

## SHINING STARS

NEWSLETTER



### 2012 – Thank you Star Academy Team

As the year of 2012 draws to a close I would like to extend my sincerest thanks and appreciation to our Star Academy team for their contribution this year. Thank you to our US

supervisors, John, Katie, Peter, Soo and Tasia for their supervision, insight, guidance and unwavering support night and day. Next year, we will be welcoming a new Supervisor, Sarah Niehous to our team. Sarah is based at the CARD offices in Thailand and will be making her first trip to South Africa in February next year. John and Peter will continue to supervise their cases in South Africa.

This year we have sadly had to say goodbye to Katie and Tasia, who due to family reasons are no longer able to fly to South Africa and Soo, who will continue providing support on Skype.

We thank our incredible speech therapist, Cheryl Jackson for teaching us PROMPT and for supervising our PROMPT programs. Cheryl will be returning next year and you will find her expected dates and the CARD supervisor's dates in the 2013 calendar. Cheryl continues to inspire us with her skill and wisdom and is an extremely important member of our team.

We thank Akil, our local supervisor, who will continue in his role as supervisor and Star Academy manager for his dynamic leadership and supervision this year. To all our Team leads who have with great inspiration guided our teams, we thank you for your contribution, which has earned you the appreciation of the children and their families. We also want to thank each and every therapist for their passion, faith, patience, determination and commitment to the children of the Star Academy.

A special thank you to Jo, for attending to

each and every detail and a warm welcome to Jody who has joined our administrative team. Lastly, we thank our scheduler Reinette, for working around the clock to ensure that each child's schedule runs smoothly and for scheduling so meticulously every week.



We have been privileged to witness the incredible achievements of the children who attend our various Academies this year and we look forward to 2013 with renewed energy and commitment to the development and progress of the children.

Merry Christmas and a happy new year Ilana

## A Parent's Perspective

**OUR JOURNEY WITH AUTISM** 

(As it appeared in Vrouekeur)



"It's a long road that you have to walk and we find there is very little help for autism in South Africa."

These are the words from Liesl Swanepoel. Four years ago it was a big shock when her and her husband's eldest son, Daniel (7), was diagnosed with autism.

Then their other son, Emile (3), was also diagnosed with autism.

Emile cannot talk yet and just makes sounds, but Daniel has a large vocabulary. However, he does not speak in full sentences and his pronunciation is very unclear.

"Parents are struggling to get an early diagnosis of autism in South Africa". "I do not think our doctors are necessarily trained to make the right diagnosis. There is also a lot of new research being done in the field of autism and opinions vary greatly"

Autism is a group of complex developmental problems usually emerging before the age of three. The symptoms and degree vary and there is a wide spectrum, but most children with autism's interaction and ability to communicate with others, are affected.

Research shows that more and more children each year are diagnosed with autism. It is not clear whether a greater awareness is responsible and whether there are actually more children who are suffering.

### Do your homework

One of the main objectives in autism therapy is to improve verbal and non-verbal communication. It is believed that early, intensive treatment can make a big difference in children with autism.

Liesl and Marcus found there was not a specific South African approach when a child is diagnosed. The local trend is for a child to be referred for speech, occupational-and sometimes behavioral therapy (Applied Behaviour Analysis ABA).

The biggest trend overseas is to see autism as a disease and make use of biomedical treatments.

"We also see autism as an illness that can improve with diet, medications and supplements, and that it can even be fully healed. However, this is not everyone's view and we respect it, "said Liesl.

"Read, read, and read about it. Do not believe everything you read, but do not avoid everything because you're too afraid to try. Remember, you know your child best of all and know some of these alternative therapies can make a world of difference. Some have made a big difference in our lives despite what others say! ".

She recommends that parents initially keep their routine the same every day. "These children thrive in a structured environment. It is a challenge that can be dealt with later, in behaviour therapy."

"Use visual aids to explain the daily schedule (photos or pictures on a felt board). It makes your child feel safe if he knows what to expect.

"The best advice I got was from our first speech therapist. It was to speak like a radio commentator to your child. Through talking to your child about what you do or what you are doing, you develop his language skills."

Emile and Daniel undergo ABA behavioral therapy. "It's intensive one on one therapy. We did a lot of research and found that ABA therapy would deliver the best results. It takes anywhere from 25-35 hours a week.

"Our children are at The Star Academy. There are also other autism programs in South Africa like SNAP and REACH programs."

Liesl said Daniel and Emile both experience difficulty with sleeping and have weak immune systems, making them vulnerable to viruses. Furthermore, they have several food allergies and / or resistance, suffering from digestive tract diseases and many imbalances in the body in terms of vitamins, minerals and amino acids.

"Medical tests have made it easier for us to try alternative therapies and supplements. Through various blood, urine and stool analyses, numerous irregularities were found. You cannot look past the fact that your child is sick. Therefore, a good DAN (Defeat Autism Now) doctor or dietician is recommended to do the necessary tests and recommend the right supplements."

### Help for autism

#### BIOMEDICAL TREATMENT

Liesl said some biomedical tests are done by local laboratories, although most overseas. "We used The Great Plains Laboratory in America"

"One such treatment is to take salt baths. Because my boys struggle to get rid of toxins, they benefit from two cups of Epsom salt in their bath every night. It is also soothing and works wonders before bedtime!

Another alternative therapy that we tried with Daniel was hyperbaric oxygen tank treatment. After about 12 sessions, Daniel began to observe his environment and comment on it."

### DIET

Diet plays an important role in the treatment of symptoms.

"There are several diets, of which the best known are the gluten and casein free diet, specific carbohydrate diet and ketogenic diet. In our case it did not make a difference to our children's behaviour, but to their health.



"Daniel had many digestive tract problems and had diarrhoea four times a day for up to a year! Emile has eczema and by cutting casein (milk protein) from his diet, we make a difference to it."

Liesl emphasized the importance to a professional that can provide guidance in regard to a particular diet.

They also try to lead, as far as possible, a green and organic lifestyle.

#### SENSORY THERAPY

Sensory problems are so common among these children, that it will possibly be entered in the new diagnostic criteria for autism. Children can either have an extreme sensitivity or complete lack thereof with regard to their senses.

"For example, Daniel had hyper olfactory problems. If I put out cat food, he vomited. Through behavioural therapy and the development of his communication, he now understands that he can remove himself from the situation.

He also has problems with his vestibular system, touch and hearing. Emile experiences problems with his tasting (hypo) and therefore likes to chew everything and also likes to smear things like food, cream and mud.

### THE CHALLENGES

### **FINANCIALLY**

Autism puts huge financial pressure on families, says Liesl. In most cases, one spouse gives up his career to look after the children, because there are regular appointments with doctors and speech and occupational therapists. "To crown it all, no medical scheme in South Africa will pay for ABA therapy. Most of the supplements are not covered by medical aids and only local blood tests are covered. Speech and occupational therapists however are covered."

Liesl said in certain U.S. states ABA is being covered by the medical aid. However, it is possible for your child to be registered with the South African Revenue Service to receive tax exemption. It can cover a portion of the costs.

#### **EMOTIONAL**

Friends and family do not always know how to deal with children on the spectrum and do not always realize how heavy the initial diagnosis and subsequent heartache can be for parents.

"Everyday family outings like going to the movies, eating at a restaurant and going to a mall, is not possible," said Liesl.

Performance is also affected by the increased stress levels at home. One or both parents must request time off regularly, to attend specialists' appointments. All these factors obviously put pressure on the marriage.

The healthy child may feel that he is neglected and that the autistic child receives all the attention. There is unfortunately a stigma about having an autistic sibling. Outings, for example, could be cut short because the affected child has an outburst.

Liesl and Marcus call for greater understanding

Strangers in shopping centres: What you think is a naughty, spoiled child seemingly not getting his way and is therefore crying and

kicking, could be a child with autism who is merely experiencing sensory overload and not able to communicate it. Think twice before you condemn us. We have enough guilt to be deal with!

Marriage partners: Be patient and compassionate with each other. Both will work through the grieving process, but each in their own time. Be sensitive in each other's feelings. It can make your marriage so much stronger!

Family and friends: please do not avoid our family because you do not know how to handle it. It is sometimes easier for us if you came to visit us. My child may not speak or look you in the eye, but he is intelligent! Please do not ignore him, meet us. Once he feels comfortable, he will get acquainted. Despite what people and books say, they are actually very loving children!

Please ask parents of autistic children if you could watch the children for a while so they can go out. We need it.

Feel free to invite my child to kids' parties and play dates. We may not stay until the end, but he also has a need to socialize.

Please talk to me about my child; I do not mind explaining this complex "disease". Sometimes I need to just talk about it.

Your child: Please teach your child that the world is different and that all people should be respected

### Little



## Picasso's









Merry Christmas from Durban!





## Clowning Around!



# We love playing at the STAR Academy!







Summer in Pretoria is the best time of year!

Land ho! The Pretoria Pirates in search of treasure

The Durban Academy starts ending off the year with a bang!







### Breakout and About



variety of personal interests and recently a couple of our "little scientists" got a chance to explore the world of science at Sci-Bono. It was a day filled with exciting experiments and displays. To top it all off, the little stars had a chance to explore the Johannesburg CBD, "the city of gold". This proved to be a fun outing as the little stars had a chance to experience the exhilaration of using the infamous Jo'burg public transport system, promoting independence and giving our star moms a break from playing taxi. A fitting day for our shining stars. Sci-Bono proved to be a great adventure, one that all our little stars should experience!!



Nathan W., Thomas and James set out to discover exactly why science is fun!



## Vegas Nights!



We have reached that time of year again when we begin to reflect on the last few months and attempt to measure how far we've come by reflecting on our achievements. This is exactly what the end of year function, that took place on Thursday 29 November, was for. The therapists enjoyed a night together away from the centre where we had the opportunity not only to enjoy each other's company, but also to celebrate our achievements as a well-oiled team.

The theme was Vegas Nights which gave us the opportunity to put our 'best foot forward' in glamorous night gowns for the ladies and smart wear for the men. We let our hair down by dabbling in some karaoke (this showed us why some of us make better therapists than singers) and trying our luck at the poker and blackjack tables. Various pasta dishes and salads were served and there was an open bar to keep our thirst quenched.

Most of the staff was in attendance with their partners. One of our US supervisors, Peter Farag, was there to share the night with us. Ilana and Akil took the time to show their appreciation and thank

the staff for their hard work and dedication to the children throughout the year.

Towards the end of the night an awards ceremony was held and some of the winners from Jo'burg and Pretoria respectively were:

Team Lead of the Year - Jenna and Monique

Ladies at the Durban center had a fantastic time at our End of Year function on Wednesday, 5 December. We were treated to dinner at Nando's and a spectacular adult version of The Wizard of This was a night for team bonding and fun and that is exactly what was achieved!

Junior

Therapist of the Year – Rebecca and Carlien

Most Organised Therapist- Kerry and Angela

Most Glamorous - Sharene

Most Punctual – Lizzie

Most Improved Therapist - Keyuri and Moagi

Most Abused Therapist – Ayla and Trisha

Best Social Reinforcement- Zaheera and Roanda

Best All-rounder- Carmen

Congratulations to those therapists who received awards. We look forward to many more amazing events as we celebrate the hard work and growth of the Star Academy.

## Spotlight on...



Eunice Chinangane

How does it feelto be back?Being back has been

interesting. I was gone for 8 months and coming back and adjusting to therapy has been challenging. I've had to re-learn many things. I am very happy to be back though because I get to see the kids everyday

The kids. When working here you can't help but bond with them, so it's inevitable that it's them you'll miss most.

- What cool names do people call you (nicknames)?

Euni-Bug. Now people have made it their own so I'm called anything

from The Bug and Buggie to Bug-a-loo and Buggie Wuggie.

- What food can't you live without?

Cashew nuts, speckled eggs, tuna and mayo sandwiches and vanilla milk

- If u could be an animal, what would it be? An eagle because they can fly (which I think is awesome) and they are associated with strength and precision and I value that.

### Lebohang Koalepe

- What are you studying?
  I studied BA Psychology at UJ
- What type of food can you not live without? Tropica
- What is your favourite genre of music?
  Rock and Hip-hop
- If you could be any animal, what would it be and why?



A dolphin, because they are so gracious, beautiful and calm

- What is your nickname?
Lebo

#### Shannon Mostert

- What are you studying?

I have completed a BA Honours in Psychology.

- What animal would you be, and why?

  If I could be an animal I would be a bird, they are able to travel anywhere in the world with no restrictions.
- What food item can't you live without? I can't live without Chocolate!
- -What is your favorite genre of music? I like alternative/rock music
- **Do you have a nickname?** Shan is my nickname

### Our Academies....

### Brooklyn, Pretoria



Melrose Estate



Durban North