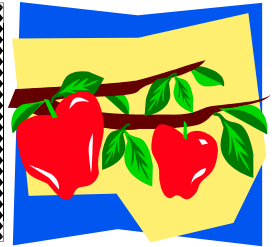




Why not go out on a limb?  
That's where the fruit is.

Will Rogers



### A Message from Kathryn

MARCH  
2003

MAMRE-BILLIA

I note how easily Agencies change the names of services, and one of the key changes I have noted has been the change from using the term "Respite Care" to the term "Family Support". Since these are two different service types, surely this must be the cause of some confusion. As I attend meetings and move from one venue to the next, I hear the different terms interchanged, and I wonder....are we all clear about what is being discussed.? In reality, the terms describe quite different realities. Let me try to describe the difference as understood by Mamre.

First, the term "Respite Care". This is about having 'time out', or 'a break from' the care of someone when another person, or agency takes on the temporary role of caring. This service is based on a belief that time out from the responsibility of caring will give time to rest and rejuvenate in order to continue in the role more positively after the break.

'Family Support' is a broader term that includes a wide range of possibilities, *including* respite care. It also includes, for example, the provision of support for a young person with disability to participate in a sports club, a craft group, support for a child to plan a sleep-over, to have a birthday party, for personal care support, support to get to the movies with a friend. It can also be about supporting the family on a holiday, supporting the children while the parents go away for a weekend. It may be that the brothers and sisters of the person with disability need someone outside the family to take the role of a 'listening ear'. Sometimes it may be about the need to purchase some special equipment. Generally speaking, Family Support is about the whole family.

Family Support works best when it *begins* with good planning, and continues with good planning. There is an ongoing need to determine how it is that the family needs support at any time and then to find the resources to address the need. It's usually about a whole range of things which, together will make a positive difference in the lives of the family members.

In 2003, Mamre is **definitely** about Family Support (one of the options offered being respite care). This is because we value the

family and want to be flexible enough to offer supports to families in the most effective way for them. And...this will be different for each family, and be different at various life-stages and times.

We believe that respite care or 'a break' is needed by every parent whether they have a child with disability or not. However, with most children, these breaks usually occur very naturally, as the children engage in life activities—sports, interest groups, going out with friends, visits to friends and relations and so on. We acknowledge that these natural breaks do not appear as readily when a child has a disability. This is for a whole range of reasons but not acceptable.

In the big picture, Mamre wants to assist families by supporting the young person with disability to get involved in different aspects of life. If this happens, then the breaks for the other family members will occur. This is how it is in families world wide. This is a challenging way to work, because it means that work needs to be done in different settings,- with the individual, with the family, with the community. It's about changing the vision of what is possible for all involved, but especially for the person with the disability and it involves some risk taking. It is complex but very rewarding work.

The most important component in all of this is *the need to HOPE, hope in a good today and a good future for those we know who have disabilities*. With the set-backs that happen, it's sometimes difficult to hold on to that necessary hope. *That, I believe, is what we should support each other in, most of all.*

This is why at Mamre adopts the term 'family support' because it keeps doors open and implies that with support, gains can be made. As per my above definition, does the term 'respite care' have some slightly negative overtones that we need to change?

I would be foolish to think that there are no glitches in our service provision. Together with you we have to work on these. What I do know, is that your dream, and ours, is for your son or daughter with disability to have the support he/she needs to do things that he/she loves, to broaden his/her opportunities, and to feel valued. The key work of Mamre is to support families in turning dreams into realities.

## THE FIRST, POSITIVE STEP.

**A**pprox 3 years ago, my then 8 year old daughter asked whether she would be responsible for looking after her sister when we were no longer around. After recovering from my shock I realised that if we did not put some measures in place, Laura would indeed live the isolated life of most people with a disability, relying on family and paid workers.

So began a dream, that Laura would grow with the love of a family and friends, and we felt that to best achieve this, she should participate in community life as much as possible i.e. Kindy, School, Church, etc.

In 2001, Laura attended a local Kindy, and graduated to the Pre-School class the following year. It wasn't always smooth sailing, but through discussions, negotiations and commitment, Laura progressed. When she was invited to her first birthday party, we knew we were on the right track - she has since attended 5 birthday parties.



The next obvious step was school. Laura has a severe intellectual impairment, coupled with physical needs and a hearing loss, therefore we wanted a program that would offer her an opportunity to mix with peers, learn social skills and ultimately form friendships. We approached the local State School who told us that they "could not offer us much". We then approached a local Catholic school and their response was both positive and welcoming from the start.

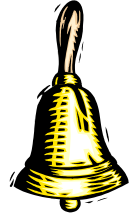
The Principal convened a Support Group for Laura's enrolment and any future issues and decisions. Members of this group are - Principal, Learning Support Teacher, officers of Cath Ed Spec Ed Unit,

Pam our Key Worker from Mamre, David and I. Once we outlined our plan for Laura's education, her abilities and needs were assessed through visits to FECS, SEDU and Pre-School.

Although inexperienced with severe special needs such as Laura's, they were happy and willing to welcome her to the school. She attended Orientation afternoons, was assigned a "buddy" and her attendance was anticipated by many - particularly her sisters and their friends.

Since January, Laura has attended the Catholic school for two mornings per week and Geebung SS for the remainder of the week. Staff at both schools have met, discussed and planned Laura's inclusion and are committed to our decision of a split placement. Some adjustments have been made to accommodate Laura but these have been accepted by all - particularly the children.

To date, Laura's inclusion has been a resounding success. Every morning her buddy meets her at the school gate and walks her into the class room. Her classmates then help her outside to assembly when the bell rings, sit in a large circle to include Laura at morning tea, and the "big kids" play ball games with her at play time. Laura's aide is her voice for "News", and whilst the other kids practice their letters, Laura does puzzles and fine motor skills activities.



We are still a long way off achieving our ultimate dream of Laura being part of a circle of friends; however, we feel that we have taken the first, positive step.

Rose Humphrey

## HOME BASED—SOUTH

The past few months have been a privilege to share a little in the lives of families. So much has been happening on a personal level for families. Children have started school or preschool (which in any case brings its own set of struggles and celebrations), some families are grappling with news of new health issues for their child, some are exploring host family options, and all are giving much energy and love into pursuing whatever it is they feel is the best road for their family.

Recreation and sporting ideas for young people with disability has been something a couple of families have expressed an interest in. Sometimes parents feel that

options for their child seem limited, however there are a few avenues you may like to consider if you think this is something you and your child may like to explore. One of them is The Sporting Wheelies and Disabled Association. We've included some info on page 9 for you to read if you are interested.

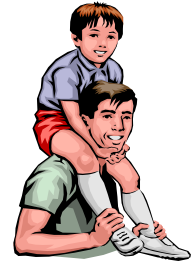
As for me, after four months I'm not so much 'the new girl' anymore. Thanks again for sharing your time with me. All the best for the next few months!

Laini Armstrong

# BEING A DAD! WHAT DOES IT MEAN NOW AND INTO THE FUTURE?

The Parent Support Program would like to extend a warm invitation to you to join other dads over dinner to discuss what it means to be a Dad of a child/person with a disability.

Denis Cowan who has a son with a disability will be facilitating a discussion with you around your experiences, thoughts and ideas.



Date: Friday Night April 4, 2003

Time: 7pm

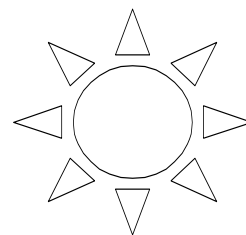
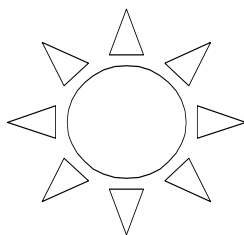
Place: Food for Thought

38 Main Street Kangaroo Point

(between Pineapple Hotel and KFC)

Plenty of parking at rear of restaurant

Cost: \$10 for the meal and BYO alcohol



## Natural Therapies for Carers Centre Brisbane North and Pine Rivers Areas

The Commonwealth Carer Respite Centre—Brisbane North has recently established a Natural Therapies for Carers Centre at Ashgrove for Carers in the Brisbane North and Pine Rivers Areas. Carers who are experiencing stress due to their caring role can contact the Carer Support Officer on 3621 5444 to discuss their needs.

The centre has three qualified therapists who work at the centre a couple of days a week. Therapies include Reiki, Bowen Technique, Aromatherapy and massage.

Therapists are available Tuesdays from 9am until 4pm (last appointment) and Thursdays 3pm and 4pm appointments. The cost of the therapy session is \$30—however depending on individual circumstances the centre can subsidize the therapy

## HELLO FROM STAFFORD

Life continues to be busy at Stafford. Each Monday our very faithful volunteer James is here with us. We are very fortunate to have his assistance with everything from collecting the post, checking stationery, and collation of mail outs. He handles being in an office full of women very well!

Every second Monday we begin our week in a very calm and peaceful way with Sr Niki leading us in reflection. We all benefit from this and sincerely thank you Niki for your time and energy. If you are interested in attending these mornings, please give us a call on 3352 5133.

Welcome Tim and thank you for the work you are doing outside. Tim sometimes prepares a lunch for us as well. The pizzas are great!

Coffee Mornings and Evenings continue. The next one will be held @ Gloria Jeans Coffee Lounge, Taigum Shopping Centre, on March 25, at 9.30am. Everyone is very welcome. These times provide an excellent opportunity to share—be it the highs, lows, and/or information. Many a hearty chuckle is heard. It has been lovely to see the friendships that have developed since these get-togethers have been happening.

Home Based Support is meeting and welcoming families. It will soon be 4 years since HB began on the north side. This is a long time especially in the life of a little person. I have been very privileged to have watched the children grow and now go on to school. An exciting as well as emotional time.



On a lighter note, recently I was in Myer searching for just the “right” birthday card. Behind me I heard laughter and this continued for a few minutes. Being a “nosey parker” I simply had to check this out. What I discovered was a lady having the time of her

life simply reading the “humorous” cards! I joined her and for next 10 minutes or so, we shared a fantastic time just laughing!

So often we feel that pleasurable moments in our lives are few and far between, and we also forget they can be so simple.

Laughter is indeed excellent medicine.  
Until next time,

Pam, Rachel, Kerrie, Kym, & Bronwyn.

## POET'S CORNER



*Janice is a parent whom I have the pleasure of knowing. She is gifted with a poetry bug through which she often expresses insights into poignant everyday situations. One of Janice's poems will be in each of the 2003 Mamrebillia. Should readers want to talk with Janice about her work, just call me on 3847 1681 and I'll put you in touch with her.*

Judy

On the afternoon of 8th September, 1998 our son Daniel pulled over a chair and stood up on it at the kitchen sink. I was overcome with emotion, tears and joy. I watched Daniel with such love in my heart as I thought back to when he couldn't do such things - the little things that we take for granted in life, the expectations that are placed on us and that of our children. Even though at times life gets difficult and we sometimes cannot see past our problems, these little things seem to say, “hey it's been worth the journey”. Thank you, my son, for bringing me back to reality.

### THIS LITTLE BOY"

This little boy, stood up at the sink  
This little boy, he stopped to think  
He put his hands in, and played with a plate  
He thought boy! This is great  
His mother watched him in tenderness  
As she had prayed to God in faithfulness  
Not long ago her little boy  
Couldn't even pick up his toys  
Nor could he walk, talk or run  
Let alone stand at the sink and have fun  
For he wasn't quite born the “Norm”  
He didn't quite fit to form  
But he is loved, cherished and cared  
Even though at times it seems unfair  
This mother, this child  
Stop and think  
Both have grown, while at the sink.

Janice 1998

## THANK YOU.



My name is Adam, I am 16 years old and I go to Redlands Bay Special School. The reason I am writing this article is to thank all of the people and organizations for helping me reach my goal of purchasing an electric wheelchair.

First of all I would like to thank Michelle from Xavier and Mamre, for without Mamre's assistance I would not have been able to realize my dream. I would also like to thank The St George's Foundation very much and the Redlands Sporting Club for their generosity.

It has made my life much easier as I am now able to access the community. It has opened up a whole new world for me, as now the family are able to take me for walks and picnics and Specialist's visits, as the old manual wheelchair was too heavy to push.

I really love my new chair and don't want to use the old manual chair now.

Thanks again to Mamre, Xavier, St George's Foundation and the Redlands Sporting Club for their fantastic help and great generosity.

Yours sincerely, Adam Carmody and the Carmody family.

## A WORD OR TWO FROM JUDY BROWN

Mamrebillia time again! Whoopee! Another chance to share an opinion or two.

What I like to do is provide readers with something which has been running around in my awareness at a given point in time. If it strikes a chord in you, great! If it elicits a spark of dissent, let's have a chat. The Irish in me loves a hearty discussion anytime.

So what has floated to the top of my awareness in recent months? What have I personally experienced in Mamre? What matters have I heard discussed around me or what have I become aware of?

Uppermost in my mind is the number of times I have become aware of families being without supports or inadequate/unsuitable support arrangements and not coming forward to say so.

It is customary for Mamre to welcome requests, suggestions, misgivings, complaints and see them as opportunities to improve current situations. We regard them as a sign that

families know themselves as being in partnership with us and feel positive initiating discussion.

As a key worker it gives me grief when I become aware that I have overlooked doing or providing something which a family required. It is the same when I realise that there has been, e.g. hospitalisation/surgery/loss of a family member and I have either not been in contact enough to know this or not been thoughtful enough to offer extra support at these times. An organisation which gets regular complaints, I reckon is either way off the planet and due to hang up its hat or pull up its sox, OR it is one which has an open door policy, respects families as the key people for whom it exists and makes people welcome to voice opinions. This is what we aim for.

Please let me hear from you so that together we can do an even better job.

Judy Brown

The Brisbane City Council website has a list of free and not so free activities happening in Brisbane. Go to <http://www.brisbane.qld.gov.au/> and click on what's on.

## Parent Support

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A warm hello to you all! Parent Support has kicked off to a big start already this year with 4 mother's enjoying a weekend up the coast at Caloundra in February and 6 mum's indulging in a pampering day at Mamre Kedron several weeks ago.

You will see a couple of advertisements in this edition promoting a Dad's Dinner in April and an information session in May on Mainstream Schooling Options. Please feel free to tell other parents you may know about these events too. We are always delighted when the word spreads around.

Parent Support has some exciting events planned for this year. Apart from those mentioned above as well as the annual events that happen each year we have the following activities planned:

- May 16-18 Mother's Spiritual Retreat (filling fast so hurry and reserve your spot)
- July 25-27 Parents weekend with a focus on parents experience of Grief and Loss
- September 12-14 Father's Weekend
- October 11 Family Day out to Moreton Island



If you don't have a copy of the Parent Support Events Calendar for 2003 please give me a ring at Mamre Coorparoo on 3847 1681 and I'll send you a copy.

Parent Support also has capacity to offer families some one-off support during times of stress and crisis. If you and your family are experiencing some additional difficulties at present please feel free to contact me at Mamre Coorparoo to discuss your needs.



Parent Support is seeking to employ some additional pamper people for pamper days and events away. If you know of someone (who is a qualified massage therapist or beautician) who is looking for some periodic work then please ask them to call me to discuss things further.

I look forward to meeting up with you during the year and please remember to call us at Mamre if you are experiencing a particularly difficult time.

Peace and blessings,  
Julie Johnson  
(Parent Support Co-ordinator)

## YOUNG ADULT BROTHERS AND SISTERS !!!!!

Mamre Sibling Support is looking for adult brothers and sisters interested in becoming mentors/buddies for younger brothers and sisters from time to time.

Mentors/buddies get to know and spend time with young people experiencing difficult times. Training and support will be provided.

Please call Marianne on 38471681 if you would like be part of this exciting initiative.

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## DID YOU KNOW?

Mary Kenny who is Mamre's Admin Assistant, is a member of the Lord Mayor's Women's advisory group. Mary would appreciate any ideas from women about issues relating to families and disability in Brisbane. Feel free to phone her on 3847 1681.

The Community Resource Unit is holding a Conference between April 10—12 at the Hilton Hotel. For more information call 3870 1022

### SPORTING WHEELIES

The Sporting Wheelies and Disabled Association offer resources and programs to help young people find an activity / sport they love doing, and innovative ideas to help maximise their ability in a particular sport. The Association can assist you link your child into a generic club or team; or you can choose to take part in one of their programs.

The *'No Limits'* program is for people aged 5-15 y.o. and offers a wide range of activities like archery, boccia, athletics, wheelchair basketball, cartooning, canoeing, cricket, surfing, camping, golf, kite-flying, swimming, ten pin bowling, movie and theatre outings and more (like African style rhythm dancing classes!). Children are more than welcome to bring siblings or friends along. There is a small annual membership fee.

The *'Recreation A.D. Ventures'* program is for over 18's and also has a wide range of activities, including the arts. The Association provides opportunities for members with acquired brain injuries, cerebral palsy, multiple sclerosis, polio, spinal injuries or spina bifida, vision impairments, or other physical disabilities.

### SHARE A CUPPA, MOVIE OR VIDEO?

I'm keen to start a social group of parents who would like to meet for informal morning teas, movie mornings or video nights. If you are interested in being part of this group, please give me a call on 3353-3470.



I anticipate starting ASAP, particularly while there are some great movies on, and definitely before the Easter school holidays.

Mamre sends warm wishes for a speedy recovery to our friend and colleague Ros Nipperess who is recovering from unexpected and major surgery. We are with you Ros, cheering you on!

The RACQ provides free servicing to both manual and electric wheelchairs. Services include:

- pumping up tyres
- tightening wheel nuts
- replacing tubes in tyres - recharging batteries in electric wheelchairs
- repairing tyre punctures.

For more information phone 13 19 05.

The glorious autumn weather is with us again. The reappearance during recent rains of two little butcher birds that I have been feeding on and off since they fell out of their nest last spring started me thinking. How do we recognise when someone needs help? The day I rescued the birds, one of their parents actually flew into my kitchen and I followed it to chase it out. The other parent was fighting off some noisy miner birds attacking the babies on the ground. It took great courage for that bird to leave its mate and go for help but at some stage they realised that they couldn't manage on their own. They needed someone to help them put things in place so that they could continue on their life journey. This family now pops in and out of my life (and house) as they need and I am thrilled by their beautiful song. This is how I see Sibling Support. It is true that many families who have a member with a disability manage the challenges and are enriched by their experiences. At times parents need to reach out for assistance to enable them to continue on. This is the same for brothers and sisters but these young people have a limited voice and rely on parents to realise those needs. If you would like to see how sibling support could work for your family please contact me at Coorparoo on 38471681. There is no need to



fly into my kitchen ☺.

### Focus Groups

Focus groups for brothers and sisters aged 6-8, 9-12 and 13-15 are being organised now. If you believe your child would benefit from participating please register your interest as soon as possible.

### Information Package

The information package about Sibling Support was sent to families in February. If you didn't receive it, need more information or wish to access the supports available please contact me at Coorparoo or speak with your keyworker.



Best wishes  
Marianne Schmidt

## KEDRON NEWS

Well we've had our two weeks off after the hustle and bustle of Christmas and school holiday. We've attended several Mamre training days between us, and the odd one outside as well. We've got together to discuss our perceived strengths and weaknesses, we've checked to see how close we came to bettering our own expectations of the previous year and how much higher to set the bar for this year. Basically, a grease and oil change for all of us.

After going back over the end of last year, one of the highlights for us all was when we invited families over for dinner when their son or daughter visited with us. Having families over for dinner or lunch not only proved to be lots of fun and a great way to get to know each other, it also helped build our support skills in a personalized, individual way and gave us a better feeling for the routine each guest experiences while at home. After getting together over coffee in the back yard and at our house meetings, we all agreed that it would be a positive experience to continue to invite families to share a meal and have some fun (though don't forget everyone is welcome any time).

Over the same cups of coffee we got talking some more (we do a lot of this) and thought hmmm, wouldn't it be nice to invite other Mamre Support Workers and Key Workers over for dinner as well. So, if you have a little spare time and you'd like to join us sometime for lunch, dinner, or for the really keen breaky (We all have pretty bad "bed hair" at breaky, just to warn you), or if somewhere in between suits better, let us know and we'll work it out.

Hope to see you all soon, Kris, John, Zoë, Stevan, Nadine, Bridget, Yeukai and Melissa.





### The Power of Choice

I'd like to share with you some profound realisations that I have recently experienced. Some of these may challenge your beliefs and experiences but I invite you for a moment to allow for the possibility that **you are choosing all the experiences in your life**. This includes your thoughts and feelings in all situations.

"Rubbish!" I hear you say. "You try raising my kids or working in my job!!" Could it be that you are frustrated with your children or stressing out at your job because you *expect this to happen beforehand*? Think about it. What are your thoughts, prior to speaking to your children, or arriving at work? Are your thoughts becoming self-fulfilling prophecies? This requires honest self-inquiry. Most of the time, we run on automatic pilot. That is we are operating on uninvestigated, subconscious patterns and then we tend to project blame onto other people or experiences outside of us. This is primarily because we believe that people/things have to be a certain way in order for us to be happy. Put in another way, we believe that happiness can only come from certain conditions.

I'll gently challenge you to reflect on this statement: ***Happiness is not created as a result of certain conditions, certain conditions are created as a result of happiness.*** You may substitute any other experience as well: Love, peace, compassion. It is always from what you are being that will produce what you are doing. One does not do certain things in order to be happy, one is happy and then acts in a certain way. This therefore places the source of your happiness within you. It beautifully ties into what Jesus said "As you think, so shall you be".

I'd like to share some quotes from Neale Donald Walsvh's book, *The New Revelations*.

- "A decision to come from peace and love, rather than try to get to there turns everything around... at present most of your states of being are 'reactions'. They do not have to be this. You can make them 'creations'".
- "When you decide ahead of time that your inner state of being is going to be peaceful and loving, understanding & compassionate, sharing and forgiving, no matter what any outer moment brings, then the outer world loses its power over you".

These are powerful revelations indeed. I invite you to become like a scientist and experiment with them. Be gentle with yourself, if you find that you are slipping back into old patterns. Remember you are planting seeds and they need to be continually nurtured with gentleness and love. Also reward yourself for the little 'victories' that happen - Even if you were only calm for 2 minutes - that's a great achievement!! Remember that there really is no such thing as failure ***as every trying is a success and that every effort is what achieves the victory, with the first no less honourable than the last.***

Gandhi reminding us to "Be the change you wish to see in the world". Let's make this a reality in our lives. I'd love to hear your thoughts and comments so please email me:

b.funda@student.qut.edu.au

### CATHIE'S BACK!

Hello everyone, Greetings from Cathie Rogers. I am back, as yet another re-cycled Mamre person. I will be working 3 days a week in the Family Support South program. I am looking forward to meeting all of the families I do not know as yet. It is good to be back at Mamre. I have so far been busy ringing and visiting families and getting to know them and the support workers.



## With a little help from Dad

My husband and I are fortunate to have three beautiful boys. Like many families we live with the challenges of raising and caring for a child with multiple disabilities.

Our eldest child Luke, who is four was born in a very poor condition, and in those early days of his life it was obvious that he had sustained significant brain damage, and if he survived would have significant disabilities. Four years on, Luke is a beautiful, good natured little boy with severe cerebral palsy. He is visually impaired and suffers from epilepsy. A 'hat trick' of disabilities that at times for long periods impact on his health and well being.

Through all of this we try to remain positive and hopeful, and we do the best we can to live a 'normal life', not only for ourselves but also for Luke, our younger son Isaac, and our new baby Nathan.

As the primary carer and the 'mum' I have lots of time to reflect on our life. In doing so I am able to see what is good and positive.

One of the greatest allies my boys have in their life is their dad. From the moment of Luke's birth, Dan has been by Luke's side supporting him and ensuring that Luke's life is rich and full of positive experiences. The two of them have got up to many things during the few years of Luke's life.

Dan is a push bike rider, and Luke has spent many hours strapped into a baby seat, hurtling down hills with the wind in his hair and a great smile on his face. Or he has been out in the surf, with the odd waves crashing over his head, loving every moment of the drenching — well nearly every moment. Jumping on

trampolines till he's almost helpless with laughter and playing rough with his dad are also two of his favorite pass times.

His latest adventure however, is his greatest. Not only is Dan a keen bike rider but he loves to hike, mountain climb and sleep under the stars. The last time he went mountain climbing, he took Luke with him, along with a support crew of two uncles and a couple of friends.

Luke climbed a mountain in the sunshine coast hinterland by moonlight on Dan's back, slept under the stars on the top, and climbed down the next morning at dawn. Neither of them got a lot of sleep (about 2 — 3 hrs), and



there were a few hiccups on the way, but to see Luke smiling and to hear him laugh on the way home made it worth every moment. Luke smiled and laughed all that day and unbelievably didn't sleep. His animated reactions made me realize how much he must have loved the experience.

He made it to 8 pm that night, and then slept the clock around. Our son has no speech, cannot see very much at all, cannot walk, yet was able to tell us with such enthusiasm what a good time he had.

I cannot find the words to describe how lucky I am to be married to someone who will not limit Luke's life because of his disabilities. Dan has said all along that while ever he is physically able, he will be the means through which Luke experiences many things.

I have said to Luke and to others since that he may have been the first child with cerebral palsy etc to climb that mountain.

Let's hope he won't be the last.

~ Ann O'Brien