

Down Syndrome Family Support and Advocacy Group Newsletter

October 2010

Portolese

(By: Kevin Pearson for his daughter Anna's Program Assistant Mrs. Portolese)

Side by side we sat
For three years in a row
10,000 smiley faces
A few without a nose

Letter by precious letter
You taught me how to read
We started out with A
And ended up with Z!

You taught me all my colors
But mostly yellow, red and green
One meant that I was a good girl
The other meant... a little mean!

You taught me to Pledge Allegiance
To my country's flag
And to place my hand upon my heart
Whenever I see it wave

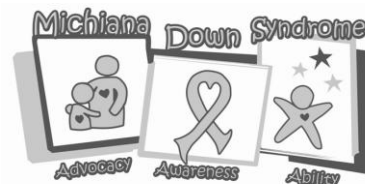
Alone, I sometimes wondered hallways
While you watched me from afar
Sometimes I watched you watching me
As you stayed hidden in the dark

You taught others to accept me
And to try and understand
While some of us are different
We're all part of God's big plan

Of all the lessons that you taught me
The one I will most embrace
Is the gentleness of your touch
Each time you hugged my face

And while I may no longer see you
Each and every day
I will ask God to watch over you
Each night I kneel to pray

Love Anna



In this Issue	Page
Poem – Portolese	1
Fall Party	1
Walk for DS 2010	2
Mark Your Calendar	2
Martin's BBQ	2
Expect. Don't Accept	3
Outreach to Hispanic Families	4
Down Syndrome Cook Book	4
2010 Fundraisers	5
Shop for a Cause	5-6
Applebee's Fundraiser	6
Lending Library	6
Transition Bags	6
2010 Walk Sponsors	6-7
Advertisements	8
Birthday greetings	8



Fall Party

When: October 30, 2010
Where: Hannah and Friends
Eck Rec Center
Time: 1:00 pm – 3:00 pm
RSVP: Anne Revell 574-243-3808

Please make plans to come to our fall party!
We will eat lunch at 1:30, with horse pulled wagon rides starting at 2:00.
There will be crafts, and kids may dress up in their Halloween costumes if they want to.
Please bring a side dish or dessert to share.
We will provide the main dish, drinks and table ware.
You may also bring Halloween treats to pass out at the end of the party.

Walk for Down Syndrome 2010

This year's Walk, our biggest fund raising event of the year, proved to be our most successful event thus far. We raised over 34K and we expect some funds to trickle in over the next few weeks. At a time when the economic climate of our immediate area remains in a downturn, this is a huge success! Many non profits in the area would love to duplicate our efforts. Congrats to everyone who helped to make this possible.

Our effort was successful in other ways as well. We have had some members of the group express that some of the siblings of those with DS had an especially good time this year. Naturally, this is welcome news! Overall, we have noticed that those in the group who have attended for several years in a row are becoming very well acquainted with each other. I am referring to those with DS, their siblings and parents. I think it is fair to say that our biggest fund raiser of the year has become a BIG party!

Perhaps it's just me, but I have noticed that our event was just filled with smiles! We have our young adults who are having a great time with the ballroom dancing. In at least one case one of the girls was helping out with announcements. Our kids (and young adults) are singing on stage and generally playing with each other without any supervision. Everyone is just having a good time and for those brief few hours those with DS seem to have forgotten that they are "different"! In fact, I truly believe that in a small way, for those brief few hours, we are creating an atmosphere of acceptance and understanding.

While our event was successful, we recognize we have areas that need improvement. We know we had some problems with registration and that some of you had problems with the First Giving site. We have discussed the possibility of some new signage next year to assist in where things are located. We want to further look for opportunities which the siblings will enjoy and thus look forward to our event. I am sure I am not alone in my desire to see some added participation by other ethnic groups. Down syndrome is non discriminatory. We encourage everyone to welcome minorities to give us a try. We would all like to see some new faces.

Moving forward, we should all remember the wonderful time we had this year and promote those sentiments to our friends and families. While certainly we don't want to fail to communicate that our event is a fund raiser, we can do so in the spirit that our event is also a good time filled with music, laughter, friendship and love. We need to let others experience firsthand what a beautiful experience you can have with a room full of faces with DS. Truly, our event is becoming a Celebration of Life!

Sincerely,
Kevin Pearson

Mark Your Calendars!



We are partnering with the Penn-Harris-Madison School Corporation to present a workshop by **Kim Voss** on Saturday, March 26th, 2011. We will give you more details (registration fee, etc.) as we get them. Kim Voss wrote the book "Teaching by Design" (which we have in our library).

Martins BBQ

On October 23, 2010, we will have our annual BBQ at Martin's Supermarket on Bittersweet Road. This is a really fun event to work and we need volunteers for this fundraiser.

Shifts usually last a minimum of 2 hours but any time you can give is welcome. We start at 10:00 am and the event is over at 5:00 pm. If you are interested in working the Martin's BBQ, please fill out our volunteer form on our website www.michianadownsyndrome.org or call our BBQ committee leader Cheryl Speheger at 574-277-6343.

Just a reminder that you can use these hours towards your service hours for a mini grant.

Excerpts from
Expect. Don't Accept.
2009 Keynote Address by Paul
Daugherty

(Paul Daugherty delivered this keynote address at the Remarkable Families Symposium on Friday, April 3, 2009)

Thank you very very much for inviting me to speak to such a "remarkable" group of people. Life has given you a gift. If you don't realize that already, you will in time. I promise you.

(My daughter Jillian) has Down syndrome. In some respects, that matters a great deal. In others, it matters not at all. It's about perception, mostly. It's about insisting on getting what you pay for, and not leaving the ticket counter or the insurance office -- or the high school conference room -- until you get it. Ultimately, it's about giving your child the chance every other child gets.

We never say never, never is not a word. It's a self-defeating state of mind. Don't put up Stop signs for my kid. Let her direct her own traffic. If you don't, we will be there, hauling you into a meeting, demanding for Jillian what you so freely offer every other kid: An honest chance. Let her tell you the height of the bar. Expect, don't accept.

Great strides are made when we remove the word No from our vocabularies, when we expand our thinking to account for the impossible. We went to the moon, didn't we? We eradicated polio; we can take pictures with a telephone. We elected an African-American president of the United States.

All any of it required, at base, was a disbelief in limitations. She can't learn? No, you're not willing to let her try. As parents, we cannot let that go unchallenged, not ever. We owe our kids that much. **Expect, don't accept.**

As parents, we've spent lots of time hearing what our kids can't do, will never do. We heard it from the first day. She'll never be able to... complete the sentence. We never bought into that. You get what you expect. Not what you

accept. It is the difference between settling and battling. The difference between daydreams and real ones, you get what you expect. Not what you accept.

Education should be the business of instilling hope. Too often, it isn't. I don't like being a pioneer. I'm not curing polio. I'm just expecting teachers to do their jobs. I'm not accepting any less. There are teachers at Jillian's school now who frown at the mention of my name, and my wife's. We're a pain in the rear. Other parents have to change diapers. We have to change minds, but what a payoff.

Here is what Jillian does. Here is the service she performs, by being her: She opens my eyes to the wonder of the ordinary. I've enjoyed the little wins with Jillian I took for granted with her brother: Using a fork, spelling, times tables, discerning the incredibly vital difference between homogeneous and heterogeneous mixtures. Actually, for several years, Jillian has had homework I can't do, making me wonder who's got the syndrome thing here.

I would never have seen any of this without Jillian's vision. I look forward to the next generation of milestones: Jillian home alone overnight, Jillian in her own apartment. Jillian, God help us, learning to drive.

It's called Down syndrome because a guy named Down identified it. It's not down at all, not for the kids and the teachers and classmates who choose to embrace them. Certainly not for those of us who are privileged to know them and love them.

As parents of children with disabilities, we face unusual challenges. But also, unique opportunities. As we blaze the trails, bend the minds and tweak the perceptions, we reap the rewards of knowing we've made the world a better place. We're only as good as the way we treat each other.

(Read the rest of this remarkable speech at <http://www.xavier.edu/familyresiliency/paul-daugherty-keynote.cfm>)

Hispanic Family Outreach

We now have new parent bags available for families whose primary language is Spanish. Included in the bag is a copy of *Bebés con síndrome de Down: guía para padres (Babies with Down syndrome: a guide for new parents)* as well as several informational articles written in Spanish. In addition, we are pleased to announce that Rocio Rodriguez, a young lady who has young brother w/Ds, has offered to be a translator/resource person for our group. She is fluent in English and Spanish, and is very enthusiastic about this outreach project. We recently met with some of the Elkhart Ds group to coordinate outreach efforts with them as well.

If you know of anyone who would benefit from having written information about Down syndrome in Spanish, please contact Kathy (574) 234-0590. To speak to Rocio, call (574) 387-7209 after 3 pm.



Michiana Down Syndrome Cook Book

We are making a final request for recipes, stories and pictures for our Down Syndrome Cookbook. The holidays are fast approaching, and the cookbooks would be great items for teachers, therapists, doctors, family and friends. So please get me your information by **NO LATER than October 29th**. You can email me at mmurasko@gmail.com.

We are still looking for stories and recipes for our cookbook.

GOAL: This book is a fundraiser for our group. It will be a celebration of our children and their accomplishments.

CRITERIA TO SUBMIT A STORY:

- Please keep your story 200 words or less.
- Font: Times New Roman 11 pt.
- The story should be of a glimpse into the life of your child. Maybe a funny story they told, a picture from a recital or sports event. This is to be a celebration of their accomplishments... a story about them and why we love them so much.
- Submit a digital picture (if possible) that relates to your story or just a picture of them (if you want one posted in the book) with their name if you are emailing it to me separate from your story/recipe.
- Please submit a recipe (this is a cookbook) with short stories about our kids.
- Email it to me at: mmurasko@gmail.com
- Deadline for submission: October 29, 2010

Here is an example of a story submitted:

So, when Christian was born, sure I was scared, disappointed, but quickly with all kinds of support from the local down syndrome support group and the people around me, plus because of the cuteness of Christian all those feelings subsided.

Right now, I feel very blessed with Christian as he has low muscle tone, but that seems to be the only thing delaying him. He is a good eater and sleeper. He loves playing with his older brothers and sisters. I have two therapists who see him on a regular bi-weekly basis, so I know he is getting the preventative care he deserves to be able to lead the best life he possibly can. I just feel blessed and I am so excited to be part of his life. He brings me and the family so much joy.
~Claire Shely~

We are looking for recipes for the following sections:

- Main Dishes & Casseroles
- Breads & Pastries
- Cakes, Cookies Desserts
- Soups, Salads & Sauces

Look forward to receiving your recipes, stories and pictures (you can scan the pictures and attach as a jpg. File).

2010 Fundraisers

Old To Gold:

Each spring, students from Notre Dame leave behind several tons of items when they leave campus for the summer. In the past, those items ended up in the landfill. Several years ago, Notre Dame started a program called from Old2Gold and invited local nonprofit agencies to help sort out the stuff left behind (which takes almost a month) and sell the items in a huge 4 hour sale. Getting the items ready for the sale is a huge job, and over 60 nonprofit agencies were involved this year. 100% of the money made at the sale is divided up among the participating agencies based on the number of hours worked by members of the agency. This year, the sale made over \$56,000. Mary O'Callaghan, Vicki Maenhout, Edie and Phil Petrie, Emily, Nathan, John and Kathy Ratkiewicz worked a total of 230 hours and earned \$3,253.07 for our group.

DAD'S Nelson BBQ:

This year, one of our dads, Kevin Pearson headed up what we hope will be an annual tradition of a Nelson's BBQ chicken sale for our dad's to work and raise funds for our group. In addition to raising over \$1500 for our group, the dads, and extended family and friends that worked the BBQ had a great time working together and getting to know each other better. Thank you to all who worked and to Kevin for getting this annual event started!

Fore Guys Open Golf Outing:

Four local men have started a new fundraising group called Fore Guys Open. They plan to have an annual golf fundraiser for local charities, and chose our group as the recipient of their generosity this year. 108 golfers, as well as many corporate sponsors participated and raised over \$1600!

If you haven't checked out our **New Web Site** yet then please do so now!

www.michianadownsyndrome.org

We have been busy filling all the pages with resources we hope you find useful.

Shop for a Cause at Macy's

I want to tell you about a new fundraising effort that our group is participating in -- Macy's 5th annual **Shop for a Cause on October 16, 2010**. If you've never heard of it, Shop for a Cause is Macy's national charity shopping day that offers the opportunity for local nonprofit organizations to raise funds in their communities. Since 2006, Shop for a Cause has helped raise more than \$34 million for thousands of charity partners.

How it works:

Macy's invites charities to sign up, sell \$5 tickets and keep **100% of the proceeds** of every ticket they sell. That's right, for every \$5 Macy's pass we sell, the entire \$5 goes to our group.

Customers purchasing tickets benefit by receiving incredible storewide shopping savings all day on October 16, 2010. On October 16, Macy's also hosts special events, prizes and other in-store excitement.

Shop for a Cause tickets have two offers: Macy's guests are entitled to exclusive 20% or 10%* savings in most departments all day long plus an additional 25%* off a single purchase. **That savings is on sale, clearance and regular-priced items.** Shop for a Cause is special because you can save on most items throughout the store and online. In addition, customers will be eligible to win a \$500 gift card from their local store, no purchase necessary.

So for the price of \$5, you and your friends, family and neighbors can donate to a very worthy cause (*our group!*) as well as shop & save at the Macy's at the University Park Mall and online. That means that if you spend more than \$25, your savings pass is well worth it!

I know that not everyone shops at Macy's but this bargain shopper is here to tell you that you can get some very good deals there. :) I went there for back to school shopping and found some really nice things for my kids that were a steal – girls' shirts for a little over \$4 and Levi's boys' shorts for \$9, the same price I paid a few days earlier at Target for a much inferior pair.

Continue page 6

Shop for a Cause continue

I am the contact person for the event, so if you want to purchase some passes or have any questions, feel free to email me at cmreck@comcast.net. Here is a link to the Macy's website <http://www.macysinc.com/shopforacause/>

Anyone can shop at the store that day but in order to get the savings and for our group to benefit, please buy your pass from me! You can also print off the attachment and pass it out at work or to your friends & family. Fill in my name & number, Colleen Reck 675-9356.



DINE TO DONATE

Dine at Applebee's and 15% of your bill will be donated to

Down Syndrome Family Support & Advocacy Group

Present this flyer to your Server on

Date: October 11, 2010

Only valid at the following:



Granger	Mishawaka-South	Scottsdale	South Bend
6615 N. Main Street	4515 Lincoln Way East	1150 Ireland Road	3703 Portage Road
574-273-0003	574-256-9501	574-291-8522	574-277-2640



Lending Library

Here is a list of new titles added to our Lending Library that we keep in the Autism Resource room at LOGAN Center.

- Up Syndrome DVD
- Baby Babble DVD
- Baby Babble 2 DVD
- Let's Talk Together: Home Activities for Early Speech and Language Development (paperback)
- The Little King and His Marshmallow Kingdom (written by the father of a young child w/Ds) good note to parents in the back
- Homemade Blended Formula Handbook spiral bound

School Transition Bags

We know that transitioning into the school system from First Steps can be overwhelming. Our group has put together a Transition bag that we hope makes this process a bit easier. Please contact us if you would like to receive one of these bags. You can find more information about these bags, other school resources and bags for teens and adults at our website www.michianadownsyndrome.org. Please call Anne at 574-243-3808 or email her at artrevell@aol.com to receive a bag.

2010 Walk Sponsors

Advance Ophthalmology of Michiana Dr. Gerber, Dr. Schwartz and Dr. Yoon
Allegiant Airlines
Andrea Perlis
Applebee's Grape Road
Ask
At Home Realty Group
Ballroom Dancers
Bargain Books

Between the Buns
 Bruno's Pizza
 Build-A-Bear
 Cabi Clothing
 Cardinal Fitness
 Carrabba's Italian Grill
 Certified Transmission Inc
 Challenger Little League
 Chuck E Cheese
 CiCi's Pizza
 Clever Container Gift from Marla Murasko
 Country Inn and Suites
 Cricket Berry Design a Love Jean Jacket
 Detroit Pistons
 Family Video
 Fazoli's
 FitStop
 Granite City
 Hacienda Mexican Restaurant
 Hannah and Friends
 Indianapolis Children's Museum
 Jersey Mikes
 Jimmy John's
 Karen Rieth Independent Scentsy Consultant
 Kelly Family for ND Tickets
 Kroger
 LaSalle Grill From Lisa Farrell
 Leonardo
 Lexus
 LOGAN Resource Center
 Louvered Door
 Master Styling Salon
 McDonalds
 Melissa Goepfrich of Cheveux Hair Salon
 Melissa's Jewelry - Andy's sister
 Marigolds
 Midwest Orthotics
 Mikes Car Wash
 Moe's Southwest Grill
 Notre Dame Athletic Department

Notre Dame Fire Department
 Outback Steakhouse
 Panera Bread
 Parrots Pottery
 Penn Station
 Pepsi Cola Bottlers
 Pet Palace
 Potawatomi Zoo
 Powell the Florist
 Praxair
 Regal lanes
 Reins of Life
 Revell/Banes Electric
 Rossini Pizza
 Ruth Brown a Mary Kay Gift
 Shedd Aquarium
 Six Flags Great America
 South Bend Silver Hawks
 Special Olympics
 Splash Universe
 St. Claire Apparel
 Strikes and Spares
 Studio 23 (Shannon)
 Sweet Pickens Floral & Gifts
 Target
 TGI Friday's
 The ARC of Indiana
 The Share Foundation
 Tonya Albertson Tastefully Simple Basket
 Tootsie Roll
 Twister Mike
 USA Skate Center
 Valentino's
 Van Horne Jewelers
 Vogue school of Beauty
 Wal-Mart
 Wings Etc
 WSBT Radio Group
 Zikers Cleaners

Thank you to all the volunteers that helped make our event a success!



EXECUENTIAL ADMINISTRATIVE
SERVICES, INC.
An administrative professional who provides
the following services remotely from my home
office:

- Executive Administrative Services
- Newsletters, Brochures, Invitations
- Meeting/Event Planning ...and more!

www.execuessential.com 866-542-2535



Benefits:

- No headcount
- Pay only for hours worked

Birthday Greetings

The DSFSAG would like to send each of our members with Down syndrome a Birthday greeting, but in order to do this we need their birthdates. If your family member with Down syndrome is not receiving a birthday greeting from us , but would like to please contact Tonya Albertson at 219-778-9049 or at bteatrp421@verizon.net



David Perry
Broker Associate



3010 Hickory Road
Mishawaka, Indiana 46545
Office: (574) 968-4256, Toll Free: (800) 697-2824
Voice Mail/Fax: (574) 651-1775
davidperry@remax.net
DavidPerrySellsHomes.com



Each Office Independently Owned and Operated

Advertise Your Services

We have many talented members who offer a variety of skills, services or goods. We are offering our members an opportunity to advertise in the newsletter. This is a great opportunity to broaden the ways we support each other. A business card size ad will cost \$25/year for members only and your ad will run for a year (approximately 3 to 4 newsletter).

DSFSAG
51201 Old Cottage Dr
Granger, IN 46530

BULK RATE
US POSTAGE
PAID
PERMIT NO.
00000

Fall Party October 30th!

