Letter from the President
By Craig Parker

As I struggled to come up with what to say in my final “Letter from the President” I read back through some of the articles and letters I have written in the past three years. One phrase jumped off the page as I looked at a year-end giving letter from 2011.

“The number one resource on Down syndrome in Minnesota and the surrounding region.”

For any of you that have read the book “From Good to Great” you may recognize this as the Down Syndrome Association of Minnesota’s “BHAG” or Big Hairy Audacious Goal. When that phrase was stated at our strategic planning session earlier in 2011, I think we were all overwhelmed and excited at the same time. What a challenge! What an opportunity! Where do we start?

When I look back over the past six years I realize this has been our goal all along. Not just for my time on the board, but since DSAM was started around the kitchen tables of families almost 30 years ago. They may not have known it at the time, but they were starting us on the path towards that goal. A goal we continue to make progress towards today.

I’ve witnessed new programs start such as our travel club and our sponsorship of the iCan Ride bike camp. We’ve piloted a program to help meet the healthcare needs of adults with Down syndrome and have exciting news to share on this front as we move through 2014. We started our Adult Matters conference and have begun to take other conferences “on the road” to better serve our members in greater Minnesota.

And our progress towards this goal will continue. We will build on our strong relationships in the medical community to continue to share the complete story of what it means to have Down syndrome. We will always be there to welcome families with open arms, a listening ear, and local connections, throughout their own personal journey. And we will continue to reach out to our community across the region to understand needs, build programs, develop partnerships, and create opportunities.

I want to wrap up by saying “thank you” to everyone I’ve had the opportunity to meet and work with over the past six years. It is the commitment of our amazing volunteers, staff and board members that will continue to make DSAM the number one resource on Down syndrome in the region and I have been blessed and honored to work with you all.
Thank you

We wanted to take a moment to let you all know how much we appreciate our DSAM community. We are strong because we are here for each other and we get to see that every day here at the office. You have stepped up to share your favorite resources, both with us and with other families directly. You have supported each other in parent groups and in hospitals. You have celebrated together at the Step Up Walk and other DSAM social events.

We get calls from parents looking for new activities or medical specialists. We get calls from parents out of the state (and out of the country) who are facing moving their family and starting over with new educators, new providers and a new community. And, of course, we get calls from new parents with babies who have Down syndrome. It is because of you we are able to welcome them to our community and make them feel like they will not be alone with the challenges and blessings of raising a child with Down syndrome in Minnesota.

Thank you for helping us. Thank you for being there for each other.

“For a community to be whole and healthy, it must be based on people’s love and concern for each other.” – Millard Fuller, founder and president of Habitat for Humanity

Oops, We Goofed Up.

We feel really bad! In the last issue of Special Times we thanked the Hennepin County Sheriffs for their help at the Step Up walk in St. Paul. We meant to thank the Ramsey County Sheriffs who have been part of our Walk for more than ten years.

The deputies who volunteer their time are one of the hits of the day; they are warm and inviting, interacting with our families in the most wonderful ways. They bring squad cars, ATV’s, boats in which the children can have their pictures taken, DVD’s and CD’s are also given away. We all have favorite memories of each and every walk. A few years ago, our Executive Director was visiting with Sheriff Bostrom and as she walked by one family she heard the following conversation (little boy about 8): “I am now a deputy”; Mom said, “No Brian; these men are the Deputies”. His reply...‘yes I am Mom, I got the badge and I am now in charge of law and order”. The stickers and CD’s, being able to sit on an official 4x4 or peak into a squad car – all add up to a fabulous day for our families.

We thank the Ramsey County Sheriff’s Department and again apologize for our typo!
Patron (1000+)
Frankard Foundation

Benefactor (250+)
James & Phyllis Bjork
Raymond & Patricia Chappell
Frank & Regina Maguire
Ann & Mark Peiler
David & Sally Sawyer

Contributor (100+)
Kevin & Cheryl Bardwell
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Kowalski’s Market
Alice Liptak
Jeffrey & Susan Lambert
Thomas & Joann Mason
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Donita Soucek
Ann Strom
Patrick Welch
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In Memory of
Jodi Bechtold
Brett Bertelson
Hawkin Dahn
Danny Danielson
Owen Kampbell
Sean Maher
Nora Markowski
Kenneth Randt
Jared Smasal, Jr
Irene Adeline Wenda
Raymond R. Wilson

In Honor of
Anthony Bardwell
Madison Bartsch
Louis Cossette
Brooke Flaata
Amy Fletcher
Allyson Frischmon
Connor Holcomb
Kassidy Lea
Nora Markowski
Jackson Pearce

Employee/Community Giving and Matching through:
Microsoft

Give to the Max
Marilyn Barnstorf
Lisa Bartsch
Judith Bohm
Christine Brown
Julie Carr
Laure Charleux
Wayne Courtney
Gail Davis
Sharon Doyle
Mary Doyle
Barbara Ginther
Nancy Grundahl
David Grundman in honor of Hannah Keenan
Robert Hainlen

William Hannon
Nicole Hansel-Welch
Sara Hansen
M.P. Hansen
Maria Harris From The Carly May Foundation
Leilani Heinen
Rochelle Hilson
Cammie Holcomb
Linda Keenan
Jean Koppes
John Kupris
Nancy Le
Matthew Marsolek in honor of Adam Hancock
Lynn McDonald
Marie Medvec
Carol Meyer
Jeanine Nelsen
Heather Ninow
Patricia Nolte
Daniel O’Connell
Thomas Peden
Tareasa Penn: On behalf of our beautiful Carson. He teaches us so much everyday.
Mary Jo Peterson
Marcy Rede
Kevin Robb
Christine Scholl
Beth Schoolman
Donald Schwartz
Anthony Sexton
Mary Shaprio
Donita Soucek
Joseph Spitzmueller
Paul Tanghe Andy
Jack Thompson
Karen Timm
Sarah Verdoorn
Roxanne Vetsch
James Wazlawik in honor of Max Wazlawik/Kaitlyn Sm
Joe Wettemach: For our most awesome nephew and cousin Ethan Christenson
Darii Wohlers
Matthew Wolfe
Deborah Wynne: For my sweet and spunky Sophie.
Robert Yerxa: Dedicated for Winston Eugene Yerxa

Donors through employee matching:
Scott Lee
Sarah Suk
Michelle Hosfield, Allina Health
Christopher McClellan
Kevin Groth
Anne Forslund
Craig Miller
Alan Saffert
Jay Kasner
William Jarvi
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Angela Skeer
Timothy Landro
David Willits
Lesley Ginther
Joel Tyler
Brian Lashomb
Mark Nateh
Michael Garry
Sean Heath
David Zetah

Continued on page 7
Helping your child with special needs to be independent

By Lauren Agoratus, MA. Parent, State Coordinator - Family Voices NJ at the Statewide Parent Advocacy Network, Southern Coordinator – Family-to-Family Health Information Center at Statewide Parent Advocacy Network

Families of children with special needs may be overprotective, and often feel justified because of the challenges their children face. But children with special needs need to reach their personal best potential, and should be encouraged to be as independent as possible starting at an early age.

Do start early

Even a toddler may express a preference about which outfit to wear. If there are homework struggles, ask which subject would they like to do first. Getting input from your child from an early age will help them feel like their opinion counts, and will begin to build their capacity to make decisions for themselves.

Do give your child choices

Even if your child can’t avoid a situation, giving them choices may help them feel more in control. For example, if your child needs a shot or bloodwork, ask them which arm they want to use. Children should be allowed choices, especially as they get older, with the exception of decisions that significantly impact their safety.

Do remember that transition is more than school-to-work

Your child may need to consider post high school education and ThinkCollege.net has good ideas on college for students with special needs. Your child must also transition their healthcare from pediatric to adult care, so start this early. Your pediatrician may have ideas on which adult healthcare providers would be a good fit for your child. Kids as Self Advocates is a good group for them to join to advocate for their own healthcare. Find them at http://www.fvkasa.org/index.php.

Do help set realistic expectations

Even if your child can’t do exactly what they want to do as a career, there may be a way to adapt it. For example, there was a young student who really wanted to be in the military but physically couldn’t pass the exam. So he ended up working at a recruiting center, still working in the field he wanted. Another young person said they wanted to be a veterinarian. When questioned, it was clear that they wanted to work with animals. So they now work as a pet groomer! Parent Training and Information Centers (PTIs) can teach parents to advocate for their child, and then families can in turn teach their child how to advocate for themselves. You can find the PTI in your state at www.parentcenternetwork.org.

Do teach your child to self-advocate

You child needs to speak up for himself as early as possible. One good first step is having the student prepare a simple one pager for his IEP meeting which could include their strengths, struggles, goals, and what helps them learn. There’s even a Got Transition website for students at http://www.gottransition.org/. Also families can make sure that adults speak to their child, not the parents, especially as he gets older. Older students will have to decide if they need to disclose their disability for accommodations at post secondary education or in the workplace.

Don’t wait until your child is almost an adult

Many things need to be in place by age 18. Does your child need a special needs trust? Is he eligible for SSI? Is he eligible for Medicaid? Start the process of getting these systems in place before he’s an adult. Also, your child should be preparing for transition all along anyway.

Don’t ignore your child’s wishes

Ask yourself if your child wants to go into a certain field or go to college, if that’s your dream for him. If your child has a special interest, perhaps he can get a job in that field. Another example is many students with autism are detail oriented or like the predictability of repetitive tasks such as data entry.

Don’t do things for your child

You shouldn’t do things that your child can do it for himself. Although it may be easier to help a young child get dressed, allowing them to do it for themselves will give them practice at doing it. You may need to allow more time, but let your child do the things for himself that he can. And remember not to speak for your child unless he can’t.

Don’t rule out possibilities like work, college, or living independently

Assistive technology, including communication devices, allows students with disabilities to do more for themselves. Technology can help them speak, take notes, organize their schedules, including medication reminders. Ask your child what they want to do as an adult and get services and supports in place such as independent living skills from Centers for Independent Living (CILs). You can find your closest CIL at http://www.ncil.org/. There are also now a wide variety of living options using universal design such as supervised apartments, assisted living, etc.

Summary

Families need to decide how much their child is able to make educational, vocational and medical decisions. Centers for Independent Living help with employment but also financial literacy, transportation, and other life skills. When students learn self advocacy, this will help them live as independently as possible as an adult.

For more information or assistance with your child, you can reach out to your state Family to Family Health Information Center (www.familyvoices.org) or PTI (see above).
News from the office

iCan Shine Bike Camp

We will be holding our third bike camp this summer. Please watch your mail, email and DSAM social media for updates. Make sure we have your correct contact information so you don’t miss any updates!

2014 Conferences

DSAM will be holding three conferences this spring: The Regional conference, Adult Matters and Youth & Adult. If you have a topic or a workshop that you would love to see at any of our conference, please let us know! We are also looking for volunteers to serve on the planning committee for the Regional Conference and the Youth & Adult Conference. If you are interested, please contact Kathleen, either by phone (651) 603-0720 or by email Kathleen@dsamn.org for more information.

We also need lots of volunteers at the Youth & Adult conference as support for attendees. If this is something you would be interested in helping out with, please contact Catherine by phone or email Catherine@dsamn.org.

Step Up for Down Syndrome Walks

The planning for our biggest event of the year starts early! We are looking for volunteers to serve on the planning committee. If you are interested, please call Kathleen at (651) 603-0720 to set up an interview.

Have you renewed your membership in 2013?

If you are not sure whether you have renewed your membership this year please contact Kate Pickford, kate@dsamn.org or (651) 603-0720. The family or individual level is only $20 a year and there is a level from $0 - $19 called scholarship that we encourage you to use if needed. Also, if you no longer wish to maintain your membership just contact Kate and she will make the change.

Library materials

There are a number of items overdue from our resource library. Please look around your house and see if you may have forgotten to return our Resource Library Material. The “rules of the road” for the library are you must be a member in good standing to check out materials, you can check out two items at a time for a two week period (if the items are sent and returned by mail we add on appropriate time). Your fellow members appreciate your help in maintaining the library!

Have you moved, changed phone numbers or email recently?

If you have, please consider letting us know so we can keep our data base up-to-date! Contact Kate at kate@dsamn.org or 651-603-0720

National Institutes of Health launches DS-Connect: The Down Syndrome Registry

In September 2013 the National Institutes of Health (NIH) and the Down Syndrome Consortium launched the Down Syndrome Registry, dsconnect.nih.gov.

The NIH-supported Down Syndrome Registry, DS Connect™, will give people with Down syndrome and their family members, researchers, and parent and support groups opportunities to share information and health history in a safe, confidential, online database. You can create and edit your profile online, share your profiles with other DS Connect™ users, and set reminders for medical care and other appointments and events. DS Connect™ will also provide access to general information about Down syndrome, as well as de-identified statistical data based on user responses to survey questions.

Who can access DS-Connect™?

Those with Down syndrome and their families will need to provide their consent for the Registry before they can create their password-protected profiles. If a user gives permission to be contacted, then clinicians and researchers who are authorized will contact these individuals to see if they are interested in participating in research studies. The Registry will comply with all regulations and laws governing privacy, personally identifiable information, and health data.

Why do we need DS-Connect™?

“The new registry provides an important resource to individuals with Down syndrome and their families,” said Yvonne T. Maddox, deputy director of the NICHD (Eunice Kennedy Shriver National Institute of Child Health and Human Development), which is funding the registry. The registry links those seeking volunteers for their research studies with those who most stand to benefit from the research.” Creating a national registry was a primary recommendation of the 2007 NIH Down Syndrome Research Plan, which helped set goals and objectives for the Down syndrome research field. The development of DS Connect™ was also supported by the Down Syndrome Consortium, a public-private partnership established in 2011 to further the exchange of information on Down syndrome research and to implement and update the Research Plan.

About the National Institutes of Health (NIH): NIH, the nation’s medical research agency, includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. NIH is the primary federal agency conducting and supporting basic, clinical, and translational medical research, and is investigating the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit http://www.nih.gov.

Information for this article is from dsconnect.nih.gov. More information about DS Connect can be found through this link.
Parent Groups

Attend a Parent Group meeting near you to meet other parents of children with Down syndrome, share information and experiences, discuss common issues or concerns, and find support. Please note: Times and locations are subject to change. Please contact group facilitators for information. If you are interested in facilitating a parent group, please contact Kathleen at 651-603-0720.

Apple Valley
Shepherd of the Valley Lutheran Church
12650 Johnny Cake Ridge Road
3rd Sunday, 5:00 pm
Suzy Runkel (952) 891-5082
suzy.nelson@hotmail.com
Childcare $3/child

Buffalo
Meeting times & location may vary, please call before attending.
Sheri Jorgensen (763) 222-9125, (763) 682-7468
s.h.jorgensen@co.wright.mn.us
Penny Kauffman (763) 498-7173
pckauffman@comcast.net

Chaska
St. John’s Lutheran Church
300 E 4th St, Chaska
2nd Thursdays, 6:30 pm
Kara Parker (952) 443-5064
kara.parker321@gmail.com

D.A.D.S.
Park Tavern
3401 Louisiana Blvd, St. Louis Park
2nd Thursdays, 6:30pm
Dave Hanson (612) 670-7382, dadsmn@dsamn.org

Duluth
St. Paul Episcopal Church
1710 E Superior St, Duluth
3rd Monday, 6:00-8:00pm
Karen Swanson kswanson@css.edu
Kathleen Halverson kathleenhalverson@downupnorth.com

Elk River
2nd Tuesday
Call or check website for location, time & activities. www.nwspark.com
Julie Mielke (763) 856-1078
mielkman@hotmail.com
Heather Coudron (763) 274-1710
woodland132@yahoo.com

Grandparents Group - Twin Cities
Perkins Restaurant
4201 W 78th St, Bloomington
3rd Tuesdays, 9:00am breakfast, 10 am meeting
Jerry Cooper (952) 432-9769

Hastings
McAuliffe Elementary
1601 W 12th St, Hastings
4th Mondays, 6:00-8:00
Jennifer Strode: (763) 291-5308
saltandlightmn@hotmail.com
Kaiya Witt (612) 670-5320
kaiya.witt@comcast.net

Maple Grove
Maple Grove Community Ctr.
12951 Weaver Lake Rd., Maple Grove
3rd Tuesdays, 6:30-8:15pm
Lisa Bartsch (763) 391-6634
ljbartsch@gmail.com

MnNetonka
Cross of Glory Baptist Church
4600 Shady Oak Rd, Minnetonka
2nd Monday, 6:30 pm
Ann Bremer (952) 939-0350
bremerann@hotmail.com
Michele McLaughlin

Owatonna
Call for meeting times and location
Amanda Gislason (507) 469-9720
amandagislason@hotmail.com

St. Paul
St. John the Evangelist Episcopal Church
60 Kent St, St. Paul
3rd Tuesdays, 6:00-7:00 PM
Lindsay Radford lradford@kstp.com

Stillwater
Rutherford School
115 Rutherford Rd, Stillwater
2nd Monday, 6:30—8:00pm
Childcare provided
Jan Kramer (651) 439-7037
ozramer@cpinternet.com
Mary Lynn Loegering (651) 430-1870
mary.loegering@gmail.com

SW Minnesota: Designer Genes
Please contact Kim Weidert for more information. kimw@iw.net

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1710 E Superior St, Duluth
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Karen Swanson kswanson@css.edu
Kathleen Halverson kathleenhalverson@downupnorth.com

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mielkman@hotmail.com
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woodland132@yahoo.com

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kaiya.witt@comcast.net

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mary.loegering@gmail.com

SW Minnesota: Designer Genes
Please contact Kim Weidert for more information. kimw@iw.net
Time to say goodbye to our outgoing board members

We’ve been very fortunate over the years to work with some very dedicated Board members — family members, professionals and self advocates who give of their time and talents to help define the strategies, programs and resources we have to meet the needs of our members.

As we welcome the newly elected (and re-elected) board members Don Schwartz, Brandon Yerxa, Caryn Addante and Jerry Cooper, we are also saying goodbye to four board members whose board terms have expired.

We are saying good by to Craig Parker, our current board president, Jessica Marsolek, our current Vice President, Ann Strom and Annah Smith.

We thank each and every one of your for your gifts of time and talents you have given to the Down Syndrome Association of Minnesota. We will miss you around the table the second Tuesday of the month!

Member Classifieds

Our son (22 years) is excitedly planning on moving out and living on his own (with support). We’re currently helping him look for a roommate (or two). He’s hoping to live somewhere in south Minneapolis. The living arrangement to be determined—just beginning to explore ideas like an apartment, house etc. If you know someone who might be a roommate candidate, please let us know. We could have a non-binding chat to explore if it might be a fit.

Jaimie Bennett, jaimie.bennett04@gmail.com or 612-799-2136

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Down Syndrome Association of Minnesota
Membership Application

Name: __________________________________________________________________________________________

Address: __________________________________________________________________________________________

City, State, Zip: _____________________________________________________________________________________

Phone: ________________________________________ Email: _____________________________________________

Name of person with DS: ___________________________________________________ Date of birth: _____________

Relationship to person with DS: _______________________________________________________________________

□ Do not include me in the Member Directory □ Please send me enewsletter only

Type of Membership:
□ New □ Renewal □ Gift for: __________________________________________________________________________

□ Patron $1000+ □ Regular (ind. or family) $20
□ Benefactor $250+ □ Alternative ($0-19) $____
□ Contributor $100+ □ Additional donation $____

Mail a check with registration to: DSAM, 656 Transfer Road, St. Paul, MN 55114 or
Charge $_____ to my credit card:
Name on card: _______________________________
Security Number: ______ (3 digit code on the back of your card)
Exp. Date: ____ /____
Special Times

Down Syndrome Association of Minnesota
656 Transfer Road
St. Paul, MN 55114
(651) 603-0720 or (800) 511-3696
dsamn@dsamn.org
www.dsamn.org

Address Service Requested

Help us save money and paper!
Remember: You can request to receive Special Times by email.
Just send your request to:
Kate@dsamn.org

Library

DSAM members may check out books from the Resource Lending Library for up to two weeks.

Calendar

January
January 8 Board of Directors meeting

February
February 12 Executive Committee meeting

Save the dates!

iCan Shine Bike Camp: August 3-8

Step Up for Down Syndrome Walk: September 29

This newsletter reports items of interest relating to Down syndrome and will provide a forum for others. Special Times does not promote or recommend any therapy, treatment, educational setting, etc. We will not espouse any particular political or religious view. Individuals or organizations referred to do not necessarily endorse this publication or its editor. We wish to bring together those interested in Down syndrome and attempt to create an optimistic outlook. The editor reserves the right to make corrections as appropriate and in accord with established editorial practice in material submitted for publication.