



Newsletter

Volume 3

Issue 3

Providing support, advocacy and resources for people with Down Syndrome in Eastern Ohio & Western Pennsylvania.

What's UP with us?...

From the President of DSAV, Kelly Donadio

To whom much is given, much is expected!

No truer words could better describe how the DSAV board feels following two and a half years of unbelievably successful Buddy Walks and the untold financial support of our vision and mission from our communities.

We know those who support DSAV and the Buddy Walk of the Valley believe in what we do and we also know it is our responsibility to be good stewards of the funds you have entrusted to us.

THANK YOU, to everyone who volunteered, contributed, walked or was in any way involved in the Buddy Walk of the Valley 2009. What a day it was. With over 2,200 people in attendance and the support of the media and businesses in our valley, we were able to raise \$75,000! Please be sure to see page 6 for a list of our top Buddy Walk teams and all our wonderful sponsors.

Change...sometimes helpful, sometimes painful, always inevitable!

Things are changing here at the Down Syndrome Association of the Valley. The biggest change is the opening of our new office - the DSAV Center for Success - on October 22nd. What great attendance we had from community leaders, our membership and new families we had never met.



Some wonderful programs are underway and more are ready to be set in motion. We need your help to continue providing the programs, resources and support to those with Down syndrome and their families in eastern Ohio and western Pennsylvania.

As you read through this edition of the DSAV Newsletter, please consider where you can become involved. We have many opportunities. Contact me at anytime with questions.

I look forward to seeing you soon,
Kelly



3rd & 4th Quarter 2009

What's UP with us?	1
Heartbeats	2
3rd & 4th Quarter Birthdays	2
"The Best Summer Ever"	2
Family Grants	3
DSAV Awareness	3
Support DSAV all year long	3
Medical Corner	4
Guidance for Adolescents	4
Annual Costume party	5
The Center for Success	5
Spotlight on Programs	5
Volunteer Venue	5
Buddy Walk 2009 Wrap-Up	6
Gift Ideas	7
DSAV Thank You	7
Back Cover- Calendar 2010	8



Heartbeats



This Heartbeats article is written about and dedicated to all the individuals from birth through adulthood that the DSAV serves.

Your accomplishments are too numerous to list, but here are just a few examples:

- ~ Graduating from high school
- ~ Saying your name
- ~ Learning to run
- ~ Reading
- ~ Going to work everyday
- ~ Going on the potty all by yourself
- ~ Naming everyone in your class at school
- ~ Zipping your coat
- ~ Renting an apartment
- ~ Golfing
- ~ Taking the bus
- ~ Riding a bike
- ~ Brightening every room just by entering
- ~ The list goes on and on.....

We are so very proud of each and every one of you and love to watch your accomplishments and hear your stories.

Our *Heartbeat* is to play some small part in helping individuals with Down syndrome reach their fullest potential and to become active participants in a fully inclusive society!

DSAV Family Grants bring joy.

I had the best summer ever!!



My summer began with summer camp, which is a program that ran 4 hours/day 4 days/week, where I got to make crafts, sing songs (one of my personal favorite activities), and play on the playground with other kids my age. At the end of the 6 - week program we had a pizza party and we put on a program for our parents. They really, really liked it!

Then I got to play soccer on a church soccer team for 4 year olds!!! I had so much fun learning how to play soccer.

What a great summer...I made lots of friends and had lots of fun!

A giant 'THANK YOU' to DSAV and CVS!!!

Alex Houy



Happy 3rd Quarter Birthday

Marcus Timmerman	7/1/1998
Nicholas Campos	7/5/1998
Kayla Rivera	7/11/1991
Jesse Ray Moore	7/16/2008
Olivia Molchak	7/19/1994
Dante Centofanti	7/26/2002
Chloe Bennington	7/30/2003
Francesca Lynn Bagnola	7/31/1995
Jessica Allegar	8/4/1978
Hunter Bond	8/5/2006
Dani Taraba	8/7/2006
William Champlin III	8/14/2006
Hailee Joy	8/16/2008
Mallory Sheffler	8/24/2007
Gabrielle Rader	8/25/2008
Ke'Aira Faulkner-Ransaw	8/25/1995
Sydney Takas	8/27/2005
Maya Saldivar	9/1/2006
Mikey Vaneman	9/26/2001

Happy 4th Quarter Birthday

Shannon McEwan	10/2/1997
Christopher Drew	10/17/2000
Camdyn DuVall	10/18/2006
Gage Everette Tichenor	10/22/2000
Marina Donadio	10/23/2005
Paul Kloos	10/24/2008
Chazz Wilson	10/24/1993
Ashley Oravec	10/27/2004
Boaz Reigstad	10/30/2005
Ty Shealy	10/3/1987
Linda Orlo	11/1998
Jessica Behon	11/1/1995
Viktor Slipski	11/4/1998
Mark Elzy	11/7/1999
Nikos Chaparas	11/17/2005
Ivy Elizabeth Clutter	11/27/1999
Anthony Merlino	11/29/1998
Nathanael Robbins	12/3/1997
Curtis Herman	12/7/2004
Christian Trella	12/8/2005
James & John Durman	12/11/1978
Evan Daugherty	12/17/1997
Vicky Brainard	12/20/1981
Samantha McCue	12/31/1984



DSAV Partners with CVS/Caremark to award over \$10,000 in Family grants in 2009!

by Michele Jones, DSAV Vice-President

The Down syndrome Association of the Valley was pleased to award 27 local DSAV families up to \$500 each for medical expenses, therapies and activities outlined in the grant application in 2009. An on-going goal of The DSAV is to offer support and resources to people with Down syndrome in Eastern Ohio and Western Pennsylvania through the family grant program. In Keeping with the DSAV mission, the family grants provide assistance to anything that directly improves the quality of life of individuals with Down syndrome. Grants were awarded to assist with additional therapy sessions, to attend integrated swim or gymnastic classes or help families with medical expenses to name a few.

DSAV was awarded \$5000 from CVS/ Caremark and an additional \$5000 was distributed from the DSAV general fund. The Down syndrome Association of the Valley matched the CVS/Caremark funds dollar for dollar and was able to put back into the valley some of what the valley has so graciously given to us! Thank you to the independent grant selection committee for reviewing the applications and making the recommendations. In keeping with the mission of DSAV, CVS/Caremark also believes that through inclusive efforts we can work together in building a future where everyone can live successful productive lives!

DSAV Awareness: Library Displays

To help celebrate October National Down syndrome awareness month, the DSAV set up library display cases in various public libraries throughout the region. Posters, pamphlets, books, and other resources were displayed throughout the months of October and November. Posters from the National Down Syndrome Congress "We're More Alike than Different" campaign were showcased. Thank you to Michelle Sheffler for coordinating the New Castle display and Michele Jones for covering Trumbull County. It is an annual goal of DSAV to create an awareness campaign in as many libraries as possible throughout the region. Please contact the DSAV Center for Success if interested in setting up and taking down display cases at local libraries in October 2010 and becoming a partner in our awareness campaign!

DSAV creates holiday magic at Mill Creek Park

The Down syndrome Association of the Valley was invited to once again decorate a holiday tree as part of the Winter Celebration 2009, "Home for the Holidays" at Fellows Riverside Gardens. Last year, over 28,000 individuals enjoyed the annual December event at Mill Creek MetroParks. Take the entire family and visit the Davis Center at Fellows Riverside Gardens from December 5th through January 3, 2010. Enjoy a wonderful holiday tradition right here in the Mahoning Valley and be sure to look for the beautifully appointed DSAV tree!

How to GIVE to DSAV all year long...

- ~ Collect used cartridges, toners and cell phones and bring to the DSAV Center for success to be processed and mailed to **Advantage Cartridge Recycling**. The DSAV received over **\$400** from combined efforts in 2009. Thank you to Doeberling Muccio, Northeast Ohio Orthopedics, the offices of Dr Nadler and Nadler and General Motors Lordstown for your continued support and collection sites. Please contact Michele@dsav.org if you are interested in overseeing a few collection boxes in the businesses and offices that you frequent.
- ~ Simply use the **Goodsearch.com** search engine for web searches or shopping and we get a percentage of the sale or a penny for each search. The DSAV has earned almost **\$350** since joining Goodsearch in 2007. For further information log into Goodsearch.com choose Down syndrome Association of the Valley as your charity and help us fundraise year-round!



M E D I C A L What is the flu?



Ken Jones, MD

O During the winter months many of us come down with illnesses. When someone asks we just say we have the “flu.” The flu is a respiratory disorder caused by the influenza virus. Early symptoms range from sore throat, sneezing and congestions much like the common cold. Unlike the cold, an individual can have high fevers, headaches and body aches. If influenza worsens it can become a pneumonia which is much more serious. Specific tests can be done to look for the influenza virus. Generally, people with this condition will be treated more aggressively and there are specific medications such as Tamiflu which can be given. For those people who have other medical conditions or are advanced in age, the influenza vaccination should be given. The vaccination does not completely prevent someone from getting the disease. The vaccination works against the most common virus that scientists predict will be common that year and can decrease the severity of the illness.

The “stomach flu” is commonly interchanged with influenza. The medical term for this condition is gastroenteritis. Abdominal cramps, stomach pain, vomiting, nausea, and diarrhea are the most common problems. Although this condition is very unpleasant and comes on quickly, it is generally self limiting and is not life threatening like influenza pneumonia. Individuals have troubles with the side effect of gastroenteritis which is dehydration. No medications work against the virus causing this disease, but medication may calm down the symptoms. Even in the face of vomiting, fluids should be pushed.

As with all of the cold weather illnesses, prevention is the key. Hand washing and proper hygiene is the most important step. If someone has a cold, but develops high fevers, body aches, or uncontrollable cough, please seek medical attention. On a final note, individuals with Down Syndrome should receive the flu vaccine. Generally, they have thicker mucous and have a tough time clearing their lungs and may develop the pneumonia quicker.

Guidelines for Adolescents and Young Adults With Down Syndrome

-Susan Van Cleve, Sheila Cannon, William Cohen

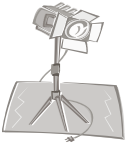
- Discuss issues related to transition to adulthood.
- Review plans for school placement and plans after high school graduation. Review future vocational plans.
- Discuss plans for alternative long-term living arrangements such as Community Living Arrangements. Parents should update estate planning and custody arrangements.
- Emphasize the importance of a well-balanced diet and routine exercise.
- Encourage good dental hygiene with twice-a-day tooth brushing. Reinforce the importance of good self-care skills (grooming, dressing) and functional skills (money handling).
- Continue subacute bacterial endocarditis prophylaxis in adolescents with cardiac defects.
- Encourage social and recreational programs with friends.
- Discuss sexuality and socialization and the need for and degree of supervision required. Review options for contraception if the teen is sexually active. Make recommendations for routine gynecologic care.
- Monitor the family's need for supportive care or counseling, respite care, and behavior management techniques.
- Adolescents may register for voting and Selective Service at age 18 years.
- Facilitate transfer to adult health care.

Another great Costume Party!

On Sunday October 25, 2009 Meinke's Creekside Gardens in Warren was transformed into a Harvest wonderland for the Down syndrome Association of the Valley! DSAV families were treated to hotdogs and goodies compliments of Creekside Gardens while the DSAV provided chips and beverages. Members enjoyed decorating pumpkins, navigating straw mazes, playing games and monster dancing! The DSAV presented the family of Mel and Bob Meinke with a plaque for their continued support of and dedication to the Down syndrome Association of the Valley!

Go “Green”

In our attempt to better manage DSAV funds and to save some trees, we are working to scale back on the printing and mailing of our paper newsletter. If you would prefer to only receive our newsletters on your computer, please e-mail us at info@dsav.org and let us know. We will be enlarging our e-newsletter to include all the helpful topics you read in the printed format.



Spotlight on Programs: Education

We are very excited about two wonderful programs focused on education that we are in the process of implementing. These two programs are funded in Trumbull county through the Sherry Freda trust and are being duplicated in each county that we serve.

LAMP – The Literacy, Arts and Math Program offers materials and resources for parents and educators to use in the home, the classroom or at the *Center for Success*®. Resources may consist of books, cards, manipulatives, pamphlets, computer programs or other supplements. Resources are provided free of charge to DSAV members and we ask that they be returned once the area of skill is mastered or you no longer need them. The DSAV will gladly provide one set or copy of the program/resource to schools and they are free to duplicate as needed . LAMP "shines a light" on strategic programs and systems that suit the specific needs of those with Ds. Dates and times may also be scheduled for specific age groups to work on various programs at the *Center for Success*® or other specified locations.

Parents & Schools in Partnership - The model program began in Kansas City and we are pleased to bring it to our area. This program promotes collaborative relationships between DSAV and local school districts to effect positive outcomes for students with Down syndrome and their families. Special Education Directors are invited to learn more about DSAV and community resources that benefit their district and the students with Down syndrome. A significant education connection is made as directors are encouraged to designate a staff person within the district to be the DSAV Down Syndrome Specialist.. The Specialist receives a resource binder and regular material updates.

Just what is the DSAV *Center for Success*® ?

- ~ an awareness center
- ~ the DSAV office
- ~ meeting room
- ~ space for tutoring
- ~ resource library
- ~ activity center
- ~ networking facility
- ~ centralized connection to our communities
- ~ your ideas?....



COME VISIT US!!!

Volunteer Venue

The place to find out,
how you can help out.

(330) 726 - DSAV or email us at
info@dsv.org



Committees

- | | |
|------------------------------------|----------------------------------|
| Buddy Walk Planning | Parents & Schools in Partnership |
| Community Connections | Playgroup Pals |
| Community Outreach | Plus 21 (young adults) |
| Corporate Contacts | Self Advocate Spotlight |
| Event Photographer | Social Committee |
| Fundraising | Sunshine |
| GRANDS (grandparents) | TULIP Parent Program |
| Healthcare Partnership | |
| LAMP (Literacy Art & Math Program) | |
| Legislative Awareness | |
| Office Assistant | |
| Parent Podium | |

BUDDY WALK® of the Valley 2009

Another HUGE Success!

Once again, the families and businesses throughout the valley stepped up and supported the DSAV Buddy Walk of the Valley. With over 2,200 people in attendance and sponsorship from 50+ area businesses, we were able to raise over \$75,000!



Below you will see the businesses and teams who helped to make it such a remarkable success.

Believe it or not, planning will again get underway for Buddy Walk® of the Valley 2010 in January. If you would like to be a part of the planning, let us know!

Our Buddy Walk Sponsors

Platinum Sponsor

Walmart

Media Sponsors

Time Warner Cable
WKBN/FOX/WYTV
Cumulus Radio
WFMJ/WBCB
Lamar Outdoor
Comcast Cable
Armstrong Cable
Clear Channel Radio

Gold Sponsors

Eye Care Associates
Payroll Pros

Silver Sponsors

Northeast Ohio Orthopedics
Litco International
First Place Bank
Best Buy - Boardman
The DeBartolo Corporation
Forum Health
Fairfield Inn - Boardman
CiCi's Pizza
Johnson Controls
Valley Acoustics
Kohl's
Covelli Enterprises
Print Factory
The Shops at Boardman Park

Buddy Walk of the Valley Teams

Lovin' Lauren
Champions for Champlin
Movin' with Marina
King Track Man
Addi's Advocates
Team Luke
Team Francesca
Marching with Mallory
All for Ashley
Crusin' for Christian
Paiten's People
Howland NHS
Team Sean
Boardman NHS
Walmart
Best buy
Team Gabby
Hailee's Comet

Team Mazzella
Team Taylor
Team Anthony
Miley's Team
Team Alex
Curtis' Curcle of Friends
Camdyn's Team
Connor's Crew
Team Austin
Team Joseph
Team Jill
Munchie's Bunch
Dante & Nathanael
Fitch NHS
Dad's Angels
Team Victor
Bobby H Team
Team Richie
Team Tyler

Our Bronze & Friend Sponsors

Eat 'n Park
Heatherwood Landscapes
Opalka Orthodontics
State Farm Insurance—Michael Joseph
Steven Lombardi, DMD
Harrington, Hoppe and Mitchell, LTD
Cortland Banks
Elder AG & Turf Equipment Co.
Delightfully Downs
Austintown Bounce
Tom's Sewer & Drain
Huntington Bank
Humility of Mary Health Partners
Akron Children's Hospital - Mahoning Valley
Sharon Regional Health Systems
Roth Brothers
TAG Distribution
Home Elements
Old Navy-Boardman
Howland National Honors Society
Pro Business Systems
Lewis Construction
BeautyFirst

Awareness Jewelry: Think Christmas!

ITEM	QNTY.	FINGER	1ST COLOR	2ND COLOR	3RD COLOR	UNIT PRICE	TOTAL
Bracelet						\$35.00	
Anklet						\$35.00	
Ring						\$25.00	

Bracelet/Anklet: The Sapphire and Jonquil colored Swarovski crystals are the signature colors for Down syndrome awareness and the three colored crystals signify the three copies of the 21st chromosome. The sterling silver tulip charm commemorates the Welcome to Holland poem. Bracelets have a sterling toggle clasp, while anklets are made with smaller pearls and beads close with a lobster clasp.

Rings: The three stones can be chosen to represent Down syndrome (two sapphire, one jonquil) or can be selected as birthstone colors. Please indicate color choice, order of colors and designate the finger it will be worn on for proper sizing. **Full color chart and photos on the Store page at www.dsav.org**

Subtotal	
Shipping 1st item	\$2.50
\$1.00 each additional item	
Total	

Name: _____ Street Address: _____

City: _____ State: _____ ZIP: _____ Phone: _____ E-Mail _____

Make checks payable to: **DSAV, P.O. Box 8651. Warren, OH 44484**

Please allow 3 weeks for delivery

Show your DSAV colors this winter

How about staying warm and toasty this winter in a DSAV hoodie or long sleeve t-shirt. They also make great gifts!

Limited sizes available!

Call the office, 330-726-DSAV to place your order.



Thank you to all who have given so generously to DSAV.

Pink Thumb Garden Club-Warren

Microsoft – Christopher Jones

Walt & Dorothy Kijowski Trumbull County Family Court

Bob & Amy Harris Dr. & Mrs. Jon Eucker & family

Ray & Judy Donadio Dr. & Mrs. Paul Gould & family

TMH Surgery Center Dr. & Mrs. Terry Philibin & family

Joseph & Norma Conti Marco & Lisa Rankin

Dr. and Mrs. Panos Zafrides & family

DeBartolo Corporation-Denise & John York

In Memory of Alice Schmalzried

~ Altar & Rosary Society of St. Mary's Church, Warren



A Special DSAV Thank You to...

Lewis Construction

Hine Memorial Fund

Pro Business

NEO Orthopedics

Harrington, Hoppe & Mitchell

Elite Digital Graphics

Executive Computer Solutions

Living Lord Lutheran Church

Walmart

Small Business Management

Anthony Rossi Jr., Esq.

Best Buy

Home Depot

Office Max

Renee's Flowers

Celeste Lisko

Thom Russo

Stacy Navarro

Mrs. Pat Morella

Eric Dess

Youngstown Curveforms

Sherwin Williams

Modern Office

Roxanne's Interiors

Randy Walters Cleaning

Shanghai River

Donadio & Wagner, Ltd

Eat N Park

Roxanne Morella

Jeff Miller

Down Syndrome Association of the Valley
945 Boardman-Canfield Rd., Suite 12
Boardman, OH 44512

Return Service Requested



Looking ahead to 2010:

1st Quarter - Legal Lecture with attorneys from Hickman-Lowder, LLC in Cleveland

March - Celebrate World Down syndrome Day

2nd Quarter - Medical lecture

August - Buddy Walk of the Valley 2010

DSAV does not endorse or recommend any particular program or article content found in the newsletter. It is our desire to make a broad array of information available to our Members.