

# THE DAILY JOURNEY

SEPT/OCT  
2011

NEWSLETTER for DOWN SYNDROME and DEVELOPMENTAL DISABILITIES

Funded in part by an FSS grant from Taconic DDSO

Contact: DSAHV, PO Box 352, Gardiner, NY 12525 845-226-1630 info@dsahv.org

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## → **EVENT UPDATE AND LOCAL HAPPENINGS**

### ▶ **SEPTEMBER 17, 2011 Noon-4pm**

DSAHV Fall Family Picnic Montgomery, NY. Join us at the Thomas Bull Memorial Park-Sally's Dream pavilion for an afternoon outing. This is one of the few parks in the Hudson Valley that was specifically created for children with special needs. Food and drinks will be provided. A fun opportunity for those families of younger children to get acquainted, but all ages are welcome. Thomas Bull Memorial Park is located at Route 416 in Hamptonburgh, New York. RSVP as soon as possible to the event coordinator Ellen Popelsky, 845-928-8685.

### ▶ **SEPTEMBER 23 - NOVEMBER 18, 2011**

Bowling with a Buddy - DSAHV hosts its first bowling league at the Hoe Bowl Holiday Lanes in Wappingers Falls on Route 9. The games begin at 6:30pm and run until 8pm on Fridays. A supervising adult must be present and the cost is \$55 for all 9 weeks. Payment includes two games on each Friday-and full payment is expected on the first night of attendance. Bowlers with Down syndrome are encouraged to bring a friend-same costs apply to the friend. All ages are welcome and bowlers will be teamed up with those close in age. Email info@dsahv.org or contact the coordinator, Al Marotta, directly at 845-380-4741. Spaces are limited and will be given out on a first come, first served basis.

### ▶ **SEPTEMBER 24, 2011 1-4pm**

DSAHV Educational Workshop-Transdisciplinary Teaming Presented by Dr. Lois Tannenbaum, Educational Consultant. Dr. Tannenbaum will discuss creative collaboration, accommodations and modifications, differentiating instruction and role release. A session will also be presented by the DSAHV Educational Coaches providing tips on what your child needs to achieve. The event will take place at the New Windsor Senior Center. Contact Rose Lisi to pre-register, roseis4us@yahoo.com or 845-565-6053.

### ▶ **SEPTEMBER 26, 2011 6-8pm**

Beyond the Time-Out Chair presented by Sheri Lauro, BCBA. Held at the Resource Center for Accessible Living, Inc., 727 Ulster Avenue, Kingston, NY and is free; however, preregistration is required. To register call Dorothy Richards, 845-331-0541 ext. 18 or Isabel Hershkowitz, 1-888-788-6268 ext. 1116.

### ▶ **OCTOBER 7, 2011 9:30am-2pm**

CPSE/CSE Parent member Training. This New York State Education Department-vetted training was developed for use by the Special Education Parent Center and Regional Special Education Technical Assistance Support Center network to promote quality special education services for all students with disabilities. The training is intended to provide CPSE and CSE Parent Members with a best practices approach to the CPSE/ CSE process and their role as a Parent Member that is consistent with State law and regulation. To be held at the WSWHE BOCES Gick Road Conference Center 27 Gick Rd. Saratoga Springs, NY 12866. To register contact Heather Loukmas-Parent Network of the Capital Region hloukmas@pncrny.org or 518-640-3320.

### ▶ **OCTOBER 9, 2011 CHECK-IN BEGINS AT 11am, WALK STARTS AT NOON**

DSAHV Annual Buddy Walk Hopewell Junction, NY. This annual "family reunion" will occur at the East Fishkill Recreation Center, 330 Route 376 Hopewell Junction, NY 12533. Food and drinks to be provided. Fun for the kids will include pumpkin painting, entertainment and a special musical performance from a group of children and young adults with Down syndrome known as the Don't Change Me Project. Online registration is encouraged on our website, www.dsahv.org--search for "Buddy Walk" in the left column of the home page. Donations can also be made via PayPal through our website.

Save The Date  
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## **BUDDY WALK (CONT.)**

Registration forms will also be provided via mail and should be returned PRIOR TO THE WALK to DSAHV, PO Box 352 Gardiner, NY 12525. If you have any questions, wish to volunteer, or would like to sponsor this event please call DSAHV 845-226-1630. (\*\*see Information and Resources section below for information on our annual meeting in conjunction with the 2011 Buddy Walk.)

A reminder that fundraising is not mandatory to attend this outing. Funds raised however are directly redistributed to our local community and will be utilized to plan future social events. If possible, ask family, friends and colleagues to make a donation to support our great cause.

How to raise \$500 in one week:

Day	Outreach	Amount
1	Sponsor yourself for \$25	\$25
2	Ask three family members for \$25	\$75
3	Ask five friends to donate \$15	\$75
4	Ask five co-workers to sponsor you for \$10 (don't forget to ask about a matching gifts program!)	\$50
5	E-mail 15 contacts and ask for a \$10 donation	\$150
6	Ask your company for a \$75 contribution	\$75
7	Ask two businesses you frequent for \$25	\$50

Total: \$500

***Don't forget to thank all of your donors for their support!***

### ► **OCTOBER 18, 2011 9:30am-2pm**

CPSE/CSE Parent member Training. The training is intended to provide CPSE and CSE Parent Members with a best practices approach to the CPSE/ CSE process and their role as a Parent Member that is consistent with State law and regulation. To be held at the HFM BOCES 2755 State Highway 67 Johnstown, NY 12089. To register contact Heather Loukmas-Parent Network of the Capital Region hloukmas@pncrny.org or 518-640-3320.

### ► **OCTOBER 24, 2011, 6-8pm**

Guardianship & Special Needs Trusts presented by Sheryl Frishman, Esq. Held at the Resource Center for Accessible Living, Inc., 727 Ulster Avenue, Kingston, NY and is free; however, preregistration is required. To register call Dorothy Richards, 845-331-0541 ext 18 or Isabel Hershkowitz, 1-888-788-6268 ext. 1116.

### ► **NOVEMBER 4, 2011**

Saratoga Bridges and Wildwood Programs, Inc. are presenting Supporting Healthy Sexuality for People with Developmental Disabilities at The Century House in Latham (Albany Metro area). This full day conference for families and professionals will include a Keynote Address by Katherine McLaughlin. Ms. McLaughlin has taught sexuality education to people with developmental disabilities and trained peer sexuality educators. For more information, contact Marie Awn Floyd 518-640-3346 or mawnfloyd@wildwoodprograms.org.

### ► **2011-2012 SCHEDULE FOR DUTCHESS COUNTY TRANSITION NETWORK 8:45 -10:00am**

The workshops will be conducted in two different places. The first half of the year from September to November they will meet at Dutchess ARC 1435 Route 44, Pleasant Valley, NY 12569. The second half of the year from January to May they will be meeting at New Horizons Resources, Inc. 123 West Rd., Pleasant Valley, NY 12569.

Tuesday, September 27, 2011	Dutchess ARC
Tuesday, October 25, 2011	Dutchess ARC
Tuesday, November 22, 2011	Dutchess ARC
Tuesday, January 17, 2012* (3rd Tuesday)	New Horizons Resources
Tuesday, February 28, 2012	New Horizons Resources
Tuesday, March 27, 2012	New Horizons Resources
Tuesday, April 24, 2012	New Horizons Resources
Tuesday, May 22, 2012	New Horizons Resources

## **TRANSITION NETWORK (CONT.)**

To register contact Karen Lynch, Taconic Resources for Independence (845) 452-3913 x112 or email k.lynch@taconicresources.org.

Tentative dates for additional workshops are as follows and will take place in the evening at New Horizons.

Tuesday, September 27, 2011 - An Overview of Transition

Tuesday, October 11, 2011 - ACCES

Tuesday, October 25, 2011 - What do we do now that the School Bus doesn't stop here?

## **REGISTRATION OPEN FOR LAGRANGE CHALLENGER WINTER BOWLING**

A league for children with special needs. Open to children and adults ages 6 – 30 with developmental and physical special needs. Bowl every Friday at 6:30 pm, January 6th through March 2nd (9 week session) OR January 6th through March 23rd (12 week session) at Holiday Bowl on Rte 9 in Wappingers Falls. Registration fee (9 week session: first bowler \$45.00, each additional special needs sibling \$35.00 OR 12 week session: first bowler \$60.00, each additional special needs sibling \$50.00) includes 2 games per night, shoe rental, shirt (if new to league or yellow shirt is too small) and trophy. A responsible adult must be present for each bowler. The registration form is posted on our website, [www.dsahv.org](http://www.dsahv.org) in the "events" section. For questions, call Sharon or Kurt Beale at 845-452-5802.

## **→ SAVE THE DATE**

### **OCTOBER 29, 2011 - TIME TBD**

DSAHV Halloween Dance. Fishkill United Methodist Church Fellowship Hall. Further details to come-check our website [www.dsahv.org](http://www.dsahv.org).

### **DECEMBER 2, 2011**

DSAHV Dinner Dance Poughkeepsie, NY. Event to be held again at the beautiful Poughkeepsie Grandview. Our young adult members with Down syndrome are encouraged to join us. Prizes to be auctioned, DJ and dancing, and a great night for parents to relax and enjoy the holiday season.

## **→ ONGOING SUPPORT**

### **EDUCATION COACHES**

Questions about your child's education plan? Having difficulty with your Committee on Special Education? Feel like you are not being heard and your child's needs are not adequately met by your school district? Contact Rose Lisi if you wish to attend an upcoming meeting: [roseis4us@yahoo.com](mailto:roseis4us@yahoo.com) or 845-565-6053. The meeting schedule for the remaining months in 2011 is as follows:

September 16th	Panera Bread-Newburgh
October 14th	84 Diner-Fishkill
November 18th	Panera Bread-Newburgh
December 16th	84 Diner-Fishkill

### **ADULT ISSUES COMMITTEE**

The adult issues subgroup began because some families were dealing with depression in their young adult children with Down syndrome. If you share any concerns, please call Al Marotta at 845-380-4741. Next meeting date to be scheduled.

## **INFORMATION AND RESOURCES**

Notice of Annual Meeting and a Note to our Members. Few of our members are aware that the Down Syndrome Association of the Hudson Valley is not the original name of our organization. In fact, when the organization was founded in 1983, we were known as the Mid-Hudson Down's Syndrome Congress, Inc. On all our not-for-profit corporation filings, that name is still used. The board of directors is proposing that we, finally, officially change the name which requires a vote of the membership.

Additionally, the board is proposing that we use this opportunity to change some other items that are in our by-laws. We are, due to the number of interested members and the growth in the membership, seeking to expand the board of directors officially to 11 members. Due to the size of the membership, we are going to eliminate the requirement that we hold three annual meetings and reduce it to one. We are also going to change the terms of office.

In order for us to make these amendments we are going to hold a 10/15 minute membership meeting at this year's Buddy Walk. We ask all members to participate. These changes reflect the growth in size of our membership and we hope you join us in feeling the sense of accomplishment these changes reflect. The proposed meeting agenda and changes are listed below:

### *The Board of Directors*

#### **MID-HUDSON VALLEY DOWN SYNDROME CONGRESS, INC. NOTICE OF MEETING OF THE MEMBERSHIP TO BE HELD OCTOBER 9, 2011 AT THE EAST FISHKILL RECREATIONAL CENTER, HOPEWELL JUNCTION, NY at NOON.**

#### **AGENDA:**

1. New business:
  - a. A proposition to change the name of the organization: "It is hereby resolved by the membership that the name of the organization, Mid-Hudson Valley Down Syndrome Congress, Inc. be changed and thereafter known as "Down Syndrome Association of the Hudson Valley, Inc."
  - b. A proposition to amend the by-laws to change the number of members of the board of directors from seven to eleven: "It is hereby resolved by the membership that Article V Board of Directors Section 2 of the by-laws be amended to read: "The Board of Directors shall consist of ~~seven~~ eleven members, at least ~~five~~ six of which shall be parents or legal guardians of children with Down Syndrome and one of whom shall be a person with Down Syndrome (self-advocate). Four directors shall be officers.""
  - c. A proposition to amend the by-laws to change the number of annual meetings of the membership from three to one: "It is hereby resolved by the membership that Article III Meetings of the by-laws is amended to read as follows: "Regular meetings of the membership shall be held at intervals that shall be determined by the Board of Directors, but no fewer than ~~three~~ one meetings a year shall be held unless the membership votes to omit or alter the date of certain meetings. A meeting of the membership will also be scheduled within 30 days of the presentation to the board of directors of a petition signed by 10 members requesting such a meeting. Members shall be notified by the Secretary no less

than two weeks prior to the date of the meeting, except for emergency meetings.””

- d. A proposition to amend the by-laws to change the terms of office of members of the board of directors. “It is hereby resolved by the membership that Article VII. Terms of Office is amended as follows:
- i. Section 1 is amended to read, “All board members, including the officers, shall serve for a term of three years beginning at the date of the meeting of their election and ending three years hence or until the qualification of their successors except for those elected at the meeting of October 2011, who shall be appointed as follows; four for 1 year, four for 2 years and three for 3 years. Board members subsequently elected or re-elected shall serve for 3 years.”
  - ii. Section 2 is deleted, “~~No officer shall be elected to the same position for more than three consecutive terms.~~”
  - iii. Section 3 is deleted, “~~No person shall remain on the board of directors for more than nine consecutive years.~~”
  - iv. Section 4 is changed to Section 2 and amended to read, “All vacancies in the elective positions, ~~except that of President~~, shall be filled for the unexpired term by persons elected by the Board of Directors.”

2. Election of board of directors:

a. Nominations:

**One year term:**

President: Richard Mangini & \_\_\_\_\_

Vice President: Kathleen Danehey & \_\_\_\_\_

Secretary: Tammy Windheim & \_\_\_\_\_

**Two year term:**

Treasurer: John Zimoulis & \_\_\_\_\_

Members: Rose Lisi, Tom Davis

**Three year term:**

Members: Susan Reeves, Andrew Moroney, Courtney McDermott, Vince Vermette & \_\_\_\_\_.

Self-advocate: \_\_\_\_\_

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Other new business

Adjournment

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[www.dsahv.org](http://www.dsahv.org)



## **DSAHV ANNOUNCES INCLUSION SCHOLARSHIPS**

Inclusion works when dedicated and creative educators make it happen. The DSAHV inclusion scholarship is designed to provide financial support to parents and to those who work within our local school systems (Dutchess, Orange, Ulster, Putnam, Columbia, Greene Counties). If you wish to learn more about inclusion and the positive benefits on the Down syndrome population we encourage you, or the members of your educational team, to seek workshops and conferences. The Down Syndrome Association Hudson Valley will reimburse those attending a workshop or training session, including those receiving continuing education credits, in areas pertaining to inclusion.

For consideration please complete an application ( located on our website [www.dsahv.org](http://www.dsahv.org) in the “Grants/ Scholarships” section) and mail or email it to us: DSAHV PO Box 352 Gardiner, NY 12525 or [info@dsahv.org](mailto:info@dsahv.org).

## **MORGAN’S WONDERLAND-SAN ANTONIO, TEXAS**

The search is over for a family fun vacation destination that truly serves children and adults with special needs. Morgan’s Wonderland opened its doors in 2010 and is the world’s first ultra-accessible family fun park, featuring rides, interactive exhibits, playgrounds, gardens, a fishing lake and other attractions easily enjoyed by those in wheelchairs or with various types of special needs. Admission to the 25-acre park is free for those with cognitive or physical disabilities; family members and friends pay \$5 a person. Reservations are required to visit, as the park caps its attendance each day. See their website [morganswonderland.com](http://morganswonderland.com) or call 210-637-3434.

## **AMC SENSORY FRIENDLY FILMS-THE GALLERIA METROPLEX IN MIDDLETOWN, NY**

The AMC website notes this “program provides a special opportunity for families to enjoy their favorite films in a safe and accepting environment. The auditoriums dedicated to the program have their lights up, the sound turned down and audience members are invited to get up and dance, walk, shout or sing! The idea for the program began with a request from a parent with an autistic child for a special screening at AMC Columbia Mall 14 in Columbia, MD. More than 300 children and parents attended the first screening.” For screening information visit [www.amctheatres.com/SFF/](http://www.amctheatres.com/SFF/) or call 845-695-1724.

## **VOLUNTEERS - SOCIAL OUTINGS**

DSAHV seeks volunteers to help coordinate social outings in each of our various counties. Ideas discussed include bowling, movie nights, dinner outings, park outings, and various theme park day trips. We are primarily a volunteer based organization and we need your help to facilitate family networking. DSAHV would provide funds and help advertise, our volunteers would coordinate contact with the interested families and participate in the outing-in the county that the volunteer resides. If interested please contact Melissa Deschamps 845-226-1630 or email [info@dsahv.org](mailto:info@dsahv.org).

## **MEET OUR BOARD**

The DSAHV Board meets monthly in alternating locations in Dutchess and Orange Counties. Our discussions include matters affecting our local population, such as educational advocacy, and event planning. Our remaining meetings are as follows:

7pm Friday, September 23rd  
7pm Friday, October 21st  
7pm Friday, November 18th  
7pm Friday, December 16th

Please contact us 845-226-1630 or [info@dsahv.org](mailto:info@dsahv.org) if you are either interested in attending a meeting, or have a topic you wish for us to discuss and help resolve.

## **FAMILY SPOTLIGHT**

This was printed in the Star Tribune in Minneapolis, Minnesota on August 9, 2011. Great ideas to foster independence amongst our young adults with DS.

Man with Down syndrome was able to get his own digs, with help from a personalized security system in his home.

On a recent tour of his home, Jeremy Collins showed off his kitchen, his chair, his bed, his new shower. It's a dream come true for the 31-year-old who has Down syndrome, and who had lived in group homes all of his adult life. Since April, he's lived on his own in a Coon Rapids townhouse, with a web of support that includes his parents, his caregivers and landlords, Anoka County and a technology company that all work together to help him be safe and continue to grow in independence and confidence.

The benefits go beyond what's good for Collins. Like other people with disabilities, he receives state and federal support to help cover the costs of his care. Right off the bat, he was able to spend more time without the help of a personal-care attendant; the shift from constant supervision to being independent 25 percent of the week meant an immediate 10 percent reduction in the costs borne by taxpayers. The percentages don't match up because group home residents shared staffing costs.

For the most part, Collins' 1,100-square-foot townhouse looks like any other in the Mary T. Villas Sand Creek development, a mixed community of single-level residences occupied by people with and without disabilities. But a closer look reveals a sensor on the front door that's activated if it's opened after 11 p.m., a security keypad required to turn on the stove, a motion sensor in the bathroom to give the alert if he's in there and motionless for more than 20 minutes, signaling a possible fall. There also is a sensor under his mattress, to detect a fall out of bed, and one in the cedar box where he keeps his medications, to alert his family if he forgets to take them. The system is monitored round-the-clock by Mendota Heights-based Sengistix; an alert triggers a phone tree that, depending on the situation, could go to Mary T. Inc. maintenance staff or to Collins' parents, Dennis and Brenda, who live in Ham Lake, or on down a list of family and friends until someone can confirm the call and check in with Collins by telephone. There have been several false alarms, triggered, for example, when he opened the door to watch a late-night lightning storm. But it's been easy to check in by phone, his parents said.

Sengistix has similar contracts in place in several Minnesota counties, wiring single- and multiple-unit dwellings to help people with a variety of disabilities who are overserved in a group home but need some help to live independently, said account executive Drew Beaulieu. The arrangement was only possible with buy-in from all parties -- Collins' family, Mary T. Inc., Sengistics, Anoka County and Collins' caregivers, through St. David's Center. Anoka County Commissioner Carol LeDoux met recently with Collins and his family. "Initiatives like this are the types of things we should be pursuing for valid health care reform," she said, calling it an "innovative and visionary project."

During 10 years in a group home, Collins was safe, his parents said. But he had few opportunities to use the life skills he has mastered so far, or to make decisions about how to spend his time and the money he earns at his part-time food-service job at Medtronic. Now, he writes out the checks for utilities and rent, which he hand-delivers (usually early) to the Mary T. Inc. office. He helps with grocery planning and keeps his home neat. He continues to learn and grow.

"He has risen to some of the issues that used to be problematic for him," his father said. For example, he used to be afraid of storms. Now, he knows how to monitor weather reports on his phone, and he knows that a siren means he should head for shelter in the bathroom. "This promotes more independence for him, which is a win-win," his father said. His family hopes that his independent time will grow, as his skills grow, to as much as 50 percent. Long-term, his parents hope that when they're gone their son will continue to be secure and not be too reliant on his three older siblings. The signs are good, so far. "It's nice," Brenda Collins said. "When he was born, most people talked gloom and doom for his future. Living here, you can see the next level of independence."



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## SAVE THE DATE

**SATURDAY, SEPTEMBER 17, 2011**

DSAHV Fall Family Picnic in Montgomery, NY

**SUNDAY, OCTOBER 9, 2011**

Annual Buddy Walk® in Hopewell Junction

**SATURDAY, OCTOBER 29, 2011**

DSAHV Halloween Dance  
Fishkill United Methodist Church Fellowship Hall

**FRIDAY, DECEMBER 2, 2011**

DSAHV Dinner Dance in Poughkeepsie, NY