



March 2005 Newsletter

Wellington Down Syndrome Association

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Editor's Intro:

Happy New Year! I hope everyone had a wonderful

Christmas and holiday – it all seems so long ago now though doesn't it.

I was most interested to see The Guardian (Thursday nights), the two main characters found out by amino that their baby had DS - they actually decided to keep the baby - I was thrilled that a TV program would actually present that as a reasonable option, the show however has now been moved to a 11.30pm slot – typical!

In the last newsletter I mentioned we would love to receive some stories, articles, questions etc. I guess, by the zero response, that right before Christmas is not a good time to ask! I hope you will find the time to send them to me now, we would love to see this newsletter reflect our membership – and that is **you!** Tell us what you like and don't like, what you think of the stories and articles in the newsletter. People I spoke to about the love story in the last newsletter were varied on whether it was good, bad or otherwise for people with DS to get married – what are your thoughts? I absolutely loved it, but we all have different perspectives and I would like to print in the next newsletter your views, on this article or anything other.

We are starting a "Help" page for members to ask for help on an issue and for other members to write in and share what worked for them. The first question is on page 2.

In the notices you will see information on our coffee mornings, if you have never attended a coffee morning I encourage you to do so, they are very positive. I put off attending coffee mornings for a while after Daniel was born as I thought everybody would be crying into their coffees! You needn't fear, it is just a great way to meet other Mum's and Dad's (yes we have regular Dad's that come and Grandparents too) and for the children to play together, although there is always support and help if you need it. Also in the notices you will find information on a Makaton sign language course, a private speech language therapist specialising in DS and a regular soccer group. We are also holding a garage sale – see how you can help on page 9.

Unfortunately (for us) Kim Porthouse will be resigning as Co-ordinator at our AGM in June, and is stepping down as Regional Contact now. Carmen Slater is our new Regional Contact, please see page 10 for details.

I look forward to hearing from you ...

Lynette Subritzky, WDSA Editor

Our Children:

For more stories go to www.wdsa.co.nz –add your story too!

Brendon

Hi my name is Brendon, I am 7 yrs old, I live on the Kapiti Coast with Mum (Kim), Dad (Colin) and Chris my 10 yr old brother. I was born with an AVSD (or AV canal) and spent the first 2 months of my life in hospital (5 weeks in neonates & 4 weeks up in Auckland at the heart unit) which was a hellish time for my family as they dealt with the DS diagnosis as well as me being pretty sick but thankfully it has been onwards and upwards since then.



Although my speech is taking off now I took a while to learn to talk but thankfully Mum was a real believer in sign language and I have successfully used Makaton sign to help with communication since about age 18 mths.

I went to Montessori pre-school from 2 ½ to 5 yrs, I now go to school where I especially enjoy the alphabet, reading and learning on the computer – the playground is pretty cool too!

I love music, my favourite groups are Hi 5 and the Beatles, I love to sing & dance along or join in the actions to favourite videos like 'Love to Sing', the 'Hooley Dooleys' and Hi 5. My favourite TV programme is 'Blues Clues'. Some of my favourite activities include jumping (esp. on a trampoline), slides & swings, throwing a ball (Mum thinks I should be the next 'Richard Hadlee' as I've got such a good eye), doing puzzles, playing on the computer and swimming – I am still learning but the water is such great fun!



My mum loves to meet and talk with other parents, she goes to most coffee mornings and we are regular attendees at WDSA events.

Editors Note: We would love to hear from anyone who is a grandparent, parent, sibling, cousin, aunty, uncle or friend of someone with DS, tell us your story, we would love to print it and include it on our webpage for others to read and be encouraged by. Alternatively, if you have Down syndrome please write to us and tell us about you, what you enjoy, your family, friends, work, school etc.

Help:

My five year old with DS is a problem sleeper, he often wakes during the night and will rock and moan, if we lie him down he goes back to sleep easily but can wake often and then ends up too tired during the day, now he is at school it is harder for him to cope with the lack of sleep. Sometimes sedatives work but not all the time and often not that well. Any ideas???

Send any suggestions to gidontknow@paradise.net.nz or phone Lynette on 5262690. Also send any questions you would like suggestions for.

Communication

<http://www.jamesdmacdonald.org/Articles/FDown/COMMUNICATIONPROBLEMSANDDD.html>

Far Too Little Interaction

The majority of children with Down syndrome studied interact much less frequently, for briefer durations, on fewer activities and with fewer people than children of similar age and developmental levels. Clearly, children will learn to communicate and talk to the degree that they have frequent social contacts with others. Consequently, the most important way to help a child communicate may be to make sure they are interacting for increasingly more frequent and longer times.

Too Little Playing in the Child's World

While most parents believe that play is important for a child's development, most think that playing with toys is the best kind of play. While a child will learn a lot from playing with toys alone, it is extremely important to realize that he will not learn to communicate that way. To learn to communicate and talk, a child must play regularly with people.

Too Much Stimulation

A common recommendation to parents of young children is to "bathe your child with language" and "talk to your child all the time". In order for your child to communicate, he needs two major things: models of things he can now do, and time to do it. Much research and parent reports show that children with Down syndrome are often barraged by much more language than they can try to do. At the same time, they are given very little silent time to try something. Often we see interactions like the following. Charley: Points to the refrigerator. Parent: "Are you hungry? I bet you want some juice. You like apple juice best. Okay, here it is." and the child drinks the juice without having the opportunity to practice communicating about it.

Parents need to communicate in a way the child can soon do (i.e., matching) then wait for the child to do something, anything, at first. Let's go back to Charley for a more effective exchange. Charley: Points to refrigerator. Parent: Points like the child and simply says juice then waits silently looking at the child expecting some kind of response. Charley: Points again and says "oo". Parent: "oo, juice"; then waits again. Charley: Points and says "oo". Parent: says "juice" and gives the child a sip of the juice then waits again. Charley: says "oo". Parent: "juice, more juice," gives the child another sip and waits again. Charley: says "mo". Parent: says "more juice," gives another sip then waits; etc. This parent is acting and communicating in ways the child can try; and the child does try. The parent rewards the child a little then waits for another communication - anything the child can do - then the parent shows the child a little next step ("more juice"). Be sure to make the most of such opportunities and not give the child the juice all at once. Operate by the rule "Keep the child just a little longer" and remember that every exchange is a chance to communicate.

Dead End Contacts

Research shows that children with Down syndrome often have the habit of popping in and out of interactions without staying long enough to learn to communicate much. We also find that parents and other adults assume that if the child wants to leave they should allow the child to do so. But, if we believe, that a child will learn to communicate only to the degree that she stays interacting longer and more frequently with others, then we will get into the habit of keeping the child a little longer.

Getting Stuck Communicating Without Words

Many parents of children with Down syndrome are so happy when their child starts communicating in any way at all - little sounds and movements - that they accept these little attempts. That is as it should be. Long before a child talks, she will need to communicate with any kinds of sounds and movements she can do. We strongly encourage this. However, there is a potential problem here. We have seen many children stuck at communicating with old sounds and movements long after it is clear that they can say some words. Children actually do not need to talk when they get attention for any old attempts to communicate. Then I have often shown parents that by simply waiting silently after a child makes an old sound or movement, the parents will see the child trying something a little more mature.

Not Knowing What to Say

Consider your child's job as moving from his own special language without words to your English language. Often when a child gestures, or makes a sound, he needs help to move from his language to yours. A very effective way to do this is to translate the child's sounds or gestures into a word. For example, when a child points to her sister, Janie, say "Janie", then wait. By doing this you are translating and giving her a word to replace her old gesture. We often then play with the word back-and-forth, treating words as the child's most important toys - as we would throw a ball back and forth.

Too Much School Language

Parents with children with Down syndrome tells us how important parents think it is to teach the child the language of school, often even before he communicates his own ideas. I have known many children with Down syndrome who can show words for the alphabet, numbers, colours, even a long list of animals they may never see; but the same children have few words for the things they are experiencing and things they want to communicate about. Be sure your child has words for communication before words for school.

Our approach, then, is to focus on helping the child learn words for two broad classes of things: their immediate experiences (e.g., fall down, hug, mommy, daddy, give) as well as words for the things they are already communicating without words (pointing to kitchen - eat, hungry; arms outstretched - up, hug or what ever you think the child means). Why are these words most important and more developmentally necessary than school words? These words are the things the child both knows and cares about. A child is more likely to use words that match his current knowledge and motivations. A child will have many more opportunities to practice talking with words that describe what he knows and wants than with words like red, three, and other words that have little daily communicative uses. Consequently, we encourage parents to give their child much more "communicative" language than "school" language.

The Habit of Supporting Old and Inappropriate Behaviours

One of the most difficult habits to change in parents is paying attention and talking to children when they are doing undesirable or immature things. A great many parents have told me that they feel it is wrong to ignore a child when he is misbehaving or communicating in some immature way. We have worked very hard to show parents that paying attention when a child does these things is much like giving the child a ten dollar bill for it, because parents' attention and words are often the most powerful rewards for a child. On the other hand, when we ignore those behaviours we usually see the child doing less of them and more of the appropriate and mature things. We teach parents to get into the habit of asking themselves "Do I want more of what my child is doing?" Then, if the answer is yes, they should talk and pay attention; and if the answer is no, they should momentarily pay the child no attention - no talk - nothing that would tell the child he gets attention for it.

World Watch

<http://www.fortunecity.com/millennium/treearbor/207/downsyndrome.html>

Editors Note: I know we had an article on Chris Burke recently but I found his website (<http://www.chrisburke.org>) and through links found this interview. Also, watch out for Chris on ER!

About Chris Burke

Doctors advised his parents Frank and Marian Burke to put their newborn son in an institution. The Burkes ignored the advice, and treated Chris the same as their other children. That decision which was made more than 33 years ago led to a remarkably talented life. Chris is best known for his role as Corky Thatchcer on the ABC-TV series "Life Goes On" which earned him a Golden Globe nomination. Most recently Chris can be seen as Taylor on the CBS-TV series "Touched by an Angel". This success then led Chris to publish his autobiography, A Special Kind of Hero, in 1992. He filmed a public service announcement with President Bush, and marched in President Clinton's inaugural parade. He has receive numerous awards including a Youth in Film award and a Christopher award, and had a New York City public school named in his honor. In addition, he continues to have a fresh television presence guest starring roles on shows like "Jonathan, The Boy Nobody Wanted", "The Commish", and the ABC mini-series "Heaven and Hell".

December 1998 Interview with Chris Burke

1. What is it like for you living with Down syndrome?

Having Down syndrome is like being born normal. I am just like you and you are just like me. We are all born in different ways, that is the way I can describe it. I have a normal life.

2. Is there anything that you can't do that you wished you could do?

Oh Boy! That is a good question. Laughs..... (he could not think of anything).

3. What is something that you have done in your life that you are the most proudest of?

To have my fan club. I am very proud of doing everything. I try to support my parents, friends and fans. I am also proud of my performing in the visual arts, and motion television.

4. Who do you consider a role model in acting?

Tom Hanks and Michael Landon

5. Who did you like the most of all the people you have met?

Marie Osmond, I met her in Ashley Johnson's dressing room who played her daughter in the TV show "Maybe This Time". I said to myself, I can't believe it, this is a dream of mine, because I remember Donny and Marie very well.

6. Who are some people that you have enjoyed working with?

Kelly Martin, I watch her on ER every Thursday night. I want the chance to get to play her brother again.

7. Where did you first start singing?

In the shower..... ha, ha, ha, ha. I was like Gene Kelly, it was called singing in the rain. No seriously, I wasn't really born with a singing voice, but my friends Joe and John taught me how to sing.

8. What advice do you have for parents with children born with Down syndrome?

Don't give up on the child. Give the child an education. Give them daily love.

9. Who are you dying to meet?

Will Smith

10. What are some of your goals?

To do theater and I am looking forward to doing more Television and Movies. I also want to direct some plays in theater workshops for people with disabilities.

11. What is the next thing that you are going to do?

I am going to see a movie starring Will Smith.

World Watch

By: LESLEY GIBSON

<http://www.ndss.org/content.cfm?fuseaction=NwsEvt.Article&article=846>, Daily Mail, August 13, 2004

FOR Paula Sage, a dream came true this week when she officially became a film star. The paparazzi cameras flashed as she stepped onto the red carpet at the London premiere of a film in which she plays a leading role. 'Paula! Look this way!' the photographers begged her, just as they would Kate Winslet or Keira Knightley. For anyone this would be a major achievement. But for Paula, 24, it is all the more special. Not only has she never acted in anything other than a college play - she also has Down's syndrome. But it isn't just her learning disabilities that set Paula apart from other young actresses - it's her personality, too. Far from letting the attention go to her head, she still has her feet firmly on the ground and had a smile and a pleasant word for everyone at the premiere at The Curzon, Mayfair. The film, *AfterLife*, follows an ambitious young journalist (Kevin McKidd) as he discovers his mother (Lindsay Duncan) is dying and realises he will have to take care of his younger sister, who has Down's syndrome.

In completing the project, Paula not only impressed the film world and her parents, she also surprised herself. 'I'd never been given such a big challenge,' she admits, 'so I'd no idea if I could do it. But I was so thrilled when I won the part that I just went for it. I found I could memorise my lines the day before a new scene, just like everyone else, and I discovered I loved acting.' She clearly also has natural talent for it. When the film was first shown at the Edinburgh Film Festival last year, it won the Audience Award and moved actor Sean Connery to tears. Giorgio Armani is also a fan and he was so touched that, instead of giving lavish Christmas presents to fashion editors as usual, he donated nearly 250,000 pounds to Down's syndrome charities instead.

What makes Paula's story all the more incredible is that when she was a baby, a so-called expert told her parents she had such severe learning difficulties she might never walk or talk. Alan, a college lecturer, admits: 'If anyone had asked us to guess which of our children would be a film star, we would never have said Paula. Marie-Louise is the dramatic one of the family. Although we knew Paula was very able, we have been astonished by the talent her role has revealed.'

'Watching her on screen was surreal,' says Alan. 'It was clear to us that she really was acting because her character is very different from the Paula we know. It was absolutely magical and something we will never forget.' Had it not been for them, Paula's life could have been very different and they vividly remember taking her, at just two years old, for an assessment by a child psychologist.

'He had never met Paula,' says Alan. 'And without trying to get to know her, he asked her a series of questions that we thought were ridiculously advanced, even for a child with normal development. 'One was: "What would you do if it was raining?" She was supposed to say: "Put up an umbrella." Another was: "What is a window made of?" 'Paula sat in silence, not because she couldn't speak, but out of shyness and bewilderment. The psychologist assessed her as being at the lowest end of the disability spectrum and forecast that she would never be able to do anything.' But Alan and Mary were enraged. 'We knew she was very able because she began to walk at 18 months. She began talking soon after that, and wasn't far behind other children. And she was very advanced socially, with a lovely, kind nature and a smile for everyone. At the nursery she attended for infants with special needs, she helped a physically disabled friend to walk, and another to talk.' The couple insisted on a second opinion. 'This time a child psychologist came to our home and made an effort to get to know Paula,' says Alan. 'She responded normally, and he was amazed at what she could do.'

'Paula loved us to read to her, and her favourite fairytale was Goldilocks And The Three Bears. To make her laugh, we would always miss a bit out and she would remind us that we had not told her the whole story. The child psychologist asked me to read to Paula, and I began. Then he asked her to take over. She did it readily and didn't make a single mistake, but she missed out part of the story, as we always did. 'The psychologist said "You missed some", and she explained what she had missed and why. He was astonished that not only was she absorbing and memorising the story, she could also play games with it.' This time, the outcome was very different. Paula was pronounced extremely able, and at the age of five she went to a mainstream school.

'No one ever picked on me,' she says. 'I loved school and even though I was the only one with Down's syndrome. I fitted in well and got on with everyone like a house on fire.'

As a teenager, she split her time between an ordinary secondary school and one for girls with special needs, but she took the equivalent of GCSEs and passed maths, English, science, and social and vocational studies. At 18 she went to a further education college and did a three year course where she learned practical skills including cooking, personal hygiene, communication, computing and office skills. It was there that she had her first taste of drama, as the wife of a medieval pub innkeeper in a play. 'I loved it,' she says. 'It was great fun.' Alan also noticed a spark of talent. 'Her performance really stood out,' he says. 'She was a natural.' But she has several other interests, too, in music, art and sport, among other things.

She also attends several activity and social clubs and is part of a netball team that will be competing in next year's Special Olympics in Glasgow. So it is not surprising that her parents did not channel her energy into acting at that stage. 'We tried to find employment for her after college, but nothing materialised,' says Alan. But that turned out to be a blessing in disguise, because if Paula had been working when talent scouts began their search for a potential star, she would probably never have been considered. As it was, hers was one of the first names to be put on the list of possible candidates when director Alison Peebles - who was adamant the role of Roberta, an overprotected 19-year-old, should be played by a girl with Down's - began scouring special-needs groups.

Even when she was on a shortlist of 12, she took it in her stride. 'I'd barely acted before and didn't think I stood a chance, but I went along and gave it my best shot,' she says. 'At the first audition I just had to repeat lines from a script; it wasn't difficult.' At the next audition, there were eight candidates. Finally, there was just Paula and another girl. Then Alan and Mary were interviewed before the final choice was made, so the film makers could be sure that Paula would cope. Mary says: 'They asked us so many questions: "Would Paula be able to memorise her lines? Could she cope with 12-hour days? And when filming ended, would the anticlimax be unbearable for her; would her old life still be fulfilling enough?" 'They were questions we, too, were anxious about, and the truth was, we didn't know the answers. We felt we had to be honest. We said we really didn't know, because she'd never done anything like this before.' The Sages were also worried about whether Paula had the social skills to cope. 'She can be quite shy,' says Alan. Indeed, this is evident when we meet. Paula spends the first few minutes observing me, remaining silent and letting her parents answer questions while she weighs me up. But when she decides she likes me, she drops her guard and smiles, chats and jokes freely.

Alan says: 'We knew how excited Paula would be if she won the role and couldn't bear the thought of her agreeing to take part, only to find she couldn't do it.' Despite her parents' understandable concerns, Paula herself was confident. She realised this was the opportunity of a lifetime and had no intention of letting it slip by. 'I didn't feel nervous about the audition,' says Paula. 'I knew I could act. I wanted the part so badly, I just did my very best and hoped it was enough. Then I waited at home, longing for the phone to ring.' For several days, there were no calls. 'It was so frustrating. I thought the other girl had been picked,' she says. 'But then Dad said: "Paula, there is a call for you." And the voice on the end said: "We want you as Roberta." 'I was so thrilled. I threw my arms in the air and yelled "Yippee!" I was going to be a star! Me! I could barely believe it.' To everyone's surprise, including her own, Paula sailed through the gruelling six-week schedule and not only coped with the challenge, but positively thrived on it.

'I had no problems memorising my lines, she says, 'but I really did have to act, rather than just being myself, because Roberta was very protected and I'm much more able and have more independence.' There was little time outside filming for socialising, but Kevin McKidd, who plays Roberta's brother and starred in *Trainspotting*, has become a family friend. 'Kevin's mother, who lives in Elgin, had set up a drama group for people with learning disabilities, so he was thrilled to take up the role,' says Mary. 'He was wonderful with Paula, as was everyone else involved in the film.' Alan and Mary were anxious about how Paula would cope when the film ended. But, like everything else life throws at this optimistic and courageous young woman, she took it all in her stride and says: 'I would love to do more acting, I love all the soaps, but it would be great to get an ordinary job, too.' And surely no one deserves a big break more than she does.

Noticeboard:

WDSA Information:

Coffee Morning / Support Group Wellington Down Syndrome Association



An invitation is extended to all parents, relatives and caregivers of children with Down syndrome to our monthly coffee mornings

10am - 12noon

6 Grays Road, Plimmerton

Easily found just off SH 1, next to the Spinnaker Motel

(except when falls in school holidays then held at Wellington Early Intervention Trust [W.E.I.T],
79a Copeland Street, Lower Hutt)

Third Wednesday of each month

Dates for 2005 are:

Grays Road: March 16, May 18, June 15, August 17, September 21,
October 19, and November 16. **W.E.I.T:** April 20, July 20.

Coffee mornings are a great way for you and your children to meet new friends and for you to share your questions and experiences, they are all about getting together, sharing support and information, for families of children of all ages.

A selection of books and videos on Down Syndrome are available for loan.

For more information contact: Veree Henderson phone 476 7471, or
Mandy Thompson (Kapiti Coast) phone 905 7775

MAKATON - SIGN LANGUAGE COURSE

Makaton is an international sign language often used to help communication with people with Down Syndrome.

If you are interested in attending a course in the Wellington region, please phone Mandy Thompson on 04-9057775 and I will co-ordinate with a Speech Language Therapist.

Noticeboard:

Information and Services

SARAH COURTNAGE
Speech-Language Therapist

Specialising in working with children with Down Syndrome

Tel/Fax: (04) 4795177

Mobile: 0210510586

50 Madras Street, Khandallah,

Email: sarahcourtnage@hotmail.com

MMedsci Clinical Communication Studies
Accredited Member of New Zealand Speech-Language Therapist
Association



Soccer and activities for Special Needs Children 4 – 8 years

Where: Upper Hutt Primary School,
Brown Street

When: Every Saturday – if wet in hall for
activities

Time: 11 am – bring a picnic lunch

Our aim is to have lots of fun and learn
some ball and other skills as well. A
donation of \$2 each week will be
appreciated to help towards cost of
equipment etc.

Contact Robyn Stokes, ph 976 7468

*Kia ora, My name is Sarah Courtnage
I'm a Speech-Language Therapist from
the UK now living in Wellington. In the
UK I set up and led Speech-Language
Therapy groups for children with Down
syndrome and their families for the
Bristol Branch of the Down Syndrome
Educational Trust. I am continuing to
specialise in working with children with
Down syndrome and I have decided to go
into private practice for one day a week
(Wednesdays). I am working with
children between the ages of 2-12 years.
Please feel free to contact me for further
details and an informal chat.*

Garage Sale

Wanted: Any item about your household that you no longer
require and could be sold for fundraising. One
persons junk is another ones treasure.

Time/Date: to be advised.

Contact: Carmen Ph. 04 479 6337 or Veree Ph. 04 476 7471

DISCLAIMER: Opinions expressed in this newsletter are not necessarily those of the WDSA. The Association does not promote or recommend any products or services mentioned in this newsletter.

Noticeboard:

WDSA Info:



Change of Regional Contact – a note from Kim Porthouse.

Hi everybody, I hope 2005 has started well for all of you. For me it brings exciting new challenges as I embark on 3 years of full time study at Massey University in Palmerston North.

I have really enjoyed my time as Regional contact for Wellington, all the things I have learnt and all the people I have gotten to know both in the Wellington region and other regions throughout the country.

However due to my new commitments I feel I can no longer fulfill this role in the manner it deserves and so I have elected to stand down as Regional contact as from now and will also stand down as Co-ordinator of the committee at the AGM in June.

Carmen Slater has agreed to take on the role of Regional contact; Carmen will now be the local contact person for the WDSA as well as fielding local calls through the NZDSA's 0800 line and being our liaison with the NZDSA. Carmen, who lives in Khandallah brings a wealth of support experience to the role, I hope she enjoys it as much as I have.

You can contact Carmen locally on 479 6337 or from the Kapiti Coast, Horowhenua and Wairarapa by ringing 0800 NZDSAI (0800 693 724) and selecting 3. If you ever forget how to contact WDSA we can be located in the Wellington white pages or through the webpage (www.wdsa.co.nz).

Committee Members Wellington DSA			
Coordinator		Kim Porthouse	(06) 364 2007
Regional Phone Contact		Carmen Slater	479 6337 or 0800 693 724, select 3
Secretary		Lynette Subritzky	526 2690
Treasurer		Carol Weston	499 0263
Silila Nickel	577 3796	Veree Henderson	476 7471
Coralie Baldwin	565 1289	Mandy Thompson	(04) 905 7775
Kate Young	970 7229	Kataraina Werekiko	233 9798
Steve Young	970 7229		



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