



WVDSA Monthly

Willamette Valley Down Syndrome Association

Christmas Party 2004: Newport Hospitality!

"Wow, Rachel did a fabulous job with the Christmas Party! Great all the way around, if you missed it you missed one of the best parties we've had as a group. Santa was incredible, he was the real thing. She had great prizes for free raffle drawings. Lasagna dinner, yummy homemade rolls,



soda fountain from Pepsi, coffees, etc. She even had the tables set with linens! Very nice. Our family had a great time. We had about 75 people there, several families from the

coast. That was great for them to be able to participate and meet new families and kids. Several older young adults with Down Syndrome that were making plans to get together in the coming year. Beth (her dad is Curt Zeisler, but I can't think of her last name!) made a friend from the coast area and they had plans to get together. Fun, fun."

-Keri Prince

"I would like to echo Keri's sentiments regarding the Christmas Party yesterday. Rachel did an outstanding job preparing. Great activities for everyone, great food, excellent decorations and gifts, etc. I was blown



away by what Rachel pulled off with much of it donated!

"Let's get the word out so people know what they

(Continued on page 2)

January: Membership Re-Enrollment

Remember that January is now our membership renewal month. Send your \$25 dues to the Corvallis address (return address) before February 28th. Thanks!! If you renewed at the Buddy Walk, disregard this notice!

January Speaker: IMPACT's Marquell Johnson

Marquell Johnson, the director of OSU's IMPACT program, is our January Speaker! Many of our group who live within easy driving distance of Corvallis have our children in what used to be called the "Motor Fitness Clinic". The children and young adults, ranging in age from infants to 21-



year-olds, get instruction, both swimming in the large

pool and exercising in one of the gyms in the Women's Building on OSU's campus. Clinicians who work with the children are usually students working on a related major, although some are volunteers who used to be in the class and have continued to help, even after

(Continued on page 2)

WVDSA
4272 NW Pintail Pl
Corvallis, OR 97330

Volume 5, Issue 3

January 1, 2005

In this issue:

Christmas Party 2004: Newport Hospitality!	1-2
January: Membership Re-Enrollment Month	1
January Speaker: Marquell Johnson from OSU's IMPACT	1-2
Future Child of the Month Candidates	2
January Child of the Month: Ian Tully	3
Directions to the January Meeting	3
Comin' Around the Corner	4



(Continued from page 1)

missed...not in a way to make them feel bad, but in a way that will make them want to come in the future."

-Mike Moore



Marquell Johnson, cont.

(Continued from page 1)

their class requirements were finished.

Marquell is a doctoral candidate doing graduate work in Movement Studies in Disability. He is passionate about motor & physical fitness needs of people with disabilities—especially those with Down syndrome. He will talk to us about the importance of physical fitness in our children's lives & how it affects their health.

The future Dr. Johnson will talk to our group on **January 18 at 7:00** in the **Community Center of the Grace Lutheran Church**. Directions are on Page 3. Be sure to come!

Childcare will be provided in the church preschool area downstairs.

Ian batted at the Piñata hanging from the old oak tree in the Tully Family's yard. With his Dad, Charlie's, help, he swatted it hard as everyone cheered him on, including Mom, Connie, brother, Isaac, and the gathering of relatives and friends. Chicken simmered on the barbecue. The picnic table was laden with inviting dishes.

The big day had come. Ian, now 6, had been diagnosed with Leukemia at age 2 1/2 and after 3 years of treatments at Doernbecher Children's Hospital in Portland, he was now off of chemotherapy! He is still required to return for check-ups for another 4 years, but the worst days are behind him. The many symptoms caused a series of emergency hospital visits (2 hours up to Portland in the middle of the night) and regular blood draws, transfusions, injections of chemo medicines, while under anesthesia, and so much more.

For Charlie and Connie, it became a "one day at a time" affair. They took turns driving to the hospitals and staying up at night to care for Ian, administering drugs, reading, and singing to him and managing his weakened body. Some days were better than others. Little Ian with his Down syndrome was unable to communicate about his pain. He had amazing patience throughout his ordeal, but, of course, there

were many tears.

A special event which lifted the hearts of the whole family, was when Ian was selected by the



Ian Ash walks on the beach at Newport

Make-a-Wish Foundation to name his fondest desire. Everyone knew how much he loved the beach and the ocean, so instead of a long trip to Disneyland by plane, where he would be exposed to whatever, they decided to go to Newport on the Oregon Coast, where they spent five days of bliss arranged by

two wonderful volunteers for Make-a-Wish: Suzette Malkasian and Robyn Sattler. Everything was completely taken care of and Ian and Isaac were both treated to everything from balloon bouquets and baskets of toys and games and certificates to absolutely anything they wanted to see and eat.

(Continued on page 3)

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 Child of the Month: Ian Tully (cont.)



(Continued from page 2)

Now that wonderful day arrived. The doctors said the next treatment would be the very last procedure. Although the treatment was postponed because Ian caught the flu, it finally did happen!!!

No one counted the number of phone calls made to doctors and nurses, but for sure it was well over a hundred. Connie and



Charlie cannot say enough good things about Doernbecker and the staff of doctors, nurses, physical therapists, anesthesiologists and the many parents of sick children who lent their support and comfort. They are so thankful for everyone who helped their son.

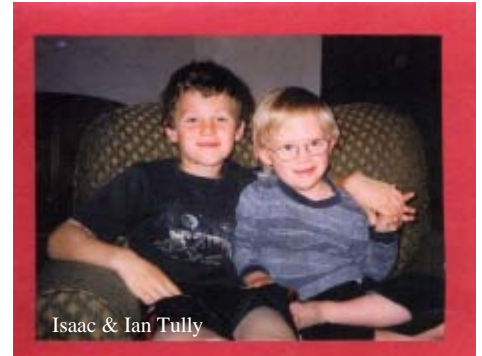
Soon after being off the chemo drugs, Ian's strength improved and he was more and more "a happy camper". Isaac and he have great fun together, especially wrestling on the living room floor and romping with their dog, Sally.

Note: Acute lymphoblastic leukemia (ALL) is characterized by abnormal numbers of immature white cells. After many years of research, ALL is considered to be one of the most curable forms of childhood cancer. About 80% of children with ALL who receive 3 or more drugs during the weeks of the intensive phase of treatment achieve complete

remission.

~*~*~*~*~*~*

Connie & Charlie Tully have had quite a time finding someone to be with Ian for a certain period of time each week. Following is the information they would like you to



know, in case you or someone you know would be able to meet this need:

"Looking for an in-home child caregiver. Wednesdays 11:00 a.m.—5:00 p.m. and Thursdays 11:00 a.m.—6:00 p.m. Six-year-old boy with Down syndrome and 9-year-old brother (comes home at 3:15 p.m.) Background check required. 30 minute drive from O.S.U. (Corvallis) Call Connie or Chuck: (541) 424-3118."

Directions to WVDSA January Meeting

WVDSA Meetings at the Corvallis site, Grace Lutheran Church, can be reached by following these directions: Coming from I-5 - follow Highway 34 into Corvallis, coming over the bridge just east of town. You will be on Harrison Street, a one-way street heading west. *Follow this until you get to the intersection with Kings Blvd. At this point, you will want to be in the right hand lane, because just as you

go through the intersection, a sign will say "Right Lane Ends". You will remain in the right hand lane, however, because you will turn into the parking lot of Grace Lutheran Church before the lane ends. We are meeting in the Fellowship Hall at the north end of the building. You'll see other cars parked near the entrance.

If you're coming in on 99W from the north or south, turn right (from the

north) or left (from the south) at Harrison and follow the directions from I-5 from *.

The church address is **435 NW 21st St** at the corner of Kings Boulevard and Harrison Street.

If you have any questions, call Mike Moore at (541) 753-3975 or Gretchen Davey at (541) 451-5215. We hope to see you at the meeting!

WVDSA
4272 NW Pintail Pl
Corvallis, OR 97330

Editor: Gretchen Davey
Phone: 541-451-5215
E-mail: daveymg@centurytel.net

President: Mike Moore
Phone: 541-753-3975
E-mail: mmoore105@hotmail.com

Treasurer: Mark Miedema
419 Dorcas Drive North
Keizer, OR 97303
Phone: 503-390-0567

Buddy Walk Chair: Keri Prince
1490 NE Carly Court
McMinnville, OR 97128
Phone: 503-434-8618
E-mail: arkprinc@msn.com

New Parent Education: Cory Harrington
Phone: 503-463-9788
E-mail: wvdsacory@yahoo.com

Comin' Around The Corner

Some more upcoming events about which you may be interested:

January 6, 2004 - How Behavior is Addressed in the IEP- in **Medford** at the DHS Child Welfare Annex from 9 - noon. Reservations are required. Please call Patt Fisher 541-776-6120 extension 251 at to register or for more information. Sponsored by Jackson County DHS Child Welfare.

January 11, 2005 - Behavior that Interferes with Learning in Albany at the Fairmont Building from 6:30 - 8:30 PM. Registration is required, please contact Shelley Joyce, 503-581-0018, or email sjoyce@orpti.org.

January 18, 2005 - Behaviors That Interfere with Learning from 6:30 to 8:30 PM, Cascade District Offices Boardroom, 10226 Marion Rd. SE, in **Turner**, . Sponsored by the Cascade School District. Registration is required, please contact Shelley Joyce, 503-581-0018, or email sjoyce@orpti.org.

February 8, 2005 - Transition from High School/Age of Majority Issues in

Albany at the Fairmont Building from 6:30 - 8:30 PM. Registration is required, please contact Shelley Joyce, 503-581-0018, or email sjoyce@orpti.org.

February 28, 2005 - High School Transition - in **Klamath Falls** at the Lucille O'Niell Education Center from 1:00 - 3:30 PM. Hosted by Klamath City Schools. Reservations are required. Please call Kirsten Thompson at (541) 608-8586 kthompson@orpti.org to register or for more information.

March 8, 2005 - IDEA/Section 504 in Albany at the Fairmont Building from 6:30 - 8:30 PM. Registration is required, please contact Shelley Joyce, 503-581-0018, or email sjoyce@orpti.org.

March 30, 2005: Transition: Postsecondary Options for Education and Employment, 6 PM to 9 PM, Newberg School District Offices, 714 East 6th St., **Newberg**. Sponsored by the Office of Student Learning and Partnerships, hosted by Newberg SD. Registration is required, please contact Shelley Joyce at 503-581-0018 or email sjoyce@orpti.org.

[org.](#)

April 12, 2005 - Statewide Assessment in Albany at the Fairmont Building from 6:30 - 8:30 PM. Registration is required, please contact Shelley Joyce, 503-581-0018, or email sjoyce@orpti.org.

April 25, 2005 - Behavior in the IEP - in **Klamath Falls** at the Lucille O'Niell Education Center from 1:00 - 3:30 PM. Hosted by Klamath City Schools. Reservations are required. Please call Kirsten Thompson at (541) 608-8586 kthompson@orpti.org to register or for more information.

April 26, 2005: ESCE Transition to Kindergarten, 6 PM to 9 PM, Newberg School District Offices, 714 East 6th St., **Newberg**. Sponsored by the Newberg SD. Registration is required, please contact Shelley Joyce at 503-581-0018 or email sjoyce@orpti.org.

May 10, 2005 - Assistive Technology in Albany at the Fairmont Building from 6:30 - 8:30 PM. Registration is required, please contact Shelley Joyce, 503-581-0018, or email sjoyce@orpti.org.