### iii. Personal/Individual support

We have parents in different areas that have walked the way of fear and anguish. These parents feel they can assist other parents by taking them out for a cup of coffee and providing them with personal support by sharing their own experiences. Our aim is to have support in all areas and although it not up and running as yet, we know that we are working towards a goal. The more people we support, the more people feel that they can do the same for others and thus we can expand our Individual Support System.

This is a voluntary service from parents who have walk the walk, and have talk the talk, and entails no financial benefit for any support person.

By speaking to somebody who has traveled the road, parents become encouraged by knowing they are not alone, and that many a premature baby has survived. By seeing the grown toddler or photos of ex premature babies, they become calm and handle the situation much better.

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### **iv. E-Mail Support Chat Group for Parents and Nursing Staff**

We have an e-mail chat group for parents and another for nursing staff. Parents all over the country speak to one another and share their fears and triumphs.

Nursing professionals working with premature babies also go through a lot of trauma in the unit and in many cases the people around them don't understand the stress they experience in the unit.

Thus the reason for the e-mail support chat group for nursing staff, this enable NICU staff to have a virtual cup of coffee with people that understand their terminology and stress.

### **2.1.3 When does SA Premies provide Support**

#### **i. Before the birth**

We tell parents what to expect from NICU, the feelings they might experience surrounding the birth of their baby and many more. The more prepared the parents are, the better they handle the situation.

#### **ii. During NICU**

We provide support to parents during the NICU period, by just being there for them to listen to all their fears, to share in every milestone achieved, to be the shoulder they can cry on.

#### **iii. Taking baby home**

We provide support by giving handy tips on how to handle their baby at home and being there for any questions, and to share in every step of the way forward.

#### **iv. Growing up years**

Many people are under the impression that a premature baby stop's being a preemie, once he or she is not seen as a baby. Unfortunately, this is far from reality. A child born prematurely still has a long way to go and parents are faced with many questions and obstacles during the growing up years. We strive to help them through this time by assistance, encouragement, and above all sharing our personal stories and experience with them.

### **2.1.4 Who provide the support**

This is a voluntary service from parents and other involved trained members who have walk the walk, and have talk the talk, and entails no financial benefit for any support person.

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### **2.2 INFORMATION AND ADVICE**

#### **2.2.1 Reason**

By education, information and advice, parents feel that they get back at least some of the power lost during the birth of their premature child. We also realise that many do not have the infrastructure we do, and do not have access to the internet, to search for information themselves.

#### **2.2.2 How do we obtain information and advise**

Advice and information is given through one of the above mentioned support methods. We obtain our information from:

- i. The Internet
- ii. Personal Experience
- iii. Professional forum

#### **2.2.3 Distribution of Information**

We distribute information to parents via telephone discussions, email and individual support.

We however also attempt to distribute updated information about the Association and other organisations to hospitals and those on our correspondence distribution list.

Information pertaining to SA Premies, about what we do and what it entails having and caring for a premature baby etc, are given to the general public as well as other Institutions and Medical Professions at exhibitions, in media coverage and many more.

### **2.3 PRODUCTS**

Premature babies and their parents/caregivers need special products.

SA Premies became a reality and is rapidly expanding as an organization rendering a service to parents of premature babies in South Africa.

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As a non-profitable organization we are depended on volunteers to sponsor us, to cover overheads. To obtain sponsors became a major issue, as we are regularly confronted with the same answers, that all major roll players are already committed to contribute towards the HIV/Aids programs.

We were faced with a serious problem that affected SA Premies detrimentally. The ongoing requests from Hospital Staff and parents to find suitable and acceptable premature products lead to SA Premies starting to recommend products.

SA Premies attempted to research products and recommend those products we believe from experience, clinical data and other to be the best for our babies and their parents.

It is however to be noted that we will only recommend a product, once we firmly believe that it's the best product available on the market. At all times we attempt to inform parents of what is freely available to them and the reasons for our recommendation of a product.

### 3. EXECUTION OF VISION

Every company needs to grow, and have a vision they can work towards. To support the parents of premature babies is very important to us, as we know the feelings and obstacles they face. However, much more can be done to relieve the enormous needs surrounding premature birth. I trust that the above inserts will give you some insight into the world of the parents of premature babies.

First world countries like the USA have around 500 000 pre-term births a year, Australia around 370 000. Both countries have very well established infrastructures to help deal with trauma and needs surrounding premature birth.

Estimated pre-term births in South Africa are 150 000. All parties involved in the care for parent and child, should stand together to build the infrastructure as available to parents in other countries.

Our economic situation however does not always permit the same infrastructure as those in the first world countries, but we can at least aim to better ourselves, and with the minimum, relieve some of the enormous need. Bare in mind the unfortunate situation of our underprivileged people who can hardly afford the minimum.

By the execution of our vision, we trust that the Company will grow, that we will be able to provide support to more people, especially those in the historical disadvantage areas (HD), and that the situation for premature babies and their parents will be bettered, from the parent's point of view.

Many changes need to take place in the Medical and Professional environment. Many of the parents involved with SA Preemies have a vast knowledge base of medical conditions and treatment options, this however is only our personal experience and opinion, and thus the standards, rules and regulations, treatment options etc, are left to be dealt with by those Organisation started for this sole purpose.

Our Vision currently is to:

- i. To inform the general public what it entails having and caring for a premature baby and what can be done from all sides to better the situation for the baby and parents, as well as preventative measures that can be taken.
- ii. To inform parents and all other involved of the importance of Kangaroo Mother Care (KMC) while in hospital and during the initial home period.
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- v. To inform all about the rights of the premature child and its parents.
- vi. To reach out to less privileged parents of premature babies who do not have access to the specialist services required to help them to develop their children to their best potential.

### 3.1 SOME OF THE REASONS WHY THE ABOVE VISION IS SO CLOSE TO OUR HEART

#### 3.1.1 To inform the general public what it entails having and caring for a premature baby, and what can be done from all sides to better the situation for the baby and parents,

Looking at the insert quoting Dianne, it's clear that parents embark on an unknown journey. However keeping in mind, that it's the feeling of a parent in a first world country, and does not really show the enormous emotional and financial implication the birth of a premature baby has on the Historically Disadvantage population of South Africa.

SA Premies needs to focus on the private sector, to enable us to get going with the organisation. The general public do not take into account the following factors in South Africa, which makes the information and support process such a big challenge in South Africa.

Many Historically Disadvantaged people now have access to Medical Aids due to employers giving medical aid benefit. However the child might be born in a hi-tech private hospital, but the parent in many cases still stay in the Historically Disadvantaged area's of South Africa. They need to travel to hospital via bus or taxi, and in the end take their child back to an area that is not always as hygienically as in other circumstances. Parents need to face the obstacles of having a premature baby, with the circumstances of not having electricity, running water and many other. Medical Assistance is far away and not easily accessible.

Certain cultures in South Africa also tend to believe, that when you go to the clinic or hospital, you are dying, and thus those in the HD areas tend to wait till the very last moment to seek medical attention or obtain information. The transition from having nothing, to that of being uplifted by the various programmes implemented by the South African government, do bring relieve but also its own share of problems.

#### 3.1.2 and preventative measures.

It's clear from the ***Saving Babies Study*** that one of the biggest problems associated with the high child mortality rate in South Africa, is the lack of attendance to antenatal classes. We need to realise that this is a new concept to many. However we do believe that one of the other obstacles in encouraging people to attend antenatal classes is that it's perceived to be just again something else to be done, it's a way for people to make money etc.

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A phenomenon SA Preemies experience on an ongoing basis is the fact that certain cultures tends to believe that their families and friends whom have given birth to their children without antenatal classes, knows just as well. They cannot understand why Medical Workers tells them to attend antenatal classes.

There is also a known link between premature birth and HIV/AIDS. Pregnant HIV/AIDS mothers are at a higher risk of having a premature baby. By education on general health issues, the signs of premature labour which are not so well known to those in the Historically Disadvantaged areas, good health tips while pregnant, encouragement to attend antenatal classes, and by encouraging and training our uneducated parents with whom we get into contact and stay in contact, we might just be able to relieve some of the symptoms of the situation.

By information and education, we might be able to assist the government in their goal of brining down the (saving babies) morality rate, which also implicates that we can bring down costs associated with saving the premature babies, the long hospital stay, and early treatment of problems to minimise the impact of it on all. It's to be noted that our medical profession is already very much overworked and under staffed, and with the planned state medical systems etc, work will be escalating. The birth of a premature child does not only have an effect on the child and the immediate family, but also on government in short and long run. Thus by educating and distribution of information on preventative measures, all could benefit.

### **3.1.3 To inform parents and all other involved of the importance of Kangaroo Mother Care (KMC) while in hospital and during the initial home period.**

### What is Kangaroo Mother Care ??

Definition: A universally available and biologically sound method of care for all newborns, but in particular for premature babies, with three components:

- 1 Skin-to-skin Contact
- 2 Exclusive breastfeeding
- 3 Support to the mother infant dyad.

**Skin-to-skin contact** is between the baby front and the mother's chest. The more skin-to-skin contact, the better for the mother and the child. For comfort a small nappy is fine, and for warmth a cap may be used. Skin-to-skin contact should ideally start at birth, but is helpful at any time. It should ideally be continuous day and night, but even shorter periods are helpful.

**Exclusive breastfeeding** means that for an average mother, expressing from the breasts or direct suckling by the baby is all that is needed. For very premature babies, supply of some essential nutrients may be indicated.

**Support to the dyad** means that whatever is needed for the medical, emotional, psychological and physical well being of mother and baby is provided to them, without separating them. This might mean adding ultramodern equipment if available, or purely intense psychological support in contexts with no resources.

In Bogota, Colombia, where KMC started, "early discharge" is regarded as the third part of the definition. This is also a form of support where hospitals are overcrowded, but it also requires a good community support system. (See the INK website)

In the USA, the term Kangaroo Care (KC) is generally used. This has been defined as "intra-hospital maternal-infant skin-to-skin contact". KC is generally started later, and on stabilised premature babies, and is used as an adjunct to technological care.

While KC has profound effects on the baby, KMC does so much more!

Resource: [http://kangaroomothercare.com/Definition\\_page.html](http://kangaroomothercare.com/Definition_page.html)

## **KANGAROOING MY LITTLE MIRACLE**

**BY [KRISANNE LARIMER](#)**

Shortly after my daughter, Kaia Michele, was born at 24 weeks gestation (1 lb 12 ozs) she was transported an hour away to a level III nursery. The first time I was able to visit her was the scariest day of my life - the monitors, breathing tube, wires and bili lights made her look even smaller and sicker. Every time I touched her the alarms would sound and a nurse would have to rub her till her heart started again. I felt totally rejected and felt sure she wouldn't survive.

The next day, within 15 minutes, and after three alarms at my touch, the nurse asked if I wanted to hold her. I was petrified! If she had reacted that badly to my touch, what would happen if I held her?

I was finally convinced to take off my shirt and bra, put on a gown and sit down in a comfortable chair. One nurse carried the wires and vent tubing while another placed Kaia on my bare chest, tummy down wearing only a diaper. A few receiving blankets were placed on top of her - which were later removed because she was too warm. Vent tubing and wires were taped to the sleeves of my gown. After the nurses stopped fussing over her she squirmed for a couple minutes and then fell into a deep sleep. No alarms! No brady spells! Just peaceful sleep. She made me feel like a Mom for the first time, and I knew at that moment she was going to live.

There are many proven benefits to Kangaroo Care. In fact, of the several hundred studies done to date, every study has yielded positive results. For the parent, Kangaroo Care promotes earlier bonding, makes the guilt of early delivery more bearable, gives parents a chance to do something for their baby, and increases lactation (better milk flow). For the babies, Kangaroo Care regulates breathing, stabilizes heart rates, regulates the baby's body heat (mom's naturally regulate their body heat depending on their baby's needs), stimulates more rapid weight gain, shortens hospital stay and allows baby longer periods of alertness and sleep.

Kangaroo Care has been seen by some hospitals as a 'risk', 'not necessary' and 'time consuming'. From all I have seen and read, Kangaroo Care is beneficial, not damaging. If the baby is unable to tolerate Kangaroo Care, they can be immediately returned to the warming bed and it can be attempted again at a later date. If the nurses are properly trained and careful, the transfer wouldn't take more than ten minutes. Actually, I encourage hospitals to allow 'parent transport' where the parent leans over the baby's warming bed or isolette, pulls the baby to his/her chest and sits down while the nurses tend to wires and tubes. Within two or three weeks I was able to position all the tubes and wires on my own. She was all mine for the few hours we were together every day. ....

Resource: <http://www.prematurity.org/baby/kanga-kaia.html#Krisanne>

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Kangaroo Mother Care (KMC) is a process whereby the new born are place between the mothers breast on her chest, skin to skin. The benefit to mother and child is well documented. However many private institutions still refuse the parents the right to Kangaroo Care or it's done for a too short period of time. In many of the state hospitals, parents are encouraged to do it, but the lack of proper facilities to obtain optimal benefit, is not available.

On the other hand, people know that it is very beneficial for the parent and child to practice KMC while in the unit, however not many mothers, especially those in the private sector are told about the benefits of doing KMC at home.

There are also a general assumption in the market that the very high amount of premature babies diagnosed with ADHA, could be contributed to the fact that they were not kangaroo cared or that the time frame of kangaroo care was to short. Please note that this is only an assumption and intensive research still needs to be done on this area.

According to an article on Premature Baby/Premature Child about 1/3 of very low birth weight preemies have behaviour/psychiatric problems and the most common problem is ADHA. (<http://www.prematurity.org/research/helen-adhd.html>)

It's to be noted that Kangaroo Mother Care needs to be done skin to skin and for at least two hours continuously to obtain benefits.

Kangaroo Mother Care is also a very good way for father and other siblings to bond with one another.

The above makes it very clear why we need to inform parents of the importance of KMC not only while in hospital but also during the initial home period.

### **3.1.4 To educate and inform parents about the importance of Early Intervention (EI)**

Early intervention applies to children of school age or younger who are discovered to have or be at risk of developing a handicapping condition or other special need that may affect their development. Early intervention consists in the provision of services such children and their families for the purpose of lessening the effects of the condition. Early intervention can be remedial or preventive in nature--remediating existing developmental problems or preventing their occurrence.

Early intervention may focus on the child alone or on the child and the family together. Early intervention programs may be center-based, home-based, hospital-based, or a combination. Services range from identification--that is, hospital or school screening and referral services--to diagnostic and direct intervention programs. Early intervention may begin at any time between birth and school age; however, there are many reasons for it to begin as early as possible.

### Is Early Intervention Cost Effective?

The available data emphasize the long-term cost effectiveness of early intervention. The highly specialized, comprehensive services necessary to produce the desired developmental gains are often, on a short-term basis, more costly than traditional school-aged service delivery models. However, there are significant examples of long-term cost savings that result from such early intervention programs.

- A longitudinal study of children who had participated in the Perry Preschool Project (Schweinhart and Weikart, 1980) found that when schools invest about \$3,000 for 1 year of preschool education for a child, they immediately begin to recover their investment through savings in special education services. Benefits included \$668 from the mother's released time while the child attended preschool; \$3,353 saved by the public schools because children with preschool education had fewer years in grades; and \$10,798 n projected lifetime earnings for the child.
- Wood (1981) calculated the total cumulative costs to age 18 of special education services to child beginning intervention at: (a) birth ; (b) age 2; (c) age 6; and (d) at age 6 with no eventual movement to regular education. She found that the total costs were actually less if begun at birth! Total cost of special services begun at birth was \$37,273 and total cost if begun at age 6 was between \$46,816 and \$53,340. The cost is less when intervention is earlier because of the remediation and prevention of developmental problems which would have required special services later in life.
- A 3-year follow-up in Tennessee showed that for every dollar spent on early treatment, \$7.00 in savings were realized within 36 months. This savings resulted from deferral or special class placement and institutionalization of severe behavior disordered children (Snider, Sullivan, and Manning, 1974).
- A recent evaluation of Colorado's state-wide early intervention services reports a cost savings of \$4.00 for every dollar spent within a 3-year period (McNulty, Smith, and Soper, 1983).

Resource: <http://www.kidsource.com/kidsource/content/early.intervention.htm>

**Clinic in South Africa to promote communication for high risk babies**

The Center for Early Intervention in Communication Pathology at the Department of Communication Pathology at the University of Pretoria, South Africa, is operating an important "Clinic for High Risk Babies." The primary functions of the clinic are as follows:

- Providing early identification, assessment, and intervention of at-risk infants, toddlers, and their families to facilitate their communication development
- Teaching and training of undergraduate students in the handling of at risk infants and toddlers
- Teaching and training of speech-language and audiology graduate and post- graduate students in early communication intervention
- Presenting continuing education programmes to graduate professional groups
- Conducting research on undergraduate, graduate, and post graduate levels
- Developing the field of early communication intervention within the unique South African context

Resource: [http://depts.washington.edu/isei/resources\\_links/SAfricaClinic.htm](http://depts.washington.edu/isei/resources_links/SAfricaClinic.htm)

Although the cost benefits of EI, can not yet be proven in South Africa, we know that from a parents perspective this forms a crucial part in caring for a premature child.

We encourage our parents to take their children for evaluations at a high risk clinic, and if a clinic is not available in the area, to take the child for an evaluation by a SANDTA accredited physiotherapist or occupational therapist. In some chases where the NICU roller coaster ride were very difficult, we might suggest that the family take a break and just enjoy their precious little angle, before they start with EI, but it's not t be put off for to long.

Encouragement to take children for EI, is given by one of the support methods. We also recommend that parents take their children for an evaluation at least once a year, after EI treatment is stopped, until the child goes to school.

The problem that we however face is again that the HD areas are not accustomed to taking their children for evaluations, government high risk clinic's are in many cases over worked, parents can not afford to take time off work to take the child for the evaluation etc. We need to educate not only those in the

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HD about the importance of EI, but every parent need to be informed about the crucial part. Please see Project planning for more information as to how we would like to address this problem.

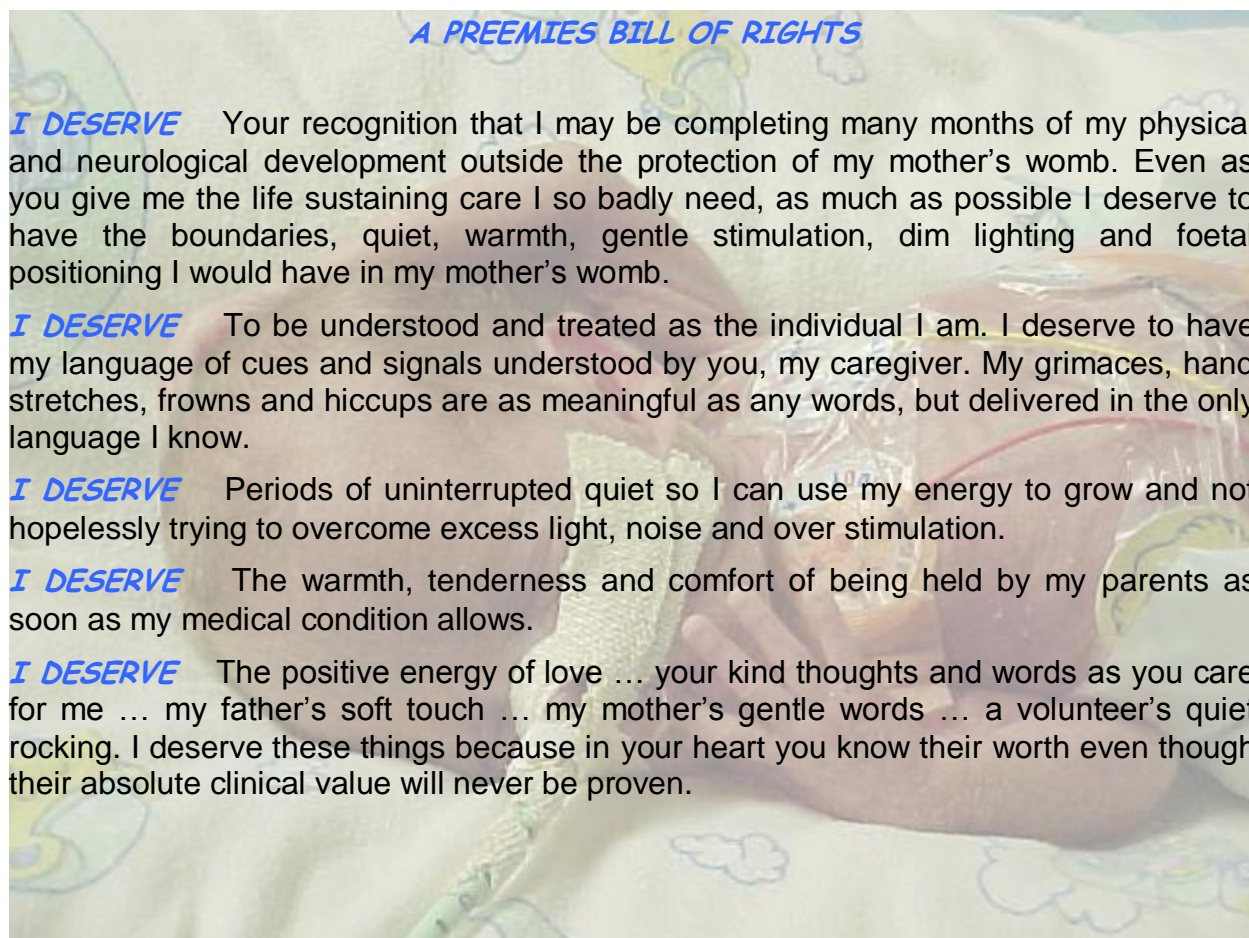
#### **3.1.5 To provide support to everybody in their preferred language.**

We are a multi-nation, multi-culture and language country. The high tech language involved in caring for a premature child, we have discovered are in many cases overwhelming to parents and stress them out more, making the whole situation more difficult to handle.

We thus strive to provide support to parents in their main language, as we find that they understand the terms better and identify better with their feelings. This however is not always possible, due to the lack of support people speaking the different language. We do however believe, the more people we support, the more people will be available to help support others and that one day we will be able to help each person in their own language.

We also strive to provide support culture to culture, believe system to believe system, as the different cultures and believe systems, handle the situation different that others.

#### **3.1.6 To ensure that everybody is informed about their premature child rights as well as their own.**



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*I DESERVE* Your understanding that what is normal and routine for you, as my caregiver, is abnormal and frightening for my mom and dad. So please answer kindly no matter how many times they ask the same question. They deserve your support and the support of other families as they go through the roller coaster experience of the NICU.

*I DESERVE* Your recognition that my parents are an integral part of my care giving team and should be allowed and encouraged to the best of their ability to help care for me during my stay in your hospital.

*I DESERVE* Your understanding that part of your job is to help my family and me bond as we learn to trust each other as they prepare to bring me home.

*I DESERVE* Continuity of care from the NICU to my home ... from my neonatologist to my primary caregiver ... so together my family and I can reach our full potential.

You deserve my thanks and recognition  
I am here because of YOU

By Read McCarty

In many cases the parents feel that they are not part of the caregiving team looking after their baby. They feel that their child belongs to the NICU staff. We inform parents that they have the right to be part of the process, to ask questions, to be informed about treatment options and the care given to their child.

However, the premature child also has certain rights, those stated above, but more so during the growing up years. The child has the right to be dressed in age appropriate clothing etc, and thus SA Preemies set out to fill this market need and to attend to these rights, via our support systems and recommended/endorsed product line.

#### **3.1.7 To reach out to less privileged parents of premature babies who do not have access to the specialist services required helping them to develop their children to their best potential.**

Please review our project planning as to see how we would like to accommodate this part of our vision.

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### **4. PROJECT PLANNING**

Various needs were discussed with hospitals via a survey done in January 2003, to prioritize the importance of each need.

However many of the projects could not be started due to a lack of funding. We also tried various working methods for contacting people and to provide the support. All of this contributed to where we are today.

Some of the above included hospitals faxing us with information about parents and then we can contact them, however, this did not work so well and we have made some changes to our whole operating procedure and infrastructure.

#### **4.1 EARLY AWARENESS AND INTERVENTION**

We would like to make as many people as possible aware of SA Preemies and prematurity in general. This would give us the opportunity to achieve the following:

- i. Inform parents before or just after the birth of their baby, about what they could expect from NICU and the road ahead.
- ii. Products and Services available to them in South Africa.
- iii. The importance and benefits of Kangaroo Mother Care and Early Intervention
- iv. A better understanding of prematurity.

#### **4.2 EARLY INTERVENTION**

We would like to authorise a booklet, detailing basic developmental exercises in association with the SA Neuro-Developmental Therapists Association (SANDTA), to be distributed to parents. Distribution will take place at hands-on workshops to be hosted in low-social economic areas' clinics. (Ref. booklet two)

We would also like to run/attend workshops and/or seminars to inform parents and Health Workers about the importance of early awareness and intervention, and provide them with basic information about home programmes.

#### **4.3 OUTREACH PROJECTS**

We are planning the following outreach projects. However, many of these projects have been included in our Business Plan from almost day one, with no action taken to date, as many of them can not be started without the much needed funds:

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### 4.3.1 Charity events

SA Preemies, in conjunction with Ackermans arranged for the donation of clothing and other much needed items to Tygerberg Hospital's neonatal unit. Due to the great need in state hospitals we plan to facilitate more such projects.

### 4.3.2 Neuro-development Programme

Technology has improved dramatically over the past decade or so to keep babies alive who were born at 22 and 23 weeks (normal gestation is 40 weeks). Unfortunately the expertise does not yet exist to effectively prevent premature babies.

Premature babies may have neurological and other delays and defects. The more premature or smaller the baby, the greater the dangers are for the baby

It is a well known fact that the first three years are vital in a child's development and that neurological damage can optimally be improved or even repaired in this time.

To achieve this, however, children need specialised help in the form of therapy.

The United States has an Early Intervention (EI) programme, which is not only provided at no cost to parents of premature babies, but is compulsory. This is because authorities have calculated that for every dollar they pay for EI, they save 7 dollars by ensuring that the child will not be a burden to the state one day.

In South Africa such a programme does not exist. There is a lot of expertise around, but it is generally poorly co-ordinated and often tends to be in the private sector and therefore only available to children on medical aid schemes. Other children – the vast majority – are dependent on State programmes, which are good, but because of cost and transport problems, the queues are long and the services are not always available to be effective enough. Parents are uninformed about the necessity of therapy.

Our plan is to find sponsors for individual children who are in great need of therapy but do not have access to it. We will work closely with SANDTA and state hospital's high-risk clinics to find suitable candidates, who will then receive regular evaluations and therapy from therapists.

SA Preemies Association will fund the treatment of these babies in full or part. Criteria for acceptance into such a programme still needs to be finalised, but to date the following have been suggested.

- i. Candidates should not have access to medical aids, which cover neuro-developmental therapy.
- ii. Parents in low socio-economic circumstances will have preference.

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- iii. Micro-preemies (babies born 27 weeks and under or who weigh less than 1.2 kg) will have preference.
- iv. After micro-preemies, preemies born between 27-32 weeks will be considered.
- v. Preemies referred by state hospital's high-risk clinics (where their needs have already been assessed by neuro-developmental paediatricians) will be considered.
- vi. We need to have a qualified therapist in the area or someone who will be willing to make home visits.
- vii. Application will have to be done in writing and if the child has not been seen by a high-risk clinic yet, we will arrange for a qualified therapist to evaluate the child.
- viii. Applications will be discussed with our Professional Forum.

#### 4.4 OTHER PROJECTS

##### 4.4.1 Booklets and other (status – 0%)

With technology at our finger tips, many parents have the resources to search for information about premature babies, the outcome, feelings etc. However many of our premature babies are born in the state environment, and these people don't have access to advance technology like internet. We would like to find ways to get the relevant information to them in a language that they can relate to.

SA Preemies therefore plan to authorise booklets or to make video's. The first booklet/video will inform parents about the most commonly used equipment in NICU, terms and how to handle their feelings etc. This booklet will be made available in all official languages. A sponsorship is needed for this project urgently.

The second one will be covering: How to handle your premature baby at home, what to look for, what you as parent can do to help you child achieve his/her milestones as soon as possible and many more. This booklet will in such a way as to accommodate both literate and illiterate people and will be in all official languages.

##### 4.4.2 Media Coverage

SA Preemies Association organises media coverage on an ongoing basis to raise awareness about preemie issues and inform parents of our existence. Much of this is concentrated around Premature Baby Day on October 22. We also make ourselves available for comment on appropriate news events. Where appropriate, we will try to include exposure of our sponsors.

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### **4.4.3 Premie get-together (Status – 0%)**

The need amongst parents to meet with other parents of premature babies is great. We would like to host a preemie get-together in conjunction with a sponsor, so that parents can meet. This get-together can be hosted as a fun run/walk while parents have a picnic. Funds raised can be utilised for the Neuro Development Programme. It would be great to arrange such a get-together around National Premature Baby day, 22 October. Expert speakers could also be invited.

### **4.4.4 Detailed research project**

To date statistics on premature babies born in South Africa are unclear with regards to: the reasons for pre-term birth and the outcome for most of our preemies, survival rates etc. A detailed research project needs to be undertaken to get the statistics in place.

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### **5. MOTIVATION FOR FUNDS**

#### **5.1 MONTHLY RUNNING COST**

##### **5.1.1 Company secretary**

Due to escalating work load of SA Preemies, it was necessary to appoint a company secretary to help in the office. We have therefore appointed a company secretary to handle tasks.

##### **5.1.2 Telephone**

###### **i. Share Call and Golden Number**

To enable us, to be contacted 24 hours a day, without the need to change telephone numbers when people move and to have a number that is easy to remember by all, we have opted to go the Share Call Golden Number route. Monthly charges for these services are applicable.

###### **ii. Call charges**

Telephonic contact is a critical part of running S A Preemies, for the various office related activities and enable S A Preemies to interface with parents via telephone. Numerous faxes need to be sent regarding S A Preemies as well.

##### **5.1.3 Travelling**

The CEO of S A Preemies will often be required to travel to sponsors to facilitate negotiation and to various others for support and marketing purposes.

The CEO of S A Preemies is often invited to be a guest speaker at functions outside the Durban area. In such instances she will be required to travel long distances by car, which can be expensive. Funding or alternative options are needed.

##### **5.1.4 Office supplies and other**

Funds are needed to purchase office stationary (paper, print cartridges etc.) and other to cover the cost of office supplies, etc.

#### **5.2 PRINTING**

##### **5.2.1 Booklet for use in the NICU**

SA Preemies will authorise this booklet. It however needs to be printed and distributed to hospitals etc.

#### **5.3 MOTIVATION FOR NEURO-DEVELOPMENT PROGRAMME**

We need to obtain funds to pay SANDTA therapist for their services.

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This can be done in two ways:

- iii. A donation is made to SA Preemies Association, and we utilise the funds as we see fit
- iv. After an application is made and approved, we send a request to you, detailing the amount and extent of treatment. This can then be accessed and you can “adopt” the child and pay for treatment until the child is at least three years old. Accounts will be sent to SA Preemies Association, whom in return will supply you with an invoice, receive payment and then pay the therapist.

The reason for the above is that more than one therapist might be utilised at once, and this will enable us to give you a consolidated account.

### **5.4 CHARITY PROJECTS**

Assistance can be provided financially or in the form of products to needy hospitals and parents. We will try to arrange for publicity around such donations, but can unfortunately not promise it, as it will depend on the media.

### **5.5 PREEMIE GET-TOGETHER**

Financial assistance or assistance in the form of products will be needed. The sponsor(s) will receive exposure at the event.

### **5.6 MARKETING / AWARENESS**

In order for the general public and those requiring the services of S A Preemies to know about the organisation, it is crucial that ongoing advertising be done to promote the awareness of the organisation and the services offered by S A Preemies.

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### 6. BREAKDOWN OF COSTS

#### Monthly running costs

Company Secretary		R 4 000.00
Internet access		R 230.00
Telephone		R 2 300.00
Share Call with Golden Number	R 300.00	
Telkom Line calls	R 2 000.00	
Travelling		R 3 000.00
Office Supplies and other		R 1 000.00
Marketing / advertising		R 1 500.00
<b>Total monthly cost</b>		<b>R 12 030.00</b>

#### Neuro-Developmental Programme

Ongoing

*Note: Estimated cost could be R3600 to R9000 per year, per child, depending on the tariffs we can negotiate and the extent of the treatment. Estimates based on therapy twice a month.*

#### Printing of information

Ongoing

*Note: Detailed costing needs to be drawn up for each individual project.*

# **ADDENDUM A**

# **“SHAREHOLDER” BREAKDOWN**

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## MEMBERS OF THE COMPANY (SHAREHOLDERS)

Name & Surname	Current Occupation	Representative off	Equity
Adele Benvie	Chief Executive Office of The Success Company	Marketing, Fundraising	White, Female
Lavonne Prinsloo	CEO of Little Miracles and founder of SA Preemies	Operations, Media, Chat groups and products	White, Female
Catherine Jordan	Full time home executive. Mother of a premature baby.	Support	White, Female
Amanda Martin	Registered nurse. NUK representative	Medical	White, Female
Kim Lawson		Financial Director	White, Female
Stacey Aires	Developmental physiotherapist	Support	White, Female
Debbie Bernard-Mmusi	Works for ABSA bank	Support	Black, Female
Lindiwe Nkwanyana	Works for ABSA bank	Support	Black, Female

#### Board of Directors

Adele Benvie	-	CEO
Lavonne Prinsloo	-	Operations Director
Catherine Jordan	-	Support Director
Amanda Martin	-	Medical Director
Kim Lawson	-	Financial Director

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