



# WVDSA Monthly

## Willamette Valley Down Syndrome Association

### Estate Preparation with Kevin Mayne

For anyone who has wondered what will become of their disabled child if they are suddenly removed from the picture, Kevin Mayne had some very practical advice to offer.

One of the first suggestions he had was to make a notebook of information that is easy to find. This needs to be an "Everything You Ever Wanted to Know about 'Johnny'" notebook, designed to allow someone, who may not know him well, to become acquainted with your child. Besides important information such as Social Security number, birth certificate, medical history and medications, and things crucial for his well-being, you should also include more personal infor-

mation. For example, what kinds of food does "Johnny" like best? Does he have a favorite story? Is there a "security blanket" he'll need to keep him from feeling totally lost? What things does he like to do? You're introducing your child to the person who may become his caregiver—or may need to communicate with his

potential caregiver.

This notebook needs to be kept in an easy-to-locate spot, communicated to a trusted friend or relative ahead of time. It could be titled, "The Story of Johnny" or something.

In addition to this important item, Kevin went

*(Continued on page 3)*



### Looking Ahead

Our session with Kevin was so helpful that we've had requests to repeat it for those who missed his April presentation. He has kindly agreed to do his meeting on Estate Planning in Salem for our June 17th meeting.

We'll be meeting in the Marion Room at the Willamette ESD (directions will be provided in the June newsletter) on Pringle Road. We will meet from 6:00—9:00 PM. Kevin will provide a very helpful handout for those attending, but come

prepared with questions you may have about your own, individual needs in regards to planning for your child's future.

Thank you to Debbie Lisle, who was able to set this up on short notice! See you next month!

WVDSA  
2598 NW Maser Dr.  
Corvallis, OR 97330

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## Creating Collaborative IEPs:

Creating Collaborative IEP's:  
Building Parent/Professional  
Partnerships That Work

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- What parents bring to the IEP discussion
- What professionals bring to the IEP discussion
- Developing positive communication skills
- How to work as a team to provide successful outcomes for students

May 15, 2003  
6PM - 9PM  
3886 Beverly Drive, Salem  
OTAC Conference Room  
Bldg. I—Room 35

(Beverly Drive is off Lancaster Drive, north of Market Street.)

Class is limited to 20 people, please make reservations by contacting Shelley Joyce at 503-581-0018 (Salem) or E-mail shelljoyce@attbi.com.

Oregon Parent Training and  
Information Center  
1745 State Street  
Salem Oregon 97301

503-581-8156  
Toll free: 888-505-2673  
www.open.org/~orpti



## May 2003: Spring Social

It's hard to believe that it's already time for our next Spring Social, but the month of May is upon us! This is always a time of a lot of fun and fellowship, but we're kind of cutting back in the "organized activities" department.

What we're planning to do is have a "Pizza Night" this year. The WVDSA will provide pizza for everyone and we'd like each of you to bring either a salad or dessert—or both if you feel so inclined! Katie Ross is getting

things together and we plan to have paper plates and plastic utensils to cut down on the clean up!

The social is going to be held at the Grace Lutheran Church in Corvallis on **Tuesday, May 20th at 7:00 PM**. We'll probably try to get some kind of activity together for the kids, but mostly this will just be a nice time for the adults to visit and get to know each other a little better!

If anyone feels the urge to be in charge of a craft project for the kids

or some other activity, we'd love to hear from you. Call Katie Ross at 541-929-2884 and let her know you're willing to help out in that capacity! This is going to be a group-project and we're not going to turn down **any** offers of assistance!

**May Meeting**  
**Spring Social**  
**7:00 PM**  
**Grace Lutheran Church**  
**435 NW 21st St**  
**Corvallis, OR**

## Meet Madison Howell, Our Newest Member!

Madison Ann Howell, daughter of Jim & Kim Howell, whose birth was announced in our last newsletter, came to her first meeting in April, at only 6 weeks old! She is a precious little bundle of pink - pampered and loved by her two big brothers.

Madison underwent open heart surgery on Friday, April 25th. We were fully expecting this to be the "usual easy procedure" that so many of the

heart surgeries they do today are, but, unfortunately, Madison's little heart presented some unique problems. It has some symmetry problems that are re-



quiring additional surgeries to correct. At this date, she's still up at Legacy Emmanuel Hospital in Portland, under the care of their expert heart team.

Kim says they'll keep us posted on her progress. In the meantime, if you're inclined to keep them in your prayers, please do so! Each one of our special kids is a precious gift, but each one comes with his or her own unique challenges! At these times, it sometimes helps to leave things in the care of a "higher power."

## Kevin Mayne (continued)

(Continued from page 1)

into the importance of careful preparation for your child's financial care. He had prepared an excellent hand-out: "Issues to Address in Life Planning for a Disabled Child". This covered the four main areas parents need to think about when planning for their child's future.

The first area is the "Lifestyle Planning" section, where you need to consider such issues as where your child will live, what kind of diet will he need, what medications he is on, in what religion has he been raised (and do you prefer he continues in this faith), etc. This is the sort of thing you will want to have listed clearly in the information notebook you make up, including a "To-Do List" for immediate action after you are gone.

Another area to continue is the Government Benefits to which your child will be entitled. These are divided into two categories: benefits not based on resources (SSDI and Medicare) and benefits based on resources (SSI and Medicaid). Where your child needs to be categorized will be an important thing to determine before you are gone, if at all possible. Kevin covered all of this in some detail.

## Directions to May WVDSA Meeting

WVDSA Meetings at the Corvallis site 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



The third area covered was "Legal Planning", which includes disposition of assets through a will or trust, consideration of guardianship or other decision-making roles for your disabled child, etc. There are many different ways to be sure your child's needs are taken care of and won't result in his being "penalized" for having too much in the way of assets (or having these assets turned over to the government).

The final area was "Financial Planning" - how will you pay for your plan? Again, there are many options in this area—ways you can make sure you are

able to provide for your child's future.

If you want to find out more about this subject or have questions after

reading this "overview" of Kevin's talk, be sure to attend the June meeting in Salem (see front page). If you already attended the April meeting, don't hesitate to come again!

**For Child of the Month Entries: Submit your child's information to: Gretchen Davey**  
**370 Center St**  
**Lebanon, OR**  
**97355**  
**wvdsa@ookla.com**

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

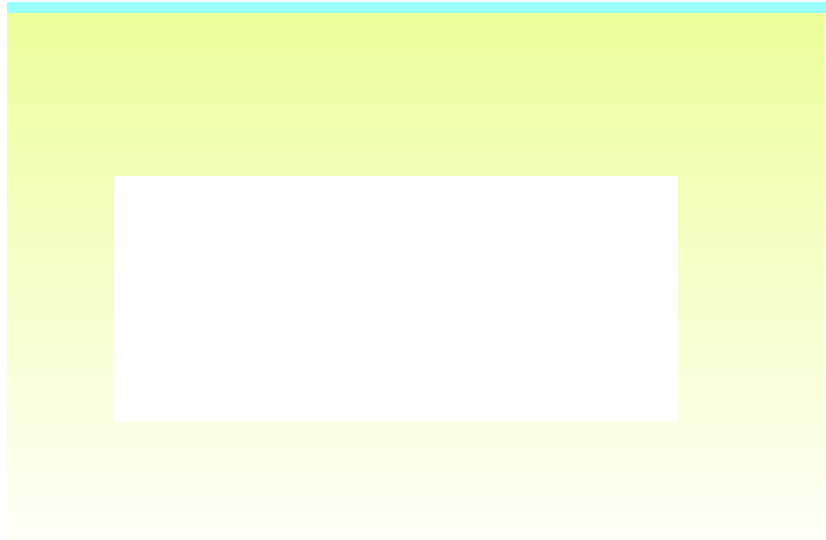
If you have any questions, call Mike Moore at (541) 753-3975 or Gretchen Davey at (541) 451-5215. We hope to see you at the Social!

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E-mail: nbimike@pacifier.com



## President's Corner

Dear WVDSA Members,

After nearly two years of hard work, Debbie Lisle has stepped down as our president. To honor her contribution to the group, at our April meeting she was given a bowl of growing bulb flowers—daffodils, etc.—and gift certificates for some much-deserved pampering, along with a card from the group. We appreciate all she has done—especially the terrific job she did organizing our very successful Buddy Walk last October!

Debbie will continue to be active in the WVDSA, but has stepped back to let others have a turn as the president. Mike Moore has agreed to be the acting president until we are able to hold an election—probably at the May Spring Social on the 20th. If any of you have an interest in serving in this capacity, please be sure to

attend and let us know of your interest.

We will also elect a secretary, treasurer, and vice president. The current officers are Gretchen Davey, secretary; Keri Prince, treasurer; and Mike Moore, vice president in charge of membership and fund-raising. Since Mike will be stepping into the presidency for the time being, we would be glad to have someone who is interested in taking over any of his current duties.

We have lots of plans for the WVDSA in the future. Our 2003

Buddy Walk is coming up and we'd love to have lots of help planning it and getting things set up. Last year's walk was a very successful fund raiser for the group, bringing in several thousand dollars. With everyone's help, we'd love to do even better this year!

The key to a thriving group is participation and we've been delighted with the number of people we've had at the last few meetings! The more of you who claim an active role in the group, the better we'll do in the future. Our mission continues to be educating our community about Down syndrome and providing support for families of children with DS.

Thank you for all of you who are catching a glimpse of our vision for the future and are stepping forward to take an active role!

