ourcommunity.com.au

CENTACARE
Catholic Family Services

Westpac Australian Community Idol 2009

Communities in Control Conference
Melbourne, 15 June, 2009

VICTORIA GARNER

President, Cerebral Palsy Support Network

Laura Cvetkovski

Media Relations Manager, Cerebral Palsy Support Network

Victoria Garner:

I'd like to thank the selection committee for giving the Cerebral Palsy Support Network this opportunity to highlight our achievements.

In the beginning my daughter Arianne was diagnosed with cerebral palsy in 1993. Cerebral palsy is primarily a physical disability. I had very confused feelings and felt quite lost. 1993 was before we all had home computers so the automatic response of, "I'll just go and look that up on the internet," was not an option.

I wanted to meet other parents for mutual support and information sharing but there was not a specific group. With the assistance of the Regional Parents Support Coordinator a support group was organised. The first meeting was at my home and was a great success. I, like so many parents, had so many questions and few answers.

No two people with cerebral palsy are affected in exactly the same ways. It can be difficult and challenging to understand and cope with the way your child's symptoms unfold in front of your eyes.

In 1995 the CPS then became incorporated. A community grant covered the cost of venue hire and a carer to entertain children while parents chatted. So we finally got out of my lounge room.

Members lobbied anyone who would listen to the need for our organisation. As you can see Steve Bracks was on the list. No more dining table meetings. We moved our operations to an office in Carlton in 1997. The rent was $25 a week. Can you believe that? It was a very small office.

Christine Campbell, the Minister for Human Services at the time, was invited to officiate. Now we were able to establish the all-important White and Yellow Pages telephone listing and a member volunteered to develop our first website. It was exciting.

We survived on disability self-help funding, community grants and fundraising. We did trivia nights, dinner dances, raffles, you name it, we did it. But the lack of recurrent funding was starting to become a real and very frustrating issue for the continuity of service delivery to our growing membership.

Member events were popular and well attended. We have come so far since those early days. We now have 385 members, 297 of whom have cerebral palsy and range in ages from under twelve months to over fifty years. We don't go any more than fifty recording wise.

Support groups meet regularly in local cafes every week across the metropolitan area. We deliver a fabulous bi-monthly newsletter which is sent electronically or in the post for people who haven't quite caught up with the internet.

We have also developed a unique cerebral palsy brokerage program where we broker respite funds for our members so they can have flexibility and choice with their respite worker.

Access All Areas teenage social group is a new group which was established by two of our teenage members. They identified that teenagers who have the ability to be independent in the community as adults needed some supported training, as well as the opportunity to meet other teens with cerebral palsy. The Triple A members are supported by a staff member and peer group volunteers. There's a no nanas policy.

Melbourne's longest cake is our annual event, hosted by Crown Limited, and part of the Melbourne Food and Wine Festival program. An event to raise awareness and funds was in the pipeline for four years before it evolved into Melbourne's Longest Cake. Christian Astourian, the President of the CPSN from 2001 to 2006, wanted to organise an event that would raise awareness of cerebral palsy in a big, big way, no less than a Guinness Book of Records world's longest cake challenge. The cake would have to be over 1.6 kilometres long.

Christian organised a meeting with senior management at Crown. A counter proposal was put on the table to scale down the event and Crown would host it. So instead of one big bang, an annual event was offered that could grow over time.

The rest as they say is history. Companies are invited to sponsor cake by the metre. Slices of cake plus a hot or cold drink, boxes of cake to eat later and our fabulous merchandise are sold at the event.

I would now like to hand over to Laura. Laura was luckily looking for an internship back in 2006 and we snapped her up and we haven't left her out of our sight since.

Laura Cvetkovski:

Thank you Victoria. Melbourne’s Longest Cake has been a massive learning experience for everybody involved both personally and as an organisation. To be totally honest, none of us had done anything like this before.

In 2007 we had a very grass roots event. With no precedent, the hardest part was describing it to people when we didn’t even have a tangible grasp of it ourselves. So we relied heavily on the limited network of people that supported our organisation at the same time as being very conscious of burning out our friends.

Shaun Micallef hosted the event with a performance by Glenroy Special School. We had Dipper, Billy Brownless and Anthony Koutoufides there to help us cut the cake.

For a first event we considered it extremely successful. We raised $58,000 from sponsorship and cake sales on the day.

With the steep learning curve under our belt we went into 2008 with hope and excitement. Now we had an idea of how the event ran it was easier for us to go to people that we didn’t know and ask them to be involved. No longer were we met with, “What big cake?” people were now intrigued and interested.

We took a huge step forward with the entertainment involved and we found that by asking instead of apologising for the interruption that Ricki-Lee, Matthew Richardson, Rob Mills, the

Choir of Hard Knocks, Rhonda Birchmore, Peter Combe and Sue Stanley came on board with the event.

The weather was spectacular and all involved had a great time. We upped the ante from the previous year by streamlining the process. Our volunteers and merchandise added a new flavour to the event that we didn’t have in the previous year.

So this year has been the most promising year for Melbourne’s Longest Cake. By sheer chance of rain, our six months of planning was rearranged in twenty minutes at 6.00 am on the day of the event. It was moved into the Palladium Ballroom because that was the largest, driest area in the Crown complex and it definitely added a touch of glamour to the event. We had Carl Riseley there to perform and Brodie Harper, Heath Meldrum and some AFL football players also came along to help us out. The room was abuzz with people enjoying cake.

And while it’s all well and good to have an event that’s grown so much in three years and becoming marketable and attracting recognisable names, ultimately the core message is that it is about people with cerebral palsy and we actively encourage our members to come along to the event so that other attendees can see the varying degrees of how the disability affects people.

We rely heavily on our volunteers to assist with running our events. In 2007 our volunteers were a team of twenty people who all had ties to the organisation. One of our key avenues of recruitment is GoVolunteer, from which we routinely receive over 150 responses.

We love the fact that so many of our volunteers come from all walks of life, whether they're younger, older, students, parents, they might have CP, they might not, people that have lived here their whole lives. We get a lot of people who have just come from overseas. They all share the same factor. They're keen to get out into the community to meet people and to have a go.

The other large component of the event is apprentice chefs and cookery students. We have 50 to 100 pairs of hands donated by these guys from across Victoria from different TAFEs. They're vital to the assembly and decoration of the cake.

One other key aspect of the event that we're very proud of is that all cake that's left over at the end of the event gets donated to Second Bite Food Bank. Second Bite then distributes this to disadvantaged people across Melbourne.

We were pretty chuffed last year when we did invite the Choir of Hard Knocks to come and perform that a few of them had stories of them receiving the cake in 2007 that we had left over. I'll pass you back to Victoria.

Victoria Garner:

So what do we do with this money? Well we had a long, hard think about that and how best to make it work for our members. So we set up the Cerebral Palsy Support Network Members Trust Fund. The funds are deposited into that fund and all the interest generated every year is distributed back to the membership. It's a $500 per person maximum at this stage and we anticipate that as the fund grows we might be able to make larger disbursements.

There has been one funding round so far and here is a very small member with his second skin to help the functionality of his right arm. Members are encouraged to apply for something that is not funded anywhere else and that would enhance their quality of life.

Laura Cvetkovski:

The other key event that we have during the year is Cerebral Palsy Awareness Week which happens in the first week of August every year. The mascot is Buzz the Bumblebee who helps us to take the sting out of cerebral palsy. We’ve selected him to be the mascot for a very particular reason and that is that aerodynamically he should not be able to fly because his wings are too small for his big fuzzy body.

So like Buzz, the aim of our organisation is to help people with cerebral palsy to fly, to achieve things that might seemingly be impossible. Over the years we’ve tried different events and activities, from having signage on trams to art exhibitions. In 2007 with our newly created Buzz merchandise we saturated the city with volunteers and staged the Bumblebee Cup with professional wrestlers. Many people stopped to watch the show but we feel that our messages got lost. Considering the effort we put into staging this event, we don’t think it was a successful exercise.