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Newsletter

Wellington Down Syndrome Association

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Editor's Intro:

Thank you to those who replied to the help question re the sleep issue, see page 3.

TG Macarthy Trust kindly funded the revamp of our WDSA brochure. The last brochure was produced in about 1993 and the committee felt it needed updating. The money we received enabled us to print 8,000 new brochures and we are sending two to everyone on our mailing list - one to keep and one to give to anyone that you feels should have one. If you require any more, please phone Steve Young ph 970 7229.

Please note our AGM flyer, with this newsletter, our AGM will be held on Wednesday June 29, 2005. We are very lucky to have Audiologist, Wally Potts, as our guest speaker. So please join us; it would be great to see you. Give thought to whether you could join the WDSA Committee; the committee would be enhanced by any contribution you would be able to make.

Do you know of someone with DS who deserves recognition for their perseverance, attitude or hard work? If so, nominate them for a Frances Clark Memorial Award, see page 8 for details.

If you are a member of the New Zealand Down Syndrome Association please see page 7 re the Proposed Amendment to the National DSA Constitution.

Recently while looking at Daniel's birthday photos Jacob made a comment about the kids having DS. I was a little concerned at first but I think he was just trying to let me know that he now understood that Daniel had DS. So I asked him what it was like to have a brother with DS and his reply was "sort of good and sort of not", scared of what he might say and yet believing he had every right to feel what he felt, I asked what was bad about it, "it's bad because I don't get to play with him at lunchtime and because he isn't in my class so I don't get to see him all day". Wow! Although I have no idea why he would want Daniel in his class - but Jacob assures me that Daniel is much nicer at school than he is at home!

My reason for sharing this story is I have often wondered how to explain things to Jacob (6 yrs) and would love to explore via this newsletter the relevant feelings and thoughts of siblings and also what we can do as parents to help our other kids cope and enjoy their sibling with DS. How do you explain it, what do you think has contributed to them feeling good or bad about it etc? Are there any particular issues that you can forewarn us about? Submit any advice, thoughts or info to Lynette ph 5262690 or gidontknow@paradise.net.nz.

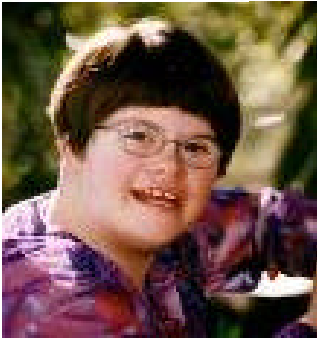
I look forward to hearing from you, and hope to see you at the AGM.

Lynette Subritzky, WDSA
Editor

Our Children:

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

Nikki



Hi, my name is Nikki. I am 12 years old. I go to Queen Margaret College and I am in year 6.

All the girls in my class are really nice and I have 3 really good friends. I do the same work as all the other girls but sometimes the teacher makes it a bit easier for me. If I get stuck my teacher aide or my friends help me. I go to swimming lessons at the weekend and play netball sometimes. My favourite things are Harry Potter and Saddle Club. I look at the videos, read the books and listen to the talking books. I also like travelling with my family and I love going to Disneyland.

WDSA NEWSLETTER

We would like the WDSA newsletter and website to reflect our membership; therefore, we would love to hear from anyone with Down syndrome or their families and friends. If you have DS or love someone with DS please write to us. Your story could be general like Nikki's above or about a triumph, health issue, friendship, schooling, work, or something that helped you, please share it with us!

Or perhaps you have seen an interview with someone with DS in a local paper that you could send in or have you read a book that you could review or recommend?

In addition, if you have a question, i.e. behaviour, a certain stage of life, a health problem etc please send us your questions and we will ask our membership for any solutions that have worked for them and print their replies in the newsletter (see page 3).

Send your stories, hints or questions to Lynette ph 526 2690 or gidontknow@paradise.net.nz.

Help:

Hi, my son (almost 4 year's old) will only eat only soft foods, without lumps, like yoghurt etc. He puts lots of different types of food in his mouth and will suck on it but will not bite or swallow it. We have tried making him fruit smoothies but he won't drink them. I would appreciate any information on what other families have done to overcome this problem.

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

Help Sleep Question from last newsletter:

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???

Replies:

Below are just a few tips that hopefully will work for you.

1. Don't give him any drink 2 hours prior to his bed time, a full bladder always wakes him up.
2. Try to make his room as dark as possible, i.e thick curtains.
3. Make sure the room is warm enough, but not over heated.
4. Try not to give him even a short nap during the day.
5. Try to make him tired enough during the day.
6. Ignore him when he wakes up if he is safe in his room, hopefully he will get used to waking up and falling back to sleep by himself, and eventually his frequency of waking could fade away. Chris Li

Vipersbugloss Airborne honey – put ½ -1 tsp of honey in a glass of warm milk for him to drink prior to bed, sounds funny but it works and is worth a try, Lyn Busby

We have had heaps of sleep issues with Harry - including a sleep apnoea study which proved inconclusive but maybe something you want to look into. At the moment one thing that is working really well for Harry is massaging his feet in warm sesame oil and then putting on a pair of socks before sleep. It is an old sleep remedy and does seem to work for him... for now anyway :) He is sleeping until nearly 7am compared to before 6am and getting up in the night. You might want to give it a try. Sue Elsworth

Editors Note: This was my Daniel causing all the sleep deprivation so thanks everyone who replied. The first reply (from Chris Li) is a great practical place to start, but we had tried most of the suggestions here already without success. Daniel was not keen on drinking the milk and honey so unfortunately we couldn't try this one well enough to see if it worked for him. I was reluctant to buy the Sesame Oil in case it didn't work (cheap sceptic!), for Sue Elsworth's suggestion, so we used a lavender massage lotion we had instead and it has been very successful so far, we were thrilled!

World Watch

'I have to show everyone what a kid with Down syndrome can do'

By: Kim McCoy Vann, Tallahassee Democrat, May 28, 2005

Like many of his friends, Daniel Jordan will stay in town to further his education after he graduates from Chiles High School today. And like his friends, Daniel will leave behind all the activities he loved about Chiles. No more handling equipment for the varsity basketball team. No more brainstorming activities with the Senior Board. The only difference between Daniel, 18, and most of his other buddies is that he has Down syndrome. He knows the real world will be different from the good old days at Chiles, but he's eager to take the next step. "I look forward to the challenges," Daniel said. "I want to see if they accept me for who I am and how I work."

Down syndrome is caused by an extra chromosome. It creates developmental delays, unique physical characteristics and usually mental retardation. Medical problems are common too. Daniel had two heart surgeries and a spinal fusion by the time he was 3.

But that's not why he stood out at Chiles. Daniel's known for his school spirit and caring ways. As a member of the Big Bad Wolves, he cheered intimidatingly with other guys at sports events. And he wore Chiles paraphernalia to school just about every day. "It's definitely not a thing where everybody is nice to him because he has Down's," said Joey Kempell, a fellow graduating senior. "He's a real person. He's cool."

Daniel's dream is to become a professional artist, but he's got a back-up plan. He's also interested in working in a video store. "I'm ready to get my future started with my new adult life," he said.

He's likely to face obstacles that his friends who don't have disabilities won't have to worry about. "What we see as the biggest problem is all the support they had throughout school is gone," said Sue Joe, a resource specialist for the National Down Syndrome Congress. "Parents have to get creative about getting the support they need." There are waiting lists for government services, so parents often pay for private help or come up with their own plans. Joe knows of a case in Atlanta where parents asked a church to allow their adult children to move into a house it owned. The men have jobs and use public transportation. They live with a support person who works for a private agency.

In addition to getting a job, Daniel plans to take computer, fine arts and vocational courses at the Adult & Community Education school, and arts classes at Pyramid Art Studio. On top of all that, he'll keep studying karate, as he's been doing for the past six years.

His mom, Anna Jordan, said the plan is for Daniel to live on his own some day. It's difficult to find services for adults with disabilities, but her family has learned to take risks so Daniel can live a fulfilling life. "We really believe there's dignity in risk," she said. "We might not think Daniel can do something, but we risk failure so he can try."

Daniel's friends seem to think he can do anything. The Special Olympic athlete became quite the basketball player through a physical-education class and by serving as the manager of the varsity basketball team. "You'd swear he'd be the next one in," said Steven Roberts, who met Daniel just by passing through the halls. "He'd always say, 'We're going to win.' We could be playing FSU next week and he'd say, 'We're going to win.'"

But he's got a no-nonsense side too. "Dan will set you straight if it's needed," said Ashley Blakeney, who's known Daniel since fifth grade. "He keeps it real. You need a friend like that."

Daniel met many of his friends through Chiles' inclusion program. He took academics in classes for special needs students, but he took his electives with the rest of the population. Saying goodbye to friends will be one of the hardest parts of leaving Chiles, he said. "It's a tear-jerker," he said. "I miss my friends already. They helped me succeed in four years. Without my friends, I'll be lost with nowhere to go." But Jordan said her family and the parents of other special-needs students in Daniel's school work to keep that social group together.

As Daniel begins a turning point in his life, his mom is reminded of a question he once asked her. "He asked me if he was the only student at Chiles with Down syndrome," she said. "I had to think about it and I said, 'Yes, you are.' Then he said, 'I have a real responsibility. I have to show everyone what a kid with Down syndrome can do.' He does take his role very seriously."

World Watch

The Ring

Published: February 23, 2005, <http://www.ndss.org>

People with Down syndrome use their creative talents to make contributions to the arts every day. One shining example is Melissa Riggio, a 16-year-old poet and songwriter. Melissa recently collaborated with singer-songwriter Rachel Fuller to produce her debut single titled "The Ring." Melissa's poignant lyrics combined with Rachel's powerful music and voice make this song a truly unique piece. Following are Melissa's thoughts on her inspiration for "The Ring":

"I like writing music because I have so much to say. When I write a song I think about a topic. Then I think about what is going on in my life and my future. I like writing songs. I get to know myself better. It goes around myself and my family. When I go inside 'The Ring' I feel like a shadow that's following myself around my heart. I hear God telling me I am special and I will be somebody. I know I am too young to know what I will become in the future. I just know there are big things to come. I would love to write songs with other kids who have disabilities."

The Ring

Words by Melissa Riggio, Music by Rachel Fuller

I'm in the Ring outside
I'm following my belief
I'm looking at the sky
I saw God following my heart
I'm an ordinary woman

The Ring is falling down my way
The wind is blowing me away
The Ring is falling down, down my way
The wind is blowing me away

And so I came back to
The center of the Ring
Am I just a broken angel?
God has sent me here to heal
To be an ordinary woman

Rachel Fuller - piano, vocals, backing vocals, keyboard
Stuart Ross - bass guitar
Jolyon Dixon - acoustic guitar
Jodie Hawkes - drums

Producer - Rachel Fuller
Engineered and Mixed - Myles Clarke
Mastering - Jon Astley
Executive Producer - Pete Townshend

You can listen to Melissa's song at <http://www.ndss.org>

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:, 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 you 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

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		

Noticeboard:

Information and Services

PROPOSED AMENDMENT TO THE NATIONAL DSA CONSTITUTION

YOU ONLY NEED TO READ THIS IF YOU BELONG TO THE NATIONAL DSA

Over the next couple of months, people that belong to the National Down Syndrome Association will be asked to vote on a proposal to change the national constitution. The Wellington Down Syndrome Association has been asked to look at the proposal and give its comments. As an association, however, we do not have a vote - only individuals that belong to the national body get a vote. Because of this, we feel that you should be made aware of our concerns regarding the proposal and then vote as you see fit. The proposal itself will be outlined fully in the national newsletter.

We believe that the proposal has a lot of positive points and the underlying purpose of it is good. However we have some major concerns which are outlined below. The proposal will be voted with a straight YES or NO, so it will either go through as is or will be rejected in total for review and further work. The Wellington Down Syndrome Association strongly suggest you vote NO as we feel the proposal needs further work and refinement before it should be passed.

The positive aspects of the proposal are that:

- we agree that the national body should be a bottom driven structure (ie ideas at the local level go up to national).
- we value the regional representation and the affiliation links that this would bring.
- we fully support the idea of the free 1 year membership to the new parents to the national magazine.

The concerns we have are as follows:

- the proposal does not safeguard local associations' identity and individualism. We have various activities that we promote (eg our newsletter and Francis Clarke Awards) on a local level. By affiliating to a national body where we only have one vote on - it is possible that 'local activities' could be shut down - we need some clause in the national constitution that safeguards our specific activities.
- we already have a set of 'rules' and would require that these be able to be retained.
- a major point is the fee structure outlined in the proposal and how it might be made compulsory. In the Wellington Region a conscious decision was made that our members wouldn't be charged a membership fee. If this fee was made compulsory then this would go against the principles that have already been laid down. We are aware that National can waive the fee but not asking a fee versus waiving a fee is completely different.
- associated with the fee structure question is the local versus national membership. We are concerned that in the proposal you must join at the National level in order to belong to the local level. We think there are a reasonable number of our members that have no interest in joining a national association and the way the proposal is worded is very limiting. We would not want people to 'quit' at the local level because we have 'forced' them to join the national body.

Noticeboard:

Information and Services



Sincere thanks to SERCO Project Engineering Limited, Upper Hutt, for their continued support to the WDSA by photocopying our quarterly newsletter.

Frances Clarke Memorial Awards

Nominations are invited for the Frances Clarke Memorial Awards, to be held in October 2005 at Government House. The awards recognize and encourage special achievements by people with Down syndrome in the Wellington Region.

There are two award categories, 8 – 16 years and 16 years and over.

Special achievements need not be spectacular or a world first.

They will have taken determination, application and perseverance. They will demonstrate the ability of someone with Down syndrome to overcome their difficulties by completing a task or by showing, through their way of life and attitudes towards others, that they lead full and rewarding lives.

If you would like a nomination form, please contact Kate ph 970 7229



Soccer and activities for Special Needs Children 4 – 8 years

Where: Upper Hutt Indoor Sports Centre,
Montgomery Crescent, Upper Hutt

When: Every Saturday (except school
holidays)

Time: 11am

Our aim is to have lots of fun and learn some ball skills as well. A donation of \$2 each week is appreciated to help towards cost of equipment etc. Contact Robyn Stokes, ph 976 7468

WDSA OPERATES PURELY FROM GRANTS AND DONATIONS WITHOUT ASKING FEES EVERY YEAR FROM PARENTS. AT THE MOMENT, THERE ARE SOME THINGS THAT WE WOULD LIKE TO DO BUT DON'T HAVE ENOUGH SPARE FUNDS (I.E. NEW VIDEOS FOR OUR PARENT LIBRARY ETC). IF ANYBODY WOULD LIKE TO DONATE ANY MONEY TO THIS WORTHWHILE CAUSE - PLEASE SEND IT TO OUR TREASURER, CAROL WESTON, 54 ANNE STREET, WADESTOWN. THANK YOU.

**AGM – please see our flyer on
the WDSA AGM on
Wednesday 29 June 2005 at
7.30pm.**

Down Syndrome Dolls Here is a chance for early childhood centres, medical clinics, early intervention teachers, parents, etc. to add a doll with Down syndrome features to their collection. There are 8 different dolls, 1 boy and 7 girls, with hand-painted faces and custom made clothing. Their body is made of soft cotton-wool blend and poly limbs. They are machine-washable in the delicate cycle. The dolls are approx. 16" 42cm) long. Check out our web-site: www.downsyndromedolls.co.nz

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.