Hi Maggie

There's snow on the hills and the fire's roaring. Still in my PJs but with fleece jacket and gumboots I go out and help load the girls into the car to head for kindy with Dad. Oh - I'll grab the mail. And there it is my second Birthspirit journal.

Huddled against the cold I race back to the fire thinking of my busy day. There's visits and paperwork before kindy pick up and a busy family evening - best not get waylaid. Perhaps I'll just let myself read the contents page and choose one article.

Half the journal later - I've cried, I've smiled, and I've felt a whole range of emotions. Krista's story of Kangaroo Mother Care with her 34 week daughter after 2½ weeks of ruptured membranes brings back the turmoil and challenge of my own so similar journey with our Ruby. Jenny's article reminds me how the simple things are SO important. I want to knit baby hats at births too but I don't want the women to have the 5 day labour I might need to complete it (not because I can't stop "doing" just because I'm a *very* slow knitter). I love the photos of Brendon's smiling face and am grateful for Kim's sharing that make me reflect on how I present screening and realise I share her sense of relief when women don't want screening. And Koro, well I've never met him but somehow I can see his furrowed brow over the curry pot and then his glowing smile behind the phone.

I could happily sit by the fire and devour the rest of it but life beckons and I'll be happy knowing there's more to enjoy later.

Thank you to all who contribute and to you and Tony for bringing it all together.

Aroha
Tracy Botica
Dunedin, New Zealand

Dear Editor

A recent Birthspirit Journal article by midwife Kim Porthouse about Pre-natal screening has received support from Parent to Parent New Zealand.

Parent to Parent is a national organisation which provides support and information to the parents and families of people with disabilities, health impairments or special needs. It is an organisation made up of parents who have sons and daughters with disabilities and who understand the value, joy as well challenges in parenting a child with a disability can bring.

Ms Porthouse's assertion that parents must be given informed, balanced and objective advice about pre-natal screening is firmly endorsed by Parent to Parent.

Expectant mothers generally get very little warning about the decisions they might be required to make following pre-natal screening, particularly in respect of termination. They are often in shock and have little more knowledge than what the media portrays of disability, when asked to make such a life changing decision.

Any informed decision about this should naturally include the perspective of parents who are actually raising a child with a disability.

Parent to Parent has nearly 600 volunteer Support Parents throughout New Zealand who provide one to one telephone support to parents who have just learned that their child has a disability or health impairment. Newly-diagnosed parents are matched with a trained Support Parent whose child has the same or similar condition for mutual support and understanding.

Our Support Parents have the knowledge, experience and expertise to inform families what living with a disabled child is really like. This perspective should be a crucial component of the decision-making process a parent must go through following pre-natal screening. While it is not a Support Parent's role to tell a parent what decision to make, they can provide expert information about the day to day reality of a particular disability so as to give a more balanced picture.

Pre-natal screening is a tool which certainly has its merits, but parents can be unprepared for the results it may produce. Health professionals can offer advice and information from a medical point of view, but lack the knowledge and understanding of the enormous value that disabled people bring to society. There are social and personal ramifications which must be considered before a parent can feel fully informed.

Anne Wilkinson
Chief Executive Officer
Parent to Parent New Zealand Inc
Phone toll free: 0508 236 236
Website: www.parent2parent.org.nz

Dear Editor,

I have just received the second issue of your journal and could not put it down. Congratulations on the range of topics covered. The article by Kim Porthouse on 'Pre-natal Screening: My Internal Turmoil' really touched my midwifery and mother being. You see, our third child was born with a slight disability. I had also chosen, like Kim, not to have interventions during my pregnancy and had a wonderful time talking to my growing baby during my pregnancy. We awaited her arrival with love and excitement. I am so grateful for the wonderful time I had during the pregnancy, a time that could have been dominated by fear and concerns, with large amounts of adrenaline floating around my body and the baby, hindering the important release of oxytocin, the love hormone that encourages bonding among many other things. The memory of the happy pregnancy enabled us to welcome and love this little person unconditionally and sustained us in times when parenting was hard. It is timely that we engage again into the debate to think about antenatal screening's long term effects, as well as it cost effectiveness.

Keep up the good work. I am looking forward to issue three.

Ruth Martis
Christchurch
New Zealand

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To the Editor
Congratulations on your latest edition of your Journal - an absolutely enjoyable read and a very nicely assembled, aesthetically pleasing and interesting collection of contributions.

Jane Stojanovic
Otaki, New Zealand

Dear Editor

Thank you for the invitation to be involved in the discussion about ante-natal Down Syndrome screening.

DPA is the national assembly of people with disabilities. It is an umbrella organisation for the full range of disabled people in New Zealand. We have about 1000 individual members who are disabled themselves, or are the parent or guardian of a disabled person and some 300 organisational members who represent or deliver services to disabled people. Our advocacy is across the range of age and impairment at a societal level and this issue-level advocacy is grounded in human rights.

We were invited to be part of an advisory group looking at ante-natal Down Syndrome screening, apparently to ensure that the needs of disabled women were catered for in any screening regime. Right from the outset we became concerned that testing for Down Syndrome was going to be done without considering a really fundamental question – why?

Despite the rhetoric about the health of mothers and their need to know, our experience suggested that this was about finding a perceived devalued human characteristic that might be eliminated. Reports from Great Britain, where screening for Down Syndrome is done, suggest that 80% of foetuses are aborted.

We wholeheartedly believe that prospective parents have the right to make an informed choice about whether or not to have a child with a certain characteristic. But by 'informed', we mean that information needs to be accurate and useful. Often when medical professionals talk about any impairment, it's couched in biased negative terms. As a disabled person myself, I have been on the end of such attitudes all of my life.

We acknowledge that it can be hard and the problems with having children can be taxing. And then there are the issues to do with impairment. Equally though, being a parent does have its rewards. For the parents of disabled children the rewards can be substantive given the proper supports.

Therefore we continue to lobby for resources to support disabled people and their families rather than more money going into improving ante-natal Down Syndrome screening to find those foetuses that should be aborted.

Gary Williams
Chief Executive Officer
Disabled Persons Assembly (NZ) Inc
Website: www.dpa.org.nz