

ON THE UP

WITH DOWN SYNDROME

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A Publication of the Down Syndrome Association of Wisconsin, Inc.

DSAW OUTREACH

The Community Outreach Committee (COC) is a newly formed committee comprised of DSAW members and other volunteers whose mission is to promote awareness and understanding of Down syndrome.

In conjunction with Down Syndrome Awareness Month last October the COC, along with the help of Advisory Board members, distributed updated New Parent Packets to hospitals across the state of Wisconsin. The packets include general information about Down syndrome, resource listings and support materials to assist new parents of babies with Down syndrome. Also included was a book, "We'll Paint the Octopus Red" by Stephanie Stuve-Bodeen. This book is a wonderful tool for parents to read to siblings, as well as other children, because it provides a sense of comfort and understanding regarding a post natal diagnosis of Down syndrome. DSAW's purchase and limited distribution of the books was a part of our ongoing efforts to provide support to families and promote the understanding of value of individuals with Down syndrome. This book is

available for loan to DSAW members from the lending library.

As a result of the New Parent Packet distribution, DSAW Advisory Board member Judy Frey received requests from two Oshkosh hospitals for formal presentations to be given to hospital staff with regard to medical issues and parent perspectives on Down syndrome. DSAW partnered with Terri Couwenhoven of the Down Syndrome Clinic of Wisconsin, to provide a formal presentation and sensitivity training entitled "Compassionate Care for Families with Newborns Who Have Down Syndrome" to both hospitals in January. Special thanks to Judy and Terri for their time and effort.

The COC also created Down Syndrome Awareness Boards which were placed at several Milwaukee area libraries and at Children's Hospital. These boards depicted themes including family and friends, education, work, persistence, goals and dreams, along with factual information regarding Down syndrome and pictures of individuals meeting and exceeding expectations.

In light of the recent non invasive chromosomal testing becoming available to the general public and the reality that the majority of those faced with the decision to abort a fetus with Down syndrome do so, it is ever so important that we as a community provide information regarding the positives as well as the negatives of having a loved one with Down syndrome. Please consider partnering with DSAW in this effort by joining the Community Outreach Committee today by calling Heidi at 414-744-0203.

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Would you like to receive "On The Up" in your **computer's** mailbox? You will be able to obtain the DSAW newsletter faster and can help save DSAW money on postage. If you would like to participate in this pilot project, send an e-mail to kcshafer@wi.rr.com. Please provide your name, e-mail address you wish the newsletter sent to (if different from the sender) and place "newsletter pilot program" in the text.



A LETTER FROM THE 2005 HONORARY DSAW BUDDY WALK CO-CHAIRS

Dear Friends,

We invite your family to join ours at the DSAW Buddy Walk on Sunday, September 25, 2005 at Hart Park in Wauwatosa.

We became involved with Down syndrome awareness last fall when our dear friends, Frank and Sherry Perez, gave birth to Nathan. Nathan is their third child and was born with Down syndrome. We have seen up close the challenges for families caring for a loved one with Down syndrome and we vowed to do anything we could to help. So we contacted the Down Syndrome Association of Wisconsin (DSAW) and learned of the Buddy Walk. The Buddy Walk is a great way to support families as well as individuals affected by Down syndrome.

Please join us, and make it a family affair promoting awareness, acceptance and inclusion of people with Down syndrome. You can walk with us or even volunteer your time to help at the 2005 Buddy Walk.

You have our deepest appreciation for your support.

Sincerely,

Leonard & Maryann Peace
Honorary Co-Chairs

This short story was written by Russell Sepanski of Franklin, a grandfather of 7. One granddaughter, Jenna, has Down syndrome and lives in Germantown. In this story, he attempts to express the innermost feelings and mixed emotions experienced by all his family members through a single flower. It is the story of a brother's search to find the most beautiful flower to give as a welcoming present to his new baby sister. As he explores the garden, he finds that not everything is as it seems-for all things are beautiful and have value. This is a touching story about a boy and his love for his new baby sister and all the promise, hope and joy she will bring to their family.

A FLOWER FOR JENNA

By Russell J. Sepanski

Cameron was a little boy who lived in a little town in a white house with a huge flower garden. Cameron lived with his mother and father in the white house with the huge flower garden.

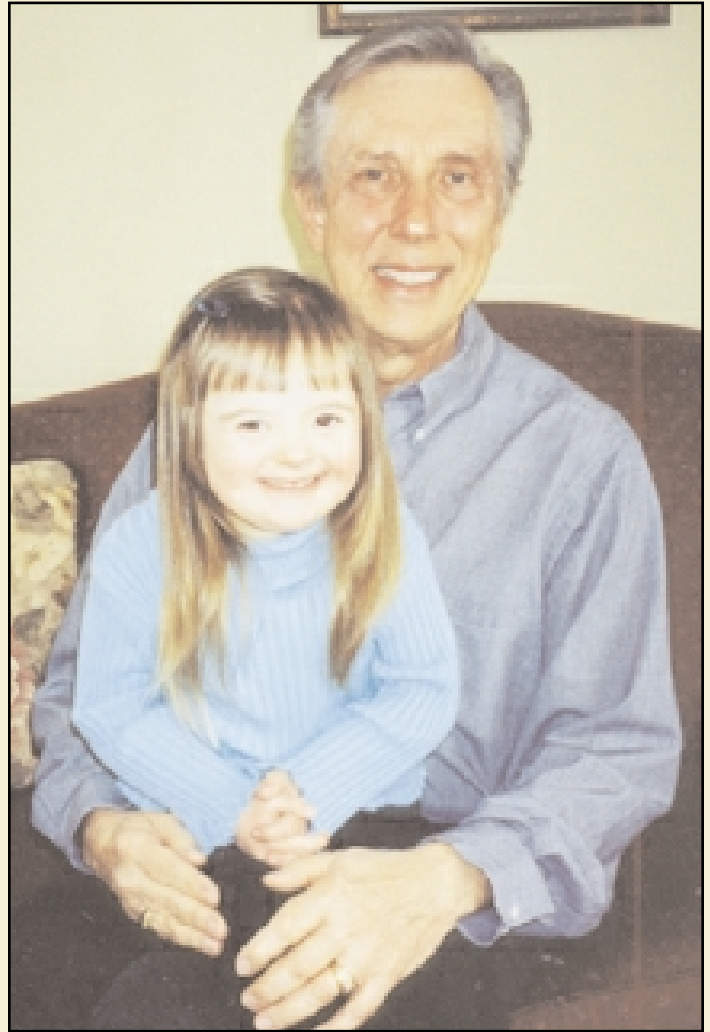
Cameron was going to have a baby sister and it was decided that her name would be Jenna. When the day arrived for Jenna to be born, his mother went to the hospital. Cameron was excitedly looking forward to visiting his new sister at the hospital.

Dad said to Cameron, "It's time for a visit to see Mother and baby Jenna." Cameron said to his father, "I would like to bring a beautiful golden flower to the hospital for Jenna." "That is a wonderful idea. I'm sure Jenna would like that very much", said Cameron's father. "You may go out into the garden and pick any flower you chose to bring to Jenna."

Cameron hurriedly ran out to the garden and began going up and down all the rows of flowers. He looked and he looked, but he could not find a golden flower. There were red flowers, blue flowers, pink flowers, white flowers, but not any golden flowers. Cameron was very disappointed at not being able to find a golden flower for he had his heart set on a golden flower for Jenna.

All of a sudden, Cameron heard a very quiet voice saying, "Pick me, pick me, I am a golden flower." The tiny voice seemed to be coming from outside the garden. Cameron stuck his head from between the flowers to peer out onto the lawn of the back yard. There, in the middle of the yard, was one lonely dandelion.

Cameron thought to himself, surely it can't be that dandelion speaking in that tiny voice. "Pick me, pick me," said the voice again. Quickly, Cameron ran over to the dandelion and said, "Are you speaking to me?" "Yes, I am speaking to you", said the dandelion. Then Cameron said to the dandelion, "I wanted a beautiful golden flower for my new baby sister Jenna, but you are just a dandelion." The dandelion answered, "I am a golden flower and I am pretty. Just because I am not growing in a garden with all of the other flowers doesn't mean I am not a treasure too!" Cameron thought carefully about what the dandelion had said, and after a little while he said, "You are right. You are golden and you are beautiful. I will pick you and bring you to my baby sister, Jenna." With that, Cameron picked the dandelion and ran to show his father and tell him what had happened.



After seeing the golden dandelion and listening to Cameron tell what had happened, his father said, "You have chosen a beautiful flower very wisely and I am sure that your sister Jenna will be very happy, and your mother will be very pleased and proud."

Cameron and his father arrived at the hospital. Excitedly, Cameron hugged and kissed his new baby sister and gave her the beautiful golden flower he had wanted so much to give her. Then he kissed his mother and breathlessly told her about how he had picked this very special golden flower for Jenna.

When he had finished, his mother hugged him and said, "Cameron, you have truly found the most beautiful golden flower in the world. You have made Jenna and I very happy!"

Special thanks to Russell for sharing his special story.

CALENDAR OF UPCOMING EVENTS

June 18th, 2005

[Puberty Workshops for Pre-Adolescents with Cognitive Disabilities.](#) It's Spring and time for the birds and the bees. Join the Down Syndrome Clinic of Wisconsin and ARC in unraveling the mystery of puberty. Female participants will have two half-day workshops on June 18th and June 25th from 9:30 to 11:30 am. Cost \$40. Male participants will have their workshop on June 18th from 1:00 to 3:00 pm on June 18th at a cost of \$25. Call Terri Couwenhoven at the Down Syndrome Clinic for more information or to register at 414-266-6259. Space is limited.

June 26th, 2005

[Our Second Annual Brewer Tailgate for Families.](#) Join other members from DSAW at Miller Park to watch the brewers play the Minnesota Twins at 1:05 pm. Join us pregame to tailgate under a tent and enjoy some burgers and hot dogs. Watch your mailbox for further information coming soon.

August 15th, 2005

[DSAW's 9th Annual Tom Pipines Classic Golf Outing at Western Lakes Golf Club in Pewaukee.](#) Cost per person is \$130 which includes 18 holes of golf with cart, lunch, beverages on the course, event shirt, sleeve of golf balls and dinner with live auction. We are in search of golfers, auction items and sponsors for this great event. Please call the DSAW office or Jon Reetz, Golf Committee Chair, at 414-282-1723.

August 21, 2005

[Summer Fun DSAW Family Picnic held at Milton Venter Park in St. Francis.](#)

September 25, 2005

[Ninth Annual DSAW Buddy Walk to be held at Hart Park, Wauwatosa.](#) We need some talented members to step forward to help make this year's Buddy Walk a success. We are in need of a graphic designer to help us create our own Buddy Walk poster based on our newly designed brochure. We are also looking for someone to aid in production of a slide show, with accompanying music, which will be shown at the Buddy Walk in addition to promoting DSAW's 15th Anniversary year long celebration. Call Angie at 414-483-3176 or the DSAW office to volunteer your time and talent.

DSAW BRAG BOOK



Jenna (6) and Josie (2 1/2) Meyer of Elk Mound. Their mom, Jennifer, writes "our family is so blessed because of a special little angel who came to us 3/15/02. She is so beautiful in so many ways and has touched so many lives. We thank God every day for opening the door to a love we could never have imagined."

MOVING ON UP

The DSAW office recently made the move to a new office space. Same building, same phone numbers, just a bigger space. We are now in Suite 311 of 9401 West Beloit Road in Milwaukee. The new office provides a more professional atmosphere which includes a bigger conference room that features DSAW's Lending Library, additional storage space for resources and materials, and a more practical, organized layout for project work. As DSAW continues to grow as an organization, this space will enable us to better serve our members and the community. We welcome you to stop by to visit and see for yourself.

JOIN THE GROUP

DSAW has created an on line support group for you! Post a question, brag about a milestone or share your exasperation at having a "Down syndrome" day. Additionally, there is a DSAW Baby Book and most recently a Listing of Summer Camps. As soon as I get information on any information relevant to helping our member families, I post it. So, stay informed and join the group today. To join, login at <http://www.groups.yahoo.com>. You will be asked if you wish to join a group. Our group name is DSAWconnects. Please note that the group name is case sensitive so DSAW must be capitalized. If you have any questions, email Carole Shafer at kcshafer@wi.rr.com.

Join "DSAWconnects" and find out more information on camps like this!

Transition Camp: My Future My Life , a transition summer camp for high school students with disabilities. The one week camp takes place on the campus of UW-Whitewater from June 19 through June 24th and helps students prepare for life after high school. In large group experiences, small group breakouts and one-to-one sessions students learn about running their own IEPs, self advocacy, choosing a career and more.

A brochure and camp schedule can be found at www.uww.edu/StdRscscs/csd/my_future_my_life.php or contact Jenny Wagner at 262-472-1492.



The Down Syndrome Association of Wisconsin receives a donation each time someone uses their Pick 'N Save Advantage Card.... providing that DSAW is the designated charity of choice. All Pick 'N Save donations to DSAW are used to support the services provided by DSAW. One of these services is to furnish New Parent Packets. These packets include valuable resource information to hospitals across the state and to new parents while they are still in the hospital.

Next time you are at Pick 'N Save, please visit the customer service counter and tell them you want to designate DSAW as one of your Advantage Card charities (if you haven't already done so). Then give them the **DSAW number - 175315**. It is that simple! Don't forget to tell your friends & relatives that shop at Pick 'N Save, too.



My Lamb on the Swing

By DSAW Member Carolyn Mae Heisey

As Daughter Two Swings at this park after seven,
I write down these thoughts of this angel from Heaven.

Fourteen years after her natural birth,
I reflect on this child of Down Syndrome girth.

Cuddly baby in blanket of pink,
Her birth went so well, all done in a blink!

They'd told me don't worry.....
Genetic testing they'd do.

Long hand line, wide nose and
Flap ears gave a clue.

I'll never forget my reactions that day;
Crying, bewildered, with total dismay.

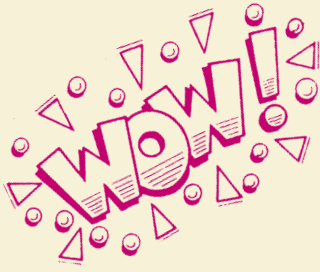
Today I'm in awe of this lamb on the swing.
No fear of her plight....just accepts everything.

She sings in a baritone voice off of key,
To her the song's perfect, as good as can be.

Others come along and apathy they bring,
Not knowing the bliss of my lamb on the swing.

Copyright 2002 Carolyn Mae Heisey.

Carolyn Heisey and her daughter, Jenna, live in East Troy.
Jenna is a student at Lakeland School of Walworth County.



Thank You!

NEW MEMBERS
THANKS FOR JOINING US!

James and Olanda Arnold
Frank, Jean and Frankie Csizmadia
Mark and Martha Flaherty
Robert and Sharon Fryjoff
Vince and Jodi Hanoski
Todd and Brigitte Klitzke
Sherry Knetter

Alfonzo and Savanna Lewis
Jessica Lovejoy
Eric and Dawn Nei
Leonard and Maryann Peace
Jacquelyn Sklander
Rob and Sue Waldkirch

TO OUR GENEROUS DONORS:

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Doug Goike & Debra Smitka
Beverly Kirst
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United Way
Vilter Foundation, Inc.

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Carol Muratore

Laverne Warren
Wellpoint Foundation/Scott Geske

Neff Family Foundation
Cindy Niegocki

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from Plunkett Raysich Architects, LLP

Memory Of Richard Ponec
from Joe and Ellen Mayer
Kevin and Angie Fech

Memory of Joe Szwalkiewicz
from Joe and Ellen Mayer

Thank You!

Jon Will's Aptitudes

by George Will

Columnist for *Washington Post*, TV Personality and Author

Jon Will, the eldest of my four children, turns 21 this week and on this birthday, as on every other workday, he will commute by subway to his job delivering mail and being useful in other ways at the National Institutes of Health. Jon is a taxpayer, which serves him right: He voted for Bill Clinton (although he was partial to Pat Buchanan in the primaries).

The fact that Jon is striding into a productive adulthood with a spring in his step and Baltimore's Orioles on his mind is a consummation that could not have been confidently predicted when he was born. Then a doctor told his parents that their first decision must be whether or not to take Jon home. Surely 21 years later fewer doctors suggest to parents of handicapped newborns that the parental instinct of instant love should be tentative or attenuated, or that their commitment to nurturing is merely a matter of choice, even a question of convenience.

Jon has Down syndrome, a chromosomal defect involving varying degrees of mental retardation and physical abnormalities. Jon lost, at the instant he was conceived, one of life's lotteries, but he also was lucky: His physical abnormalities do not impede his vitality and his retardation is not so severe that it interferes with life's essential joys--receiving love, returning it, and reading baseball box scores.

One must mind one's language when speaking of people like Jon. He does not "suffer from" Down syndrome. It is an affliction, but he is happy--as happy as the Orioles' stumbling start this season will permit. You may well say that being happy is easy now that ESPN exists. Jon would agree. But happiness is a species of talent, for which some people have superior aptitudes.

Jon's many aptitudes far exceed those few that were dogmatically ascribed to people like him not long ago. He was born when scientific and social understanding relevant to him was expanding dramatically. We know much more about genetically based problems than we did when, in the early 1950s, James Watson and Francis Crick published their discoveries concerning the structure of DNA, the hereditary molecule, thereby beginning the cracking of the genetic code. Jon was born the year before *Roe v. Wade* and just as prenatal genetic tests were becoming routine. Because of advancing science and declining morals, there are fewer people like Jon than there should be. And just in Jon's generation much has been learned about unlocking the hitherto unimagined potential of the retarded. This begins with early intervention in the form of infant stimulation. Jon began going off to school when he was three months old.

Because Down syndrome is determined at conception and leaves its imprint in every cell of the person's body, it raises what philosophers call ontological questions. It seems mistaken to say

that Jon is less than he would be without Down syndrome. When a child suffers a mentally limiting injury after birth we wonder sadly about what might have been. But a Down person's life never had any other trajectory. Jon was Jon from conception on. He has seen a brother two years younger surpass him in size, get a driver's license and leave for college, and although Jon would be forgiven for shaking his fist at the universe, he has been equable. I believe his serenity is grounded in his sense that he is a complete Jon and that is that.

Some of life's pleasures, such as the delights of literature, are not accessible to Jon, but his most poignant problem is that he is just like everyone else, only a bit more so. A shadow of loneliness, an irreducible apartness from others, is inseparable from the fact of individual existence. This entails a sense of incompleteness--we "are" social creatures--that can be assuaged by marriage and other friendships, in the intimacy of which people speak their hearts and minds. Listen to the wisdom whispered by common locutions: We speak of "unburdening ourselves" when we talk with those to whom we talk most freely.

Now, try to imagine being prevented, by mental retardation and by physical impediments to clear articulation, from putting down, through conversations, many burdens attendant on personhood. The shadow of loneliness must often be somewhat darker, the sense of apartness more acute, the sense of incompleteness more aching for people like Jon. Their ability to articulate is, even more than for everyone else, often not commensurate with their abilities to think and feel, to be curious and amused, to yearn.

Because of Jon's problems of articulation, I marvel at his casual everyday courage in coping with a world that often is uncomprehending. He is intensely interested in major league baseball umpires, and is a friend of a few of them. I think he is fascinated by their ability to make themselves understood, by vigorous gestures, all the way to the back row of the bleachers. From his season-ticket seat behind the Orioles dugout, Jon relishes rhubarbs, but I have never seen him really angry. The closest he comes is exasperation leavened by resignation. It is an interesting commentary on the human condition that one aspect of Jon's abnormality--a facet of his disability--is the fact that he is gentleness straight through. But must we ascribe a sweet soul to a defective chromosome? Let us just say that Jon is an adornment to a world increasingly stained by anger acted out.

Like many handicapped people, Jon frequently depends on the kindness of strangers. He almost invariably receives it, partly because Americans are, by and large, nice, and because Jon is, too. He was born on his father's birthday, a gift that keeps on giving.

(Originally appeared in Newsweek, May 3, 1993. Quoted above from the collection The Leveling Wind: Politics, the Culture, and Other News, 1990-1994)



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- New Member
 Renewal
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Membership Application

Name _____

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City _____

State _____ Zip _____

Phone _____

E-Mail Address _____

Parent Grandparent Aunt / Uncle Sibling Other

If this is a gift membership, list recipient's information above and write your name here: _____

MEMBERSHIP LEVEL

\$20 one year \$30 two years

Additional Donation enclosed: \$ _____

Please enclose any names and addresses of others who may be interested in helping DSAW achieve its goals.

Mail this application with your check to:

DSAW • 9401 West Beloit Road, Suite 311, Milwaukee, WI 53227

ON THE UP WITH DOWN SYNDROME

Newsletter is published quarterly by the Down Syndrome Association of Wisconsin, Inc.

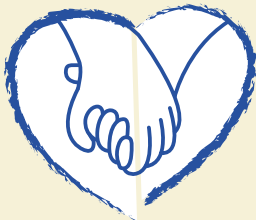
DSAW's **mission** is to provide support to families and individuals with Down syndrome through education, information, and the exchange of ideas and experiences.

The **vision** of the Down Syndrome Association of Wisconsin is the understanding of the value of people with Down syndrome in our lives and the community. We will continue to strive towards full acceptance, full access, full life and full potential.

The **policy** of the Down Syndrome Association of Wisconsin is not to endorse any medical, therapeutic or special education alternatives. The Down Syndrome Association of Wisconsin is a volunteer group consisting of people who wish to create an optimistic outlook about Down syndrome for our families and others. The purpose of this newsletter is to provide a source of information to the community and members on issues related to Down syndrome.

DSAW Office is located at
9401 West Beloit Road, Suite 311,
Milwaukee, WI 53227
Phone: (414) 327-3729 or (866) 327-DSAW
Fax: (414) 327-1329
E-Mail: info@dsaw.com
Web Site: www.dsaw.org

Thanks to **INDEX PRINTING** for their hard work that goes into the production of the newsletter.




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