



Extra! Extra! 21

Summer 2011

Medical Outreach



In April, DSA brought Brian Skotko, MD, MPP, a leading expert in health care for individuals with Down syndrome, to Omaha. Dr. Skotko presented his workshop, *Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Physicians*, to physicians at Bergen Mercy Medical Center and to physicians and nurses at Methodist Women's Hospital. He was the keynote speaker at the Advocacy

in the Midlands Conference and presented both *New Prenatal Tests for Down Syndrome: National Updates* and *What This All Means for Your Family and Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know*.

DSA is grateful to both Alegent Health and Methodist Health System for hosting the medical professionals' workshops.

Advocacy in the Midlands included presentations on healthy sexuality across the life span and on communication skills in children with Down syndrome by nationally recognized experts Leslie Walker-Hirsch, M. Ed., (right) and Libby Kumin, Ph.D. (left).



Other speakers traveling in to Omaha for the conference were Mary Schlieder (social clubs), Sean Smith (classroom technology) and Meredith Martin, (self advocate) (lower right).



Eighteen volunteers made up of DSA Board Members, general DSA members, and representatives of community services participated as panelists in breakout sessions.

DSA provided conference stipends to thirty-one members and two Down Syndrome Specialists from local school districts. DSA also hired two interpreters; six members availed themselves of interpretation services.



Feedback indicated that members would like to see the conference become an annual event.



— Roberta Tonjes, DSA Medical Outreach Chair

Fundraising

The 2011 Buddy Walk preparations are well underway!

We are focusing a lot of time toward the pre- and post-walk activities, including games, music, and other fun activities for all ages. We expect to have the donation web site, FirstGiving, live soon — so it's not too early to begin thinking about forming your team.

Whether you are planning to form a team, join a team, walk with us virtually, or register as an individual — your participation is appreciated.

For those of you who have participated in the past — what can make this year's event better? What did we miss last year? It's not too late to offer suggestions for our committees to consider!

— Dan Kline, DSA Fundraising Chair



Buddies, mark your calendars!

Saturday, October 15 at UNO

6805 Grover Street • Omaha NE 68106 • 402-991-1800 fax: 402-934-1479

www.dsamidlands.org

info@dsamidlands.org

DSA is committed to enhancing the lives of individuals and families touched by Down syndrome.

Down Syndrome Super Moms

The Down Syndrome Super Moms group is growing and thriving! There are more and more moms of older kids coming to the coffees. They are finding that they are getting things out of the meetings as well providing expert advice from a "been there, done that" stand point. Stories are shared of past struggles and how hard it was to advocate for their children. We have come a LONG way and that is in direct relation to all those moms / parents who have fought so hard to get laws passed and schools aware of our children's rights and changes in community and society in general. They paved the way and need to be thanked and appreciated for all of their hard work!

Overall the attendance has consistently stayed up to over 15 moms at each coffee with an ebb and flow of regulars, newbies and others that can only make it out a couple times a year. It's funny how they don't feel like they even miss a beat. You just slip right back into the familiarity and warm embrace of all who are there. It truly is an amazing group and you leave the meetings with a sense of confidence and a little bit more knowledge or a helpful hint that you didn't have before you attended. It is a positive and inviting group that would love to have more and more attend each month!



The moms have a Facebook group where it is easy to share ideas, advice, announcements, activities, questions and to help a fellow mom out even if you can't make it to the coffees. PLEASE consider jumping on there and making it a regular stop on your daily Internet browsing. The more moms we can get, the broader our experiences are and the more we can be of assistance to each other. Just type "DSSM" in the search bar at the top of your Facebook. Click "Join Group" and you are in!

Thank you so much to each and every mom that has been an intricate part of making our group what it is today.

— Casie Schlueter, DSA Parent Outreach Chair
DSSM Group Leader



New members
are always
welcome!

Sunday, August 28, 4—6 p.m.

Centennial Park

96th & Centennial
Grandparents & Families

Chicken & Water Provided

Contact Bella's Grandmas

Jean Hayden 402-896-9654/

jhayden3@cox.net

Barb Cullinane 402-895-7887
with family numbers & side dish.



FIRST ANNUAL DIVOTS FOR D.A.D.S GOLF OUTING

THURSDAY, SEPTEMBER 15, 2011 • 12 P.M. SHOTGUN START • 4-PERSON SCRABBLE

INDIAN CREEK GOLF COURSE • 202nd & WEST MAPLE ROAD

REGISTRATION FEES

\$90 per golfer (if received before August 15th)

\$110 per golfer (if received after August 15th)

Fees include:

- 18 holes of golf
- Golf cart
- BBQ dinner
- Flag prizes
- A chance at raffle prizes
- Golfer care package
- Free access to driving range – 10:30 a.m. - 11:45 a.m.

Corporate sponsorships are available. Please visit our website at www.dadsomaha.org.



HOLE-IN-ONE
WIN A 2011 FORD
FUSION!

- One attempt per golfer
- See full rules and details at the contest hole.

Courtesy of Baxter Ford



Letter from the President

Friends,

I can hardly believe it, but 2011 is half over! It's been a great year so far, and as promised we have been focusing on offering more special activities for our tweens and teens this year. Please keep the ideas coming for activities for all age groups, and remember – the better attended an event becomes, the more likely we are to offer it again! This month we made an appearance at the fabulous new Werner stadium for a Storm Chasers game, and will be visiting Zorinsky's Aquatic Center for swimming fun. I hope to see everyone there!

As we move closer and closer to Down Syndrome Awareness Month in October, our efforts to fundraise for the Buddy Walk will move into full swing. Please help support this very important event because the funds we raise that day pay for most of the family activities DSA funds throughout the year, as well as the bulk of our Medical and Educational outreach programs. The committee is working hard to make the Buddy Walk itself a fun and inviting event for all ages, and I am very excited about their progress!



Allison Machamer & Marcus Amua-Sekyi
Werner Stadium, July 17

I'd like to take a moment to thank all of the wonderful folks serving on the board this year. Serving on the board of a non-profit can be extremely rewarding, but challenging as well. I deeply appreciate everyone who dedicates the time to make DSA possible! We hold board elections in January every year, but we accept applications all year long to build a queue of volunteers who would like to serve. Please send a note to info@dsamidlands.org if you or your family/friends would like to join the board in January – it's not a requirement to be a parent of an individual with Down syndrome. We have several folks serving today that are simply amazing citizens from the community at large.

I hope everyone is having a fun and fruitful summer! As always, please feel free to contact me or anyone on the board with questions, concerns, or ideas.

— Allison Machamer, DSA Board President

April

Marcus Amua-Sekyi
Chase Carlon
Nathalie Castro
Ethan Costello
Clayton Dilsaver
Grace Greenwood
Edgar Jacinto
Cassie Lacy
Allen Machamer
Landon Marshall
Taylor Marshall
Connor Meng
Mary Clare O'Malley
Emerson Ostrand
Brandon Pollard
Beth Quiring
Vollen Schlueter
Kellee Snethen
Will Stoneburner

May

Jordan Andrews
Aaron Arcos
Eliana Carnazzo
Kristina Cook
Mariana Garcia
Daniel Holm
Kohen Koch
Ellie Kuecker
Stefi Kuhlers
Heather Mahlock
Bailee Mathews
Alex Mejia
Samuel Moses
Monica Sobczyk
Jesse Soto
Grant Switzer
Mason Wessendorf

June

Justin Bainbridge
Claire Baum
Bailey Beightol
Evan Bittner
Carrissa Caskey
Howie Delp
Anna Goodrich
Beth Hamm
Bella Hayden
Haley Heese
Ben Herek
Violet Hyatt
Samuel Karn
Dakota Karn
Troy Kostal
Louis Matthews
Elizabeth Million
Mya Patrick
Derek Rivard
Jackie Sage
Kevin Sieczkowski
Jerus Sime
Sean Smith
Joseph Sobetski
Michael Thome
Angel Tovar
Corena Urrutia

July

Caitlyn Adams
Sean Bethel
Ryan Bisignano
Clair Bruns
Rebekah Cook
Jamie Crozier
Taylor Dabbs
Cole Edwards
Jack Flanery
Devon Freiberg
Ella Haitz
Reichen Herley
Cesar Higuera
Marissa Palacios
Edward Pfeffer
Julian Ramirez
Alex Rohrer
Kayleigh Schoepe
Brady Shannon
Ty Stanley
Brooklyn Tonjes
Jenna Twomey
Jack Wadzinski
Benjamin Walz
Trey Yanak

Happy Birthday!

Condolences

to the family of Mary McHale on the passing of her father, Patrick H. McHale. DSA is grateful for the memorial gifts donated to sponsor the Buddy Walk.

Thank you

Dr. Jess Foster-Christiansen and Omaha Chiropractic & Acupuncture for their 12-month fundraising and awareness efforts for DSA.

Mary McHale for her donation in honor of DSA charter board member Amy Amua-Sekyi on the occasion of her retirement from the Air Force.

Volunteers are hard at work organizing and cataloging the DSA Lending Library. Until the new website is up with the library catalog, please email info@dsamidlands.org with your interest in borrowing one of these titles or in making an appointment to browse our collection.

New titles include:

Fasten Your Seatbelts, A Crash Course on Down Syndrome for Brothers and Sisters

Brian Skotko & Susan P. Levine

Grade 4-9-Skotko and Levine address preteens and teenagers who have a sibling with Down syndrome, answering questions that have been generated through their work with this population.

The Shape of the Eye: Down Syndrome, Family and the Stories We Inherit

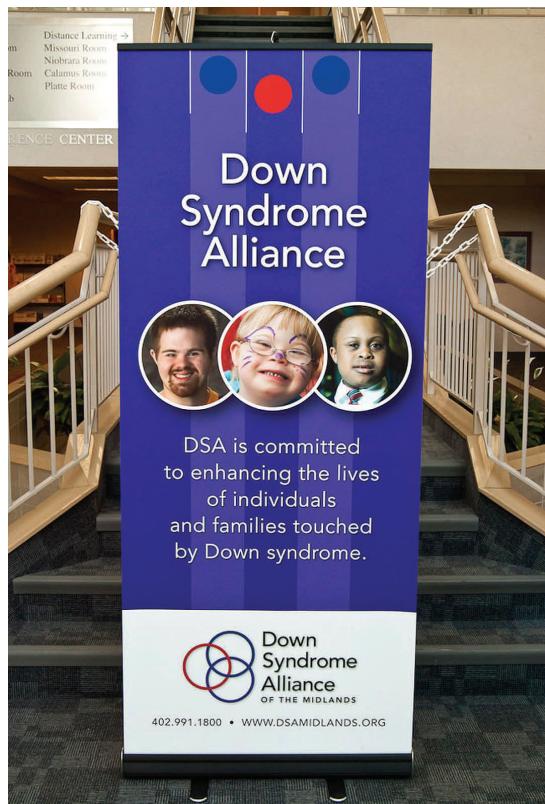
George Estreich

When Laura Estreich is born, her appearance presents a puzzle: does the shape of her eyes indicate Down syndrome, or the fact that she has a Japanese grandmother? In this powerful memoir, George Estreich, a poet and stay-at-home dad, tells his daughter's story, reflecting on her inheritance—from the literal legacy of her genes, to the family history that precedes her, to the Victorian physician John Langdon Down's diagnostic error of "Mongolian idiocy." Against this backdrop, Laura takes her place in the Estreich family as a unique child, quirky and real, loved for everything ordinary and extraordinary about her.

Managing a Special Needs Trust: A Guide for Trustees

Barbara D. Jackins, Esq., Richard S. Blank, Esq., Ken W. Shulman, Esq., Harriet H. Onello, Esq.

An invaluable resource for anyone who is managing a special needs trust for a person with a disability. Formerly called Special Needs Trust Administration Manual, this book has been completely revised, updated, and expanded to cover all 50 states. The authors, who are all attorneys, bring many years experience in guiding trustees through the complicated rules of public benefits and special needs trusts. In clear, easy to understand language, the authors provide practical strategies trustees can use.



DSA would like to thank Russel G. Lindeman of ReGaL Photography for use of the portrait of Justin Bainbridge. The photos of Haley Heese And Mahinda Melton were taken by James Keller.

Welcome To DSA

Laura & Rollin Biel
Chloe

Marge & Joe Koley
Jennifer & Family

Denise & Rob Broom
Thomas & Family

Amy & Tim Nisley
Abigail & Family

Karin Cardona
Juan

Tricia & Tim Nobis
Blake & Family

Bree & Chris Gigere,
Anthony & Family

Donna & Bogart Nomad
Zakariah & Family

Gabriela & Elmurad Hasanov
Arslan

Alicia & Peter Pol
Cooper

Shelby Hoins, brother of Beau
Hoins

Susan & Jeff Philby
Jason & Family

Sarah & Kurt Jaeger
Emily & Family

Debbie & Scott Schreiber
Lucas & Family

Jeanie & Christopher Karn
Dakota & Family



Marcus Amua-Sekyi
threw out the first pitch
at the Omaha Storm
Chasers game at the new
Werner Stadium on July
17, 2011.

