

Chairperson's CORNER

ONCE AGAIN PARENT AND FAMILY RESOURCE CENTRE CLOSED THE YEAR WITH OUR NOW FAMOUS ROCKET DAY IN MT ALBERT.

It is refreshing to see how families from across the Auckland region come together, mingle and have loads of fun. It always makes me reflect on how we need to celebrate who we are proudly and with style and flair. Again the Prime Minister joined the festivities and it was great to see everyone greeting her like one of the family!

At this time of the year the PFRC Board is planning our long term goals for 2007 and as always we are on the look out for people who may like to join the Board and help us with the direction of the organisation. We need people who are passionate about disability issues and can devote a few hours monthly to help us make a real difference in the lives of disabled people and their families.

Whilst we all gear up for the Christmas period please spare a thought for the parents and young adults using the Eastgate Respite Services in Pakuranga who are challenging

the Ministry of Health's decision not to fund a top-up amount to keep the facility open. This is a hard time for those parents and families who have poured a huge number of hours into creating a warm caring environment for young adults to get some time out in an age appropriate fashion.

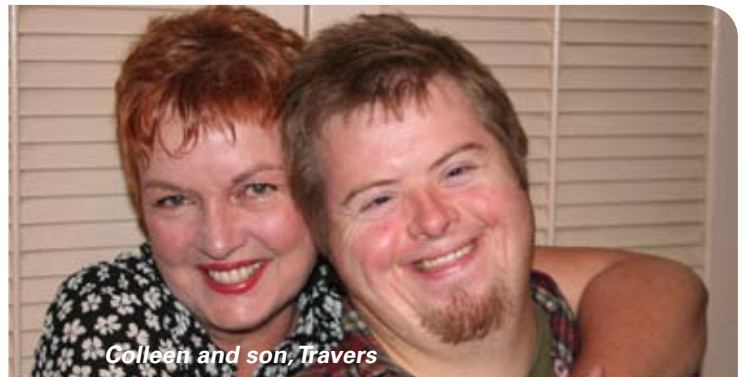
It strikes home yet again the constant need to be vigilant and aware of the many issues confronting us all in the disability community.

Next year the Board will endeavour to address many of the challenges you face in meaningful and practical ways. We are always keen to learn about the successes and issues affecting you, so please contact us and let us know.

All the Board wish you the very best for a happy, safe and fun family time at Christmas and all the best for 2007.

Colleen Brown
Chairperson
Parent & Family
Resource Centre

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www.parentandfamily.org.nz



Colleen and son, Travers

As the year quickly comes to an end I really do wonder where the time has gone. It has certainly been a busy time at PFRC in 2006. We have seen the completion of a number of projects and successful seminars and events for families. We plan to build on this success and increased awareness of PFRC so look out for further growth and new developments in 2007. We have seen the departure of one staff member (Denise Gledhill) and welcomed another.

Over the Christmas period my whole family, all nine siblings, spouses and our respective children, are gathering in Auckland from various parts of the world, for a family wedding in early January. It

has been almost 25 years since we have all been in the same country together as there is usually one missing. So for me it's going to be a big noisy Christmas although we will escape to the beach to get some peace and quiet as well. Whatever your own family make-up is, I hope that you too get to enjoy each other's company.

On behalf of the PFRC Team Karen Nicol (Community Advisor) Shannon Thompson (Receptionist), Sue Robertson (Project Advisor) and Robyn Millet (Accounting), I extend our warmest wishes for a restful Christmas and good health for 2007.

Bridget Snedden
Centre Manager



Shannon

Karen

Bridget

“Sport is my passion”

By Tammy Ewing

AS A FOLLOW-UP TO THE LAST ISSUE OF THE NETWORKER, WE FOCUS ON STEPHANIE'S EXPERIENCE AS SHE PREPARES TO MOVE ON FROM SCHOOL INTO TERTIARY EDUCATION.

In the last issue of the Networker I caught up with Stephanie Hartley (18), the adventurous swimmer aiming to take on the Cook Strait. First up though, is beginning her Diploma in Applied Sport and Recreation at the Manukau Institute of Technology (MIT).

“I’ve wanted to do this course since I started high school,” says Stephanie. “Sport is my passion,” she reiterates with a smile, knowing that I am very much aware of this by now. In the last Networker Stephanie talked of her experiences as a swimmer with spina bifida, and the pleasure she takes from being wheelchair-free: “The most exciting part of my day is being in the water”

On the Diploma course Stephanie will study subjects such as anatomy, and coaching. An anticipated highlight for Stephanie will be the end-of-year camp, which she will attend the first year and help to organize and run the second year.

Getting about

One of Stephanie’s early hurdles for tertiary education will be transport to MIT. Until she gains her restricted license her mum will probably be the driver for the first few months, although the family may apply for funding for a taxi. Once the license comes through Stephanie will use a modified car, in which braking and acceleration is all done at hand level.

Sorting out peripheral transport and access issues are critical to ensuring Stephanie can completely focus on her course. When Michelle McCormack, Programme Head for Stephanie’s course, showed her around, car-parking was part

of the tour. “It’s about making sure she has access to everything in order to be successful,” says Michelle.

Similarly Michelle took Stephanie to check out doorway widths and the weight of doors needing to be pushed open. “We provide the opportunities and make the environment work,” says Michelle enthusiastically. As interaction with schools forms a large part of the course assessment, Michelle has also taken steps to ensure that all of the schools involved have a disability-friendly physical and attitudinal environment.

Realising success is your own responsibility

Michelle’s positive and self-reliant outlook echoes the philosophy of MIT’s Disability Support Services of: “Realise your success is your own responsibility.” “Disability is only a limitation if you let it be,” says Michelle.

Stephanie’s family is the foundation of her support and encouragement. However prior to beginning the process to apply for tertiary study, Stephanie admits she was a little worried about what outside support she would receive. Happily she reports that she has had wonderful on-going, helpful and sincere support, particularly from MIT staff and Workforce Personnel, a supported employment agency funded by the Ministry of Social Development.

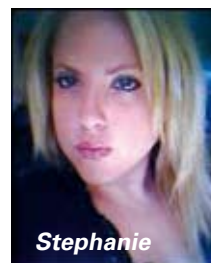
Vision planning process

Heather Taylor, Transition Consultant for Workforce, visited Stephanie regularly throughout her last year at school. Together they brainstormed and completed a “vision planning process” which extended three years into the future. Stephanie’s skills meant that she had quite a few options, says Heather, “but she wanted to follow where her heart was”

“It was great to have it on paper,” says Stephanie. “I could see it and follow it.”

Heather even helped Stephanie with her application for MIT and came with her for her interview. The plan is to do regular follow-ups for the next six months and they will likely meet again when Stephanie begins her job search.

Throwing yourself into an entirely new social situation will be daunting for most people. Stephanie, although friendly and outgoing, admits she is pleased she will know a couple of people on the course. She is also hoping there will be early team-building exercises to ‘break the ice’ and bond the group together.



“No one can steal my spotlight.”

Stephanie may well be the only person on her course with a disability. “No one can steal my spotlight,” she laughs, quickly adding that she doesn’t really care.

However it’s evident her comment does carry some truth - for Stephanie ‘standing out’ can definitely be a positive thing!

Sharing her life experience with others

After she has gained her Diploma Stephanie is considering applying to AUT for further study. She is aiming to be a coach and “would like to teach both able-bodied and disabled but will probably lean towards those with a disability”. Stephanie is aware that if she didn’t have a disability “I don’t think I’d look at things the same way” and is keen to make her life experience a valuable part of her career.

Eager to advocate for disability generally, rather than focusing on spina bifida, Stephanie would one day like to own a gym designed for people with disabilities. For now, even as she feels the pangs of saying good-bye to high school forever, Stephanie knows that a supported, goal-oriented and adventurous future awaits her.



Christmas STORIES

A time for family, friends & relatives

Christmas for me is a time for celebrating family & friends. One of my favourite memories of Christmas is the family get togethers at my maternal grandparents. All the 'rellies' used to get together on Christmas Day night.

There would be my grandparents, immediate family, aunts, uncles and cousins, 22 – 25 of us all up. There were presents under the tree for everyone. Each year one of the older grandchildren would be 'Santa' and read out the names on the presents while one or two of the younger ones were 'Santa's elves' and handed out the presents. With 10 or 12 grandchildren there was always plenty of willing helpers.

All the excitement of being together and enjoying each other's company made this family time really special. Now all the cousins have grown up, have families of their own and doing their own thing creating their own special family memories.



Katie's Story

Katie was 19 last Christmas and despite little spoken language, she had no difficulties letting us know the contents of her Christmas "wish list."

By early December we had received many written lists, re-writes of lists and re-writes of the re-writes.

Any communication is worth celebrating and loving shopping as I do, I enjoyed matching the demand to the resource!

However "live and learn" as they say: Christmas morning was over by 5.30 am. Any present that had "Katie" written on the Christmas label was opened... including those that read "Love from Katie xxx!"

This year we're designing a code for any presents Katie is giving to us.



"I think I've grown up!"

My 18-year-old son, who has an intellectual disability, has always worn the Santa suit on Christmas morning and with a helper, usually a cousin, they handed out the presents to all those assembled.

A couple of weeks ago he wondered out loud if his cousin was going to be busy on Christmas Day. When asked why did he want to know he said that he had now grown up and couldn't be Santa anymore and it was time to let his younger cousin take up the role.

For me it was just another little reminder that he really is ready to move into being a young adult, which is very exciting.



ROCKET DAY



ROCKET DAY WAS FOUNDED IN 1997 by the Kingsley-Smith family in celebration of the life of their son Yuri. It has become an annual event and is hosted by Parent & Family Resource Centre at Rocket Park in Mt Albert. It continues to be a day of celebration and community awareness of families of disabled children and young people.

This year's event on Sunday November 26 was the tenth Rocket Day. The day was attended by upwards of 200 people who enjoyed a variety of entertainment and activities. This included a Bouncy Castle, Katrina the Fairy, clowns – Jiggles, JayneO and Sam, and Oogah Hot Rod Club and their wonderful cars. Old MacDonald's

Travelling Farmyard, a regular favourite, provided a hands-on opportunity to pet and feed farm animals. Sports activities and games were organised by Halberg Trust Sports Opportunity Advisor Stacey Roche. Santa even managed to find time in his busy schedule to make a brief appearance.

Once again this year we were privileged to have a guest appearance from the Prime Minister, the Honourable Helen Clark.

Our thanks go to all involved, especially the 40 volunteers from Marist College and Mt Albert Grammar, who helped make the day successful.

Upcoming Events

FAMILY GOVERNANCE & SELF DIRECTED SERVICES SYMPOSIUM

A symposium to build greater understanding of the concepts, implementation & achievements of family governed & self directed services in New Zealand.

This symposium will draw upon the experience of families, disabled people & provider agencies who have personally engaged in bringing about a changed way of thinking around 'being of service and being in receipt of service.'

We will draw from what is happening now in New Zealand for people & agencies seeking an alternative approach to traditional service delivery, supported by the learning gained over a longer period of time by families & service agencies in Australia.

Hosted by Standards Plus and Sponsored by families commission Komihana a whanau

When: 26th & 27th March 2007

Venue: Waikato Stadium, 128 Seddon St. Hamilton

For registration details contact: Standards Plus, Phone 09 262 5374, Fax: 09 262 5371 or standardsplus@imaginebetter.co.nz, www.imaginebetter.co.nz

NB: Early Registration closes on 9th February 2007.

NEXT ISSUE: Family Governance

'DROP INN'

Wednesday 10 January 2:30- 4pm

Wednesday 17 January 2:30-4pm



An invitation is extended to families to "Drop Inn" for tea / coffee and a chat with PFRC staff. Children are most welcome. (Your responsibility will be for their safety and entertainment while they are here). Please give us a call to tell us you're coming and we'll pop on the jug. You'll find company, friendly faces and good listening ears tuned to any issues or concerns you may have. The holiday season has its own unique stressors for parents, particularly if you have family members who have disabilities. We look forward to your company.

SHARE YOUR NEWS

Send us your news and views, conference / meeting dates and reports, successes and suggestions, your child's or your own artwork or poetry. Celebrate your world by sharing it with others in the PFRC Networker. Just contact us at the Centre!

PFRC OFFICE HOURS for Festive and Holiday Season

Closed: From 22 December 2006 – 5 January 2007.

Re-Open: 8 January, 9am – 4pm. The office will be staffed part-time until February 5, when all staff are back from their holidays.

Disclaimer

The views and suggestions in this newsletter are those of individual contributors and are not necessarily supported by Parent and Family Resource Centre Inc. If you find errors in this publication – great, it means you are reading it.