



WVDSA Monthly

Willamette Valley Down Syndrome Association

Christmas Party 2002!

Thank you, Katie Ross, for an extremely well-organized and delightful Christmas Party! Not only was the event well-attended, but we had a large number of very happy kids who seemed to be having a ball while their parents enjoyed a chance to chat with other adults!

Katie had lined up an excellent selection of edibles, including cookies, cake and punch supplied by the **Benton County ARC**—all of which was much-appreciated by those in attendance! There was so much food that a lot of us ended up taking food home—a welcome addition for the holidays!

The original “Santa” who

was scheduled to appear (Tim Fredericks) ended up in the hospital, which meant that “Mrs. Santa” (Heather Fredericks) needed to be there with her husband. Katie had a “second-string” St. Nick in the wings, though, who was excellent and found himself surrounded by adoring children, vying for his lap!



Looking Ahead

The Oregon Parent Training and Information Center is holding a series of training workshops to train parents to be IEP Partners, helping other parents through their I FSP or IEP meetings. For more information, see the article on page 3. The first training session is

January 24 & 25 in Tualatin, so immediate action needs to be taken if you're interested in taking part.

Be sure to put February 18th on your calendar—the date of next month's WVDSA meeting. Our speakers will be veteran parents,

Terry Sanders' friend, Leslie, came with her guitar and a box full of musical instruments, becoming an instant success with the kids, who were her back-up band while she sang.

I think all of us who were there would agree that this was an excellent party! Thanks again, Katie!

WVDSA
2598 NW Maser Dr
Corvallis, OR 97330

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In this issue:

Christmas Party 2002 1

Looking Ahead 1

“Eleanor Helps Herself”-by Eleanor Bailey, Portland, Oregon 2

Future Child of the Month Candidates 2

January Meeting: Michael Bailey—What's the Big Idea? 3

Directions to the January Meeting 3

President's Corner 4

Bud & Dot Fredericks and others, giving us some information “from the trenches”, as well as answering questions about raising our special children! That meeting will be at the Grace Lutheran Church in Corvallis. More information coming!

Eleanor Helps Herself—by Eleanor Bailey, Portland, Oregon

Eleanor is the now-14-year-old daughter of our January speaker, Mike Bailey. She has always been part of a fully included classroom and is a happy, normally-developing teenager.

(From "Mouth Magazine:Voice of the Disability Nation", March, 2000)

I am eleven years old and in fourth grade. This year some little girls came to my school. I heard some people say that they had Down syndrome. On a Saturday I asked my Mom, "Do I have Down syndrome?" Mom said that I do.

I went up to my bedroom and closed the door. I didn't cry but I shut the door and was mad and upset. I didn't want to have Down syndrome.

On Monday I went to school and I told my teacher, Mrs. Karr, that I had an announcement to make. She gave me the microphone and I said: "I have two things to say. First, I have Down syndrome and second, I am really scared that none of you will like me anymore."

My friends were really nice. They said they already knew that and that they still liked me. Some of them cried. I got lots of hugs.

But I am still not happy!

On Wednesday my Dad and I got on an airplane and went to Chicago. On the airplane I listened to my Walk Man. I have a song that goes "Clang, clang, rattle, ping, bang. I make my noise all day." I thought that is what I can do. Even with Down syndrome I can still make my noise.

We went to the TASH meeting. There were lots of really cool people there. We stayed in a big hotel. In our room there were two bath-

rooms. One had a shower and one had a bathtub. I made a sign that said "Girls" and put it on the door of the one with the bathtub. I didn't want my Dad to come in.

I took lots of baths. I thought if I took enough baths I could wash my Down syndrome away. I also thought I would put hairspray on it but my Mom and Dad won't let me have hairspray. I tried to put sunscreen on it because I thought that maybe then I wouldn't have to have it all the time. But my Dad said that none of that would work.

I have friends that were at TASH. My really special friend is Tia Nelis. She lives in Illinois. Tia has a disability but when Tia talks people listen. They really listen. Tia is a leader and she really likes me. I told Tia that I have Down syndrome. I was surprised when she said that she had always known that. She said she didn't care. She said that I am an important person and that Down syndrome is not as important as being a wonderful person. When I grow up I want to be just like Tia.

I have other friends at TASH who told me the same thing. I meant a really nice person named Katie. Katie goes to college. Katie has Down syndrome. I also talked to my other friend Liz Obermayer. Liz has a new job and is moving to Maryland which is a state. Liz has a disability but she is a leader too. She is on the Board of TASH. Liz goes to lots of meetings and people listen to her too.

I got my name from Eleanor Roosevelt. Lots of bad things happened in her life. I have read all about her. She was a leader. I also know

about Rosa Parks, Martin Luther King, Nelson Mandela and Robert Kennedy. Lots of bad things happened to them but they were strong and were leaders. My Dad says they made people proud of who they are and made them free.

I wish I didn't have Down syndrome, but I do and I am a person with lots of plans. When I wonder what to do I will remember my song. I will do what it says. I will go 'clang, rattle, ping, bang and make my noise all day.' Even though I am sad I know I can be as tough as anyone. That is what I want to do.

Just be me.

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Subscriptions to **Mouth Magazine: Voice of the Disability Nation** are available. **Mouth Magazine PO Box 558 Topeka, KS. 66601-0558 www.mouthmag.**

**January 21st
7:00—9:00 PM
Willamette
ESD
2611 Pringle
Road SE
Salem, OR**

Child of the Month Submissions

We still would love to be able to publish a WVDSA "Child of the Month" Feature from time to time! To have your child featured, please send information to Gretchen Davey at 370 Center St, Lebanon, OR 97355. Send either a short story about your child or the information so we can write it up. Also include 1-3 pictures we can put in the newsletter. Pictures will be returned. Thanks for your help!

January Meeting: What's the Big Idea about IDEA?



We have a huge treat in store for us in the person of Michael Bailey, editor of the "Oregon Clarion" magazine for citizens with disabilities. We're fortunate enough to have him as our January speaker, planning to help us understand the "Individuals with Disabilities Education Act" (IDEA) - legislation that will affect all of us at some point or other as parents of children with disabilities.

Michael has quite a list of accomplishments to his credit: He is the President of the Oregon Advocacy Center and on the Board of Directors of the National Coalition of Self Determination. He has been a full-time advocate for 10 years, has been Oregon Coordinator for Partners in Policy Making, and has been a presenter on parenting and education issues at numerous state, national, and international conferences. He is the author of numerous articles on disability-related topics and, as stated above, is the editor of the "Oregon Clarion". Michael was recently named Director of the Community Partnerships Project, funded by the Oregon Council of Developmental Disabilities.

In addition to this long list of impressive credentials, Michael Bailey is known to be an entertaining and inspir-

ing speaker. As one person put it, "He definitely won't put you to sleep!"

We encourage ALL of our WVDSA members to try to make it to this meeting and hear what Michael Bailey has to say! Those of you in the southern valley—Eugene, Corvallis, Lebanon, and others—plan to get a carpool together so you don't miss out! Traveling is always a lot more fun with company!

If for not other reason, you owe it to your children to find out what your rights are under the IDEA legislation! What you don't know **can** hurt! Plan to come and be enlightened!

IEP Partners Training

If you have children in school—or will have in the near future—you know all-to-well what an IEP is! Here's an opportunity to help support other parents with their IEP meetings!

Oregon Parent Training and Information Center in Salem is offering several intensive, two-day workshops to train parents to help parents.

Training includes: information about IDEA (any questions left after Michael's presentation can be answered here!); I FSP/IEP components (transition and behavior); Principles of Communication; Parent/

Professional Partnerships; and MORE!

Once trained, the IEP Partners will be matched with parents wanting support at their IEP meetings. The IEP Partner will receive a stipend for every IEP meeting they attend on behalf of the Oregon Parent Training & Information Center.

IEP Partner Training Dates:

January 24 & 25: Tualatin (9-4 PM) at Meridian Park Hospital.

February 7 & 8: Salem (9-4 PM) at OTAC, 3886 Beverly Ave. NE, Bldg I, Room 35.

March 14 & 15: Eugene (9-4 PM) at Lane ESD, 1200 Hwy 99 N, Room 5

May 16 & 17: La Grande (9-4 PM) Union Baker ESD

September 19 & 20: Medford (9-4 PM) at the Smullin Center.

Registration Required: Space Limited!

To register, or for more information, call Karen Ripplinger at 503-968-7030 or 1-888-505-2673, ext. 212. E-mail: orptikaren@aol.com.



Directions to WVDSA January Meeting

To reach the Willamette ESD at 2611 Pringle Road SE in Salem:

From the North: Take I-5 S to Exit 253 - Hwy 22 to North Santiam/Stayton - and bear right on ramp at sign reading "Salem and OR-99E Business". This is also Mission St. Continue on this for 1.0 mile. Turn left on 25th St. SE and go South for 0.4 miles. Turn right on McGilchrist St. SE and go west for 0.8 miles. Turn

left on Pringle Rd. SE and go south for 0.1 miles to the WESD.

From the South: Take I-5 North to Exit 249 to Salem. Bear left on Commercial St. SE and continue on this for 2.6 miles. Turn right on 12th Street Cut-off SE and follow 12th St. until you reach Fairview Ave SE. Turn right and go east for 0.2 miles. Turn left on Pringle Rd SE and go north for 0.1 miles to WESD. (**Alternate direc-**

tions from the South: Take Exit 253 and follow the directions from the north. We've found this to be a quicker way to get there.)

We'll be meeting in the "Marion Room" on the second floor.

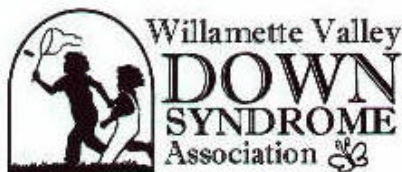
If you have any questions, call Debbie Lisle at (503) 371-3046 or Gretchen Davey at (541) 451-5215. We hope to see you at the meeting!

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President's Corner

Dear Friends of WVDSA,

HAPPY NEW YEAR!

It is just sinking in that there is life after Christmas and "The Wedding"; the two events melt together like a dream that's hard to remember. My daughter assures me that, indeed, she is in her second week of wedded bliss. We really did have a great time with our full house, new grandbaby and all.

Like stubborn weeds (or lovely perennials), business that was buried under more immediate demands resurface vigorously and I've been scrambling to get back into the "Down syndrome mode". I need only read our mission statement to motivate me to keep going with the business of the WVDSA. Our mission is to provide our children with a better quality of life in our communities now and in the future by being advocates for them through: Parent/family support and networking.

New parent education and support. Community education and awareness. The purpose of a mission statement is to keep our goals and activities focused. I have met other leaders of other groups around the country and they all have a mission statement. From the Down Syndrome Association of Greater

Saint Louis:

"To advocate for the needs of individuals with Down syndrome. To offer support, acceptance and encouragement of parents and families of persons with Down syndrome. To increase our awareness and knowledge of issues relating to Down syndrome. To educate the community about the presence, the potential and the needs of people with Down syndrome. To promote inclusive environments for all persons".

From group to group the statements vary but the intent and purpose is very similar and clear. We are an awesome group of parents working toward common goals, which help our children, and family members reach their full potential.

To that end our January meeting is planned. Michael Bailey is excited to come and speak about the IDEA. He has vast experience in law, advocacy, and public policy and as a father of a daughter with Down syndrome. (See Eleanor's story, page 2) This is a forum for all age groups.

I have a new book, which I am recommending. It is called: "DOWN SYNDROME VISIONS FOR THE 21ST CENTURY"; Edited by William I. Cohen, Lynn Nadal and Myra Madnick. It is a com-

prehensive guidebook for parents and professionals. The National Down Syndrome Society dedicates the book to the "real experts the individuals with Down syndrome and their families who are in the forefront of the Down syndrome movement. Their insight, passion, and dedication have greatly enhanced the lives of all people with Down syndrome."

So a New Year toast to our little band of dedicated, passionate people of the Willamette Valley Down Syndrome Association: Thank you for your dedication and support, God Bless you as you and your children strive for goals and reach important milestones. Have a wonderful and Happy New Year!

Sincerely,

Debbie Lisle

