PAWS FOR PEOPLE

Our Centre members were over the moon with excitement with the recent addition of PAWS for People to our activities.

PAWS for People is a voluntary organisation whereby special dogs are trained to become therapy dogs. These special dogs have to undergo a series of assessments and health checks in order to become a therapy dog.

Every second week, the therapy dogs and their handlers visit the Centres. Our furry friends, Stretch, Meg, Amber and Kelly get just as excited with the visits as our members do. With the assistance of the handlers and care-workers, the dogs get the full treat from our members – walks, grooming, love, playing ball and even the odd treat.

The dogs give off a sense of calmness and understanding and encourage our cerebral palsied children/adults to do their necessary therapy without even knowing because they are concentrating on the dog and not on the actual therapy.

Many of the members were apprehensive in the beginning and others just wanted to show love and affection straight away. We have had many breakthroughs where a child who was initially scared of the therapy dogs now can’t wait for their visit. At each session we see a new reaction, movement or milestone met by one of our children/adults.

THANK YOU to all the PAWS volunteers for your time and dedication!

"An awareness was created about his capabilities, despite his disability…” pg.4

We Don’t Cope with CP

Talking Drums
Reunion School learners receive a new Communication Device

The KZN Cerebral Palsy Association handed over the Boardmaker Programme and a Communication Device to the Therapy Department at Reunion School to enable learners to communicate a little easier.

Nokwazi is an intelligent little girl who has difficulty speaking, which she finds extremely frustrating.

With Nomthandazo’s assistance, Nokwazi was selected to try out the communication device at the handover. It didn’t take her long to understand how to use the device and she was absolutely delighted to be “heard”.

The Boardmaker programme enables therapists to compile charts with different symbols, i.e. feelings, needs, individual requirements, etc. When the child pushes the symbol on the device, it verbalises the pre-recorded word.

A fabulous feature about this communication device is that it can be programmed in any language. In the case of Nokwazi and her friends at Reunion School, it will be recorded in their mother tongue of Zulu.

Thank you Cray Valley Resins South Africa (Pty) Ltd!

GOLFERS AT IT AGAIN FOR KZN CEREBRAL PALSY

Our Association has been the proud recipients of the proceeds from The Riverside Golfers and Shafters Golf Club golf days.

We ONCE AGAIN thank you for your hard work and considerate giving. As a result of your support we were able to have CCTV cameras installed throughout our building, for security purposes, and awnings were erected outside both our day care centres.

WINNERS OF SHAFTERS GOLF DAY.
Left to right: Grant Wittstock; Graham Berry; Gareth Hall and Mark Lardent

Also at the function was the Shafters Committee. Left to right: Dave Eichstadt; Graham Agar; Tony Schillaci; Andy Roberts and Sean Drummond-Hay

Our CENTRES family has grown

Since the beginning of the year, we have welcomed three new members.

Tshepo Moshoeshoe (18 years old) is from Pinetown and is cerebral palsied. He cannot talk and has a hearing impairment. Tshepo is able to walk although he has low tone on the right side of his body, meaning that his muscles are weaker on that side. He is very shy and often covers his face when somebody tries to communicate with him. He knows a few signs and despite his hearing impairment, he is the best dancer in the entire Association.

Emihle Zenze (3 years old) is from Mariannhill. Emihle had complications at birth resulting in insufficient oxygen reaching her brain for an extended period. Her cerebral palsy is categorised as spastic quadriplegia, meaning that she has muscle stiffness in her arms and legs which limits her movements and she also experiences stunted growth.

Akshay Seerpath (14 years old) is from Isipingo and is cerebral palsied. His disability is categorised as diplegia, meaning that he has muscle stiffness in his legs that affects his range of movement, however, he is able to move around by walking on his knees. Akshay also has no speech. Prior to attending the Centres, he was being cared for by his mother at home, but the older he got the more difficult it became for her and Akshay is now thriving on the social interaction he has with the other members at our Centres.

Thank you Cray Valley Resins South Africa (Pty) Ltd!
When Julia was seven, I returned from an overseas business trip on which I had seen the musical, *Les Miserables*. I loved it and shared the story and music with the children. Julia was particularly taken with it; she played the music over and over and watched every *Les Mis* movie that came on TV (there’ve been quite a few). In a moment of madness I promised to take her to see it in London when she turned eighteen. *I like to keep my promises* but as the time drew near, we realised that she turned eighteen in her matric year. (Apart from that, there is no way I could have afforded it right then). Luckily, Julia let me off the hook and suggested we move the date out to after the other children had finished varsity. **2010 was the year.**

Another fortunate aspect was that a London friend of mine offered to put us up. This meant we could go for slightly longer. ‘Us’ included Julia’s boyfriend of five years, Tiaan. I took him along for selfish reasons such as my arthritis and Julia being a little heavier than when she was a teenager; I knew I would not manage her on my own from a physical point of view. Apart from that, it was wonderful for them to be able to share the experience.

We can hardly believe it was over a year ago. It was a marvelous trip and Julia loved London so much she wanted to stay there. In general, people are very well-educated regarding how to communicate with people with disabilities. In South Africa, most people assume she does not have a mind of her own and direct all questions to whoever is pushing her wheelchair.

In England, she was treated as an individual and spoken to directly. The other great thing is accessibility. She realised that if she lived there she could be far more independent. With an electric wheelchair she could get around as the tubes and buses are mainly very wheelchair friendly. Of course, it really helped that the weather was lovely while we were there.

My friend, Tamsyn was concerned that after a 16 year build-up, *Les Mis* may not live up to expectations. It did. We both loved it and Julia still knows all the words to the song. It was all I could do to persuade her to allow the cast to manage on their own. Another outing that meant to her was her visit to Wimbledon. She is a tennis fanatic so visiting the holy ground of tennis was another dream come true. She was able to sit in the very spot Rafael Nadal sits in when being interviewed.

Another highlight for me was spending my birthday with Julia at the Docklands Museum. We both love museums and spent hours finding out more about the history of Docklands London, followed by a pub lunch. The trip was a great success and went off without any hitches. The only drawback is that the airline puts the people with disabilities in the same section as the people with babies because of access to larger toilets. This made the flights rather horrendous as we were surrounded by screaming babies. Nevertheless we soon caught up on our sleep and have many great memories in the bank.
August was Cerebral Palsy Awareness month and members from CREST and CWAC participated in various activities to create awareness of Cerebral Palsy.

Cameron, Nivesh and Sli were thrilled to be invited to The Browns’ School Cerebral Palsy Day hosted by the Physiotherapy and Occupational Therapy Departments. They joined in all activities with other cerebral palsied learners from The Browns’ School as The Jungle Book came alive in the Physiotherapy Department and Hansel and Gretel in the Occupational Therapy Department.

Thank you to these dedicated therapists for all their hard work in creating a wonderful morning for the cerebral palsied children.
We Don’t “COPE” with CP

As a young man on the cusp of my 21st birthday, I recently started to think about how those without disabilities perceive people with cerebral palsy. Having spent all of my formative years in LSEN schools, I must admit that my upbringing was rather sheltered.

Being educated in environments where the educators understand your needs and none of the other kids shun you based on how you look is great. As a child, it’s very comforting when you don’t have to worry about feeling different to anyone else and you can just focus on normal things like homework and bullies.

Finally, the end of matric rolled around and being the bright-eyed and naïve kid that I was, I felt full of hope for a bright future. Then reality struck. Don’t worry; this isn’t a story about how hard it is for a CP-sufferer to live in the world, though I think there are a few things that make it unnecessarily difficult. From people taking our parking spots because “I’ll only need ten minutes”, to perfectly able women using our toilets just for the sake of privacy. I could go on and on.

However, all those things could be attributed to ignorance or selfishness, neither of which deserve much energy. So I began to ponder the flipside of the coin. All of us know the scenario, you pull into a shopping centre and after getting out of your car and heading towards the building, some well-meaning stranger stops you to express their admiration for how bravely you appear to cope with your disability.

Now I can’t speak for anyone else, but every time someone says that to me, I feel instantly awkward. This is not the kind of thing you can lose your temper over (at least not justifiably). Generally, when people gush in this manner, they don’t mean any offence and even though it’s mildly infuriating after about the hundredth time, blowing your top will only leave them feeling even more inadequate and guilty for being “normal”.

What’s more, strangers aren’t the only ones who fall into this trap. Even friends, some of whom I’ve known for years, will succumb to feelings of self-punishing guilt for not having to overcome the obstacles that I face. Initially, it took some time for me to figure out how to put people at ease on this subject. Luckily, one of the benefits of CP is that it forces us to mature more quickly than the average thoughtless teen.

Consequently, when others my age are complaining because the break between college semesters isn’t long enough, or they’re unhappy to be saddled with dad’s old car instead of a shiny little number directly out of the showroom, I can focus on things that really matter.

So, whenever someone begins to express awe or undue respect for the way I live my life, I like to ask the question, “What else should I have done?” More often than not, I’m answered with their strong conviction that they could never live with something like this. At which point I remind them that NO-ONE CHOOSES THEIR HAND IN THE GAME OF LIFE, BUT IT’S UP TO US TO PLAY THE CARDS TO THE BEST OF OUR ABILITY.

Launched as an extension of MySchool, the MyVillage programme focuses on community upliftment. The supporter card gives you the opportunity to support our Association in a transparent and convenient manner without costing you a cent! When you purchase items from participating retailers, your card is swiped and a small percentage of your transaction is then allocated to our Association. The supporter card is not a credit or debit card but simply tracks your transactions and your funds raised.

In order to become a supporter, please register with MyVillage and nominate our Association, Cerebral Palsy Association – KZN as your beneficiary. You can register online at www.myschool.co.za; or apply at your local Woolworths store and if you have a Woolworths card, kindly request them to link it to our Association; or contact 0860 100 445.

Introducing Lachlan…

Lachlan Nicholson was born in Johannesburg on 22 August 1990. He was three weeks premature which resulted in the occurrence of spastic cerebral palsy, rendering him quadriplegic. As an infant, he attended Sunshine Centre and was the first CP child they cared for.

He then moved to Forest Town Preschool shortly before his family relocated to KZN. He spent grade 0 to 7 at the Browns’ School in Pinetown and matriculated at Open Air School in Durban. After matric, he studied for a National Certificate in Journalism at Boston City Campus and Business College and graduated in 2010.

Lachlan is now employed by the Hillcrest Fever, which is a local community paper owned by Media24. His dream is to make a living in creative writing and his hobbies are writing, going to the movies, theatre and video games. He also enjoys working out and often does weight training.

He who wishes to secure the good of others, has already secured his own.

- Confucius -
TALKING DRUMS

Playing a Djembe is a “Speechless Communication” that speaks all languages and bridges all ages and abilities!

Music has proven time and again that it is the key to most therapies and that is exactly what happened when Michael and Tracey of Talking Drums came to visit CREST and CWAC.

The majority of our members at CREST and CWAC are wheelchair bound and rely on a care-worker to take care of their every day needs. We used special straps to tie the Djembe to each persons chair in order to keep it secure while they played. As soon as it was secure they started to beat on the Djembe. It was heart warming to see some of our children/adults who have limited control over the muscles in their arms beat on the Djembe’s with the biggest SMILES that you could find.

With the assistance of the care-workers, all our members were soon beating on the Djembe’s and it was like a magical symphony, as joy and happiness filled the room.

Some of our cerebral palsied children are cortically blind and hearing impaired but this made no difference as they were still able to enjoy the drums with the vibrations they made.

MUSIC IS WHAT LIFE SOUNDS LIKE -Eric Olson-

Obituary: The Association was devastated to learn of the passing of little Zama Sibiya (9 years old) after a long illness.

Zama started at CWAC just before his 2nd birthday and was with us for over 5 years. Unfortunately, due to his ill health, Zama was unable to attend CWAC anymore and was in and out of hospital for over 2 years before he lost his battle.

In a very rare case, Zama’s older brother, Kwanele, is also cerebral palsied and continues to attend our Day-care Centre on a daily basis.

Rest in Peace Zama!

Nivesh Gets New Wheels:

Nivesh Balraj (10 years old), a member of CWAC, recently received a brand new wheelchair as part of the 2011 Game and Vodacom Wheelchair Initiative. Thank you Game and Vodacom for your continued support with wheelchairs for our members!

Isabella’s New Challenge: Isabella James (4 years old) is categorised as a hemiplegic; meaning that she has muscle stiffness that affects her range of movement in her joints.

Isabella started at CWAC when she was just 18 months old and wasn’t able to even roll over. Through stimulation and therapy received at CWAC by her care-workers, she went from strength to strength and within a year of being with us Isabella was able to roll and started pulling herself along the floor to move around independently. Soon her vocabulary started to increase and we at the Centres saw the potential for Isabella to move on to one of our other projects, The Browns’ School. Isabella has been provisionally accepted at The Browns’ School for Grade 000.

Despite her disability, Isabella is a happy and determined young girl. We wish her all the best with her new challenge.

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To give without any reward, or any notice, has a special quality of its own.
- Anne Morrow Lindbergh -
Thabile Hloaise was born on 24 June 2007 with severe birth asphyxia and transient seizures. When her mother discovered that her precious baby whom she had waited a long time for, had a problem, she decided to stay with her in Durban, although home is in the Transkei.

She then looked around to try and find the help she needed. I first met Thabile when she was 8 months old and we diagnosed her with CP. We started her on treatment and assisted her mother with applying for a grant.

Thabile has been one of my most regular attendees and her mom’s commitment has been remarkable. Thabile was a hyper-sensitive little baby, who screamed incessantly with anything unfamiliar, so I was unable to handle her until she was around 19 months old. All treatment sessions were by remote control as I worked on a doll or another baby and mum guided Thabile along, following what I was doing. I even tried working from behind her, but that only worked ONCE because she was quickly aware that mom was in front of her and could therefore not possibly be doing the therapy! Unpleasant as it was for all of us, her mum persevered month after month, always smiling, and always encouraging Thabile.

At 2 years old this little girl’s enquiring mind got the better of her and she decided that therapy WAS THE WAY TO GO and began co-operating. She began walking all over and dragging mum by the hand as she spent ages exploring the department and making friends with the other little girls.

Thabile’s mum, who is not working, puts all her time and effort into her daughter and although living in difficult circumstances, she is one of the most diligent parents I have the privilege of working with, in terms of supporting her special little girl.

At the end of last year, to our delight, Thabile was accepted for observation at Browns’ School. Although she took a long time to settle and had her observation period extended, she was accepted at Browns’ School this year and absolutely loves it. She is a little girl who delights everyone.

Thabile comes from a home where they don’t have electricity or running water. There is nowhere for her to run around and play. She has only been able to afford her therapy monthly, yet her mum has sacrificed much to give her all the opportunities that she needs to reach her maximum potential. For the first month her mother waited around at school to take her home as she couldn’t afford to come and go twice and didn’t have a taxi driver she could trust.

Now Thabile is a seasoned traveller and is totally at home in the school and therapy environment. It is truly one of many amazing stories of families who overcome all sorts of odds because they WANT THE BEST FOR THEIR CHILDREN.

Condolences

The Association sadly mourns the loss of two of our volunteers/donors/friends:

Gamby McDonald and Terri van Wijk

“Although it’s difficult today to see beyond the sorrow,
May looking back in memory help comfort you tomorrow.” - Author Unknown -

Our deepest sympathy goes out to the family and friends of these special and much loved individuals.
Parenting a child with disabilities is a daunting challenge, but there are steps that can help you cope. Hearing for the first time that "your child has a disability is like a klap in the face," says Adi de Hoop, 49, founder of the SpiritedKidz LearnsPace school and family education centre in Rivonia. She suspected a problem when she started contradictions at 24 weeks. "I'm well informed, so when Nimoe was born two days later, and the paediatrician said an echography of her brain showed all was fine, I wasn’t convinced. The fantastic healing mechanism of the brain means it takes two or three months to show damage, and I insisted on other checks while she was still in hospital. (Tip to other parents: It’s hugely expensive to have these as an outpatient later). Nimoe has cerebral palsy with complications. "Nothing prepares you for hearing it, absolutely nothing, even if you’ve intellectually grasped it," she says flatly. "On a deep emotional level, your very identity is under attack."

"It’s all so alienating, so terrifying," says Durban photographer Angela Buckland, 48, whose son Nikki was diagnosed as "low-functioning" at three months. "One of the hardest parts is accepting there can be no proper recovery – it’s learning to let go, and just do your best."

"I wept when the specialist said Tariq had autism," murmurs Liza Aziz, 41, Durban filmmaker and founder of Able-Bodied: Scenes from a Curious Life (Zebra Press) and co-author with researchers Kathleen McDougall and Amelia van der Merwe of a photographic book on disabled children by Angela Buckland, Zip Zip My Brain Harts (HSRC). "With other big life challenges, there’s often a beginning and an end to the difficulties, so it’s possible to imagine future closure and acceptance," he says. "But with a child with a disability, parents have a long journey ahead of them with no end in sight – it’s a life-long journey, and brings a change to every aspect of family life. At each stage of the child’s development, parents may experience a new sense of loss as they think about what they would have been experiencing had their child not been disabled. But they may also become more conscious of positive aspects." It can be hard to get a balance, and parents are often encouraged to focus only on the “specialness” of the child instead of expressing difficult emotions like anger, frustration and disappointment. But bottling emotions is unhealthy – they need to be released. "Most mothers cope much as I did," says Liza. "We cry, we shout, we fight and we busy ourselves in action!"

**LET YOURSELF GRIEVE:** When you discover your child has a disability, you go through the same stages as with a death, says Jenny - DENIAL, ANGER, BLAME, GUILT, QUESTIONING WHY YOU, and FEAR you won’t cope. “You’ve lost the child you thought you’d have, your dreams for their future and yours, and your way of life." The stages don’t follow the same order for everyone, but it’s vital you let yourself go through them all, says Adi. “Because I’d anticipated what was coming, I didn’t go through denial. I just said ‘Okay, this is what it is, so what can I do to make things better?’ And I didn’t grieve properly – there wasn’t time, with a screaming, very demanding child and work to take care of. Eight years on, I’m still often an emotional wreck.”

Relatives and people in society often don’t know what to do or say when a family has a disabled child, and the embarrassment they feel often blocks them from offering helpful support to the family, says Stellenbosch psychology professor Leslie Swartz, author of Able-Bodied: Scenes from a Curious Life (Zebra Press) and co-author with researchers Kathleen McDougall and Amelia van der Merwe of a photographic book on disabled children by Angela Buckland, Zip Zip My Brain Harts (HSRC). "With other big life challenges, there’s often a beginning and an end to the difficulties, so it’s possible to imagine future closure and acceptance,” he says. "But with a child with a disability, parents have a long journey ahead of them with no end in sight – it’s a life-long journey, and brings a change to every aspect of family life. At each stage of the child’s development, parents may experience a new sense of loss as they think about what they would have been experiencing had their child not been disabled. But they may also become more conscious of positive aspects.” It can be hard to get a balance, and parents are often encouraged to focus only on the “specialness” of the child instead of expressing difficult emotions like anger, frustration and disappointment. But bottling emotions is unhealthy – they need to be released. “Most mothers cope much as I did,” says Liza. “We cry, we shout, we fight and we busy ourselves in action!"

**FIND SUPPORT:** Getting support from parents on the same journey can be a lifeline not only for coping emotionally, but for negotiating what Adi calls “the minefield” of professional and alternative health practitioners you encounter along the way. “Some are very good, but some are not, and you’re so desperate you’ll try anything,” she says. “Other parents can be invaluable, tipping you off about who is who, and offering practical advice and support." The best way to find parents in your area is to ask a medical professional. “Some say they can’t share patients’ contact details for professional reasons, but if you hear that, leave!” says Adi. “Decent doctors will gladly put you in touch." You can also contact organisations specialising in your child’s condition.

**START INTERVENTION EARLY:** Get professional help the instant you think there may be a problem with your child, says Jenny. Take them to be assessed at your clinic, local hospital or a children’s assessment centre, and always get a second opinion. Once you settle on a professional you are comfortable with, do whatever therapy they advise. “It may not cure your child, but it will help them be the best they can be,” she says. Quality of life is not about abilities, but feeling safe, comfortable, well and loveable; being engaged in meaningful activities; learning as much as possible; and having achievements to be proud of, however small - even just being able to tie shoelaces. “Keep reminding yourself of this," Jenny urges.

**HELP THEM BE THEIR BEST:** In an age when medical science seems to have answers for so much, it can be hard to accept that there is no cure for your child’s condition. It’s one thing to explore realistic options, but you can unnecessarily prolong your grief and pain – and strain your finances – by following false hopes, say she and Adi. These hopes don’t always spring from unscrupulous professionals being out to make money. Professor Swartz and his co-researchers report that doctors too can struggle to accept that there is no cure. Some then “heroically try to do more and more investigations to find a cause or cure when they suspect – or even know – this quest is hopeless”. Others try to protect themselves from a sense of helplessness and despair by trying to cut off emotionally. “What we need to learn from are those encounters where both the parents and the doctor get it right,” they conclude. “Where it’s not about fixing problems, but about working together in a constructive, respectful and helpful way.”

“There comes a point where you must stop looking for an answer and just get on with it,” says Angie. Although each child is different, most respond best to intensive tutoring and stimulation. Depending on the extent of the disability, your child may be able to fit into a mainstream school or have to attend a school for children with special needs. You can also learn to stimulate your child yourself in different areas of development – physical, sensory and intellectual, says Tammy Greyling, an occupational therapist at Pathways Pretoria. “Show them how to do as much as they can, from dressing to using the toilet – keep showing them over and over if need be.” Break down tasks and ideas, and use short sentences, simple words, gestures and pictures. Don’t expect too much or too little, and give your child the chance to do things themselves before stepping in, she adds. “Don’t criticise mistakes, encourage them to try again. And be sure to give them the chance to help you, even just sorting socks – everyone likes feeling useful and appreciated.”

This article appeared in the October 2010 issue of child magazine. For this and related material see www.childmag.co.za.