



9th Moebius Syndrome Foundation Conference in 2010

By Monica & Matt Woodall

Our daughter Madison was born on June 6, 1999 with Moebius syndrome. In addition to feeding issues, she had bilateral club foot. At three months old, Madison underwent the Nissen Fundoplication procedure to address reflux and had a G-tube placed for supplemental feedings due to her low weight. Surgical correction on both feet was also performed after unsuccessful attempts of serial casting at the age of nine months. Madison is now 10 years old and going into the 5th grade. She plays the piano and cello, loves to ride horses and despite her physical limitations, she can outrun some of her classmates!

We have attended every conference since Madison was one in 2000. Besides the wealth of knowledge we gain from the conferences, we have met many wonderful people that we consider to be some of our dearest friends. We always look forward to attending the conferences and decided to take on a different role in 2010 by hosting the conference in the Denver area. We are honored to be given this opportunity and excited to WELCOME everyone to the beautiful state of Colorado. We have chosen the Omni Interlocken in Broomfield, Colorado for the 9th International Moebius Conference and we look forward to your attendance.



9th international Moebius Syndrome Conference
Denver, Colorado 2010

Cost may be an issue for some families, so we wanted to share what we did in 2008 for the New Jersey conference. Initially when we started to check airfare, it appeared that it wouldn't be a family vacation as it had in the past and that in fact Madison and I may not be able to attend. We were devastated! Madison immediately started brainstorming and suggested we have lemonade stands and garage sales to raise money. That was when I realized how important the conference was to Madison and our family. I knew that we had to go, so I started brainstorming as well. I contacted nine airlines and after eight "no's" I received a call with a "YES." We were given two round trip tickets to New Jersey since we were attending a medical conference with specialist consultations. We also did a cookie dough fundraiser through a local company in Ft. Collins, Colorado. With those relatively quick and easy options, we raised enough

money to cover our registration and hotel. Our trip was paid for with a little hard work in a matter of two to three weeks.

I ask everyone who is considering not attending due to finances to be creative. All of the fundraising events not only financially benefit your trip, but at the same time you are promoting increased awareness and understanding of Moebius syndrome and the communities it affects. You have a year to fundraise. Hold garage sales, work for the neighbors, babysit, find local fund raisers, etc. You won't want to miss the 2010 conference. Please contact me if you have any questions, suggestions, or would like to volunteer for the 2010 conference at 303-814-2144 or coloradomoebius2010@q.com.

Tell Us About Your Experience Living with Facial Paralysis: Psychology Interview Study Coming to MSF 2010 Conference!

For information or to participate either in Boston or at the MSF conference, contact:

Kathleen Rives Bogart
Doctoral Student, Tufts University
Phone: 225-266-8638
kathleen.bogart@tufts.edu

In This Issue

Poet's Corner.....	4
Life Without a Smile.....	5
Gene Talk Survey.....	6
Questions & Answers.....	8
Resource for New Parents.....	9
Our Life with Emily.....	9
Kids' Page.....	10
Donations.....	11

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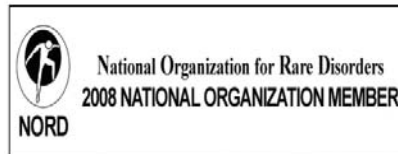
The Moebius Syndrome News is published three times a year.

Articles, photographs, suggestions, questions, and comments welcomed. The Moebius Syndrome News reserves the right to edit submitted material.

Opinions expressed in the Moebius Syndrome News are each author's and do not reflect that of the Moebius Syndrome Foundation or the Moebius Syndrome News.

The newsletter is on the web site in color at:
www.moebiussyndrome.com

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Mike Garbuzinski, son of Moebius Syndrome Foundation board member Jennifer Garbuzinski, pictured with his parents Terry and Jennifer. Mike graduated from high school in May 2009 and will be a freshman at Loyola College in Baltimore, MD in the fall.

Letter from the President

July 2009

Summer Greetings!

Congratulations to all of the young people with Moebius syndrome who graduated from various schools this spring, and to the parents, grandparents, siblings, other family members and friends who supported them through the years. I've enjoyed receiving graduation announcements and photos of young men and women I have had the pleasure of meeting over the years and am amazed at how quickly the years have flown by since our first get togethers in Van Nuys, California back in 1991.

Use of the Internet has exploded over the years also, which has made it easier for people with Moebius syndrome and other rare syndromes to find information as well as others who share their conditions. Out of respect for people who have given us permission for their photos to be posted on the MSF website, we ask that everyone respect the wishes and privacy of those individuals and not use photos from the MSF website in other websites or links.

The board will meet in August with Monica Woodall, chairman of the next Moebius Syndrome Conference to be held in Denver July 30 & 31 and August 1, 2010, to review plans for the conference. We are using suggestions gathered from the evaluations of the 2008 conference; if you have suggestions for topics, speakers, etc. for the 2010 conference please email Monica at coloradomoebius2010@q.com. We will try to get as many speakers as possible from the Denver area to cut down on speaker travel and hotel expenses. Please mark your calendars now and plan to attend this excellent opportunity to hear expert speakers and network with others. Leslie and Allan Dhaseleer have generously donated \$1000 to start a fund to be used toward conference registration fees for first time attendees who have Moebius syndrome. You can contribute to the fund by noting it on your donation to the Moebius Syndrome Foundation.

Lee Doyle, a producer for Discovery Health Network's 'Mystery Diagnosis' is looking for stories from people with Moebius Syndrome who were not diagnosed for some time. If you are interested in being on the program, you can contact Lee at 212-763-3600. A link is also on the home page of the Moebius Syndrome Foundation web site.

Research is still underway at the Hospital for Sick Children in Toronto, Mt. Sinai Hospital in New York and by Sara Rosenfeld Johnson in Tucson. There will be updates on the research at the conference.

Best wishes for a safe, happy summer,



Vicki McCarrell, President



Sean McCarrell, son of MSF President Vicki McCarrell, graduated from high school in May, and will be a freshman at Central Missouri State University in Warrensburg, MO in the fall.

The Girl without a Smile

There once was a girl who had no smile
Emotion, feelings, happiness, despair, tears, eyes, ears, nose, mouth
She has it all
But still she has no smile

She had a bed with pink sheets and blankets and pillows
More movies than anyone and great parents
But with all of this
Still she had no smile

Why doesn't she smile the kids would say
Why does she stay inside and won't come out to play
It's not her choice their parents would answer
That girl has a disease and that's why the house traps her

She used to come out and they played on the swing
She sure could go pretty high on that thing
But lately that girl has to stay inside
A machine is her lungs and without it she'll die

Ya she used to come out and she played in her pool
She sat there all day and that girl would look cool
Calm and relaxed and having so much fun
And no joke she was tanner than anyone

But now she's inside and still has no smile
But inside she's smiling right through it all
She wishes for more and is grateful regardless
This girl has so much love that I'm feeling heartless

Compared to her there is no one as tough
She's beautiful and strong and so easy to love
Her life has been hard and she has had it rough
But she keeps on going and rises above

She is always smiling even though you can't see it
She's laughing inside listen closely you'll hear it
She's happy with what she's been given today
I'm thankful for her in so many ways

Poet's Corner



*Written by Matthew Wallace in
memory of his sister, Jessica*

Life

Yesterday's wind has come and gone
A fresh new breeze blows today.
Cast out your old worries with a hearty sigh
And let them be blown away
Like petals whirling and dancing in the air
On a glorious summer's eve.
Worry only about what today brings,
Let tomorrow bring what it may.
Be vivacious; live life.
But most of all,
Make your life count.

By Aidan Lucid

Doctor, Doctor

Doctor, Doctor, 'What's the matter with me?'
Out in the real world, I can only see
The faceless eyes, staring back at me!

I feel like a movie star surrounded by white
The language is foreign the quarters are tight
The project begins the voices swell to a din
Hey wait! Wait for me, I've committed no sin!

Often I look back and see danger lurking around me
A curio mounted and displayed for all to see
By residents, doctors, nurses—onlookers no doubt
So lonely uninformed incapable of figuring it out.

For years my life was defined by what you see
I'm guilty as much for contributing to me.
No more do I want to be someone's discovery.

A word! A touch! A mile! A glance!
Could it be that hard? Come on take a chance
Towards hope and dignity and life at the brim
Just once drop your facade—go out on a limb.

Discover an answer, a chance to understand
Why my eyelid hangs loosely, why I've got one good hand
Doctor, Doctor, 'Can't you open your book
Find me a cure, give me back what they took!'

© By Matthew S. Joffe
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Discovery Health's Mystery Diagnosis

Do you have a story idea for the television show Mystery Diagnosis? The show documents the experiences of people with rare diseases on their journey to an accurate diagnosis. NORD is inviting people to share patient stories that convey frustrations and false starts that may accompany the search for a diagnosis among people affected by rare diseases. If you are interested in submitting your story, contact NORD at mdunkle@rarediseases.org.



Texas Get-Together

Get-Together in May at the Alamo in San Antonio, Texas: Leslie and Allan Dhaseleer, Roland Bienvenu, and Kevin and Lisa Smant with Ethan.

My Child Without Limits



My Child Without Limits is a new online resource for parents and caregivers of young children with cerebral palsy and other developmental disabilities. The online site includes developmental milestones, developmental delays and early intervention information. It contains caregiver forms that can be downloaded as well as forms for emergency contacts, doctors' visits, and medication lists. For more information, go to their site at:

www.MyChildWithoutLimits.org

Welcome to Holland

Several parents have suggested printing the 'Welcome to Holland' essay in this newsletter. 'Welcome to Holland' is an essay written by Emily Pearl Kingsley about raising a child with Down syndrome, but is very applicable to parents with a child with any special need. The essay is on the Internet on several sites. To read the essay, go to either:

[www.ndscenter.org/resources/
package1.php](http://www.ndscenter.org/resources/package1.php)
or
[http://www.our-kids.org/Archives/
Holland.html](http://www.our-kids.org/Archives/Holland.html)

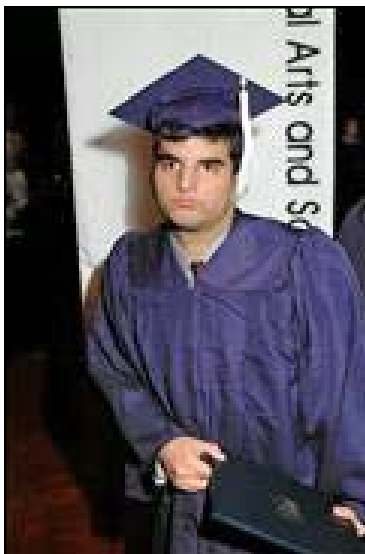
Life without a Smile

By Rak Mehta

It was an early spring morning when life began to change; my mom was rushed to the hospital and was in labor. As my mom entered the emergency room, the doctors surrounded her in a big circle and they screamed "Push, push, push" over and over again. Suddenly a little baby popped out from within the womb and the mother held him closely by her side. There was something which was unsettling about this newborn, something which was missing as the child turned his head and looked at all of the spectators who greeted him with such admiration and care. The mother tapped the infant on the shoulder, trying to make him cry; the infant made a sound, but no facial expression. What was wrong with this boy? For the next few days several labels were attached to this infant such as "mental retardation," "Down syndrome," and "kidney inflammation." Within two months there would be a revelation which would change not only the parents, but the child's destiny as well. The child featured in this introduction is me and THIS IS MY STORY.

During the early years of my development, I was being constantly evaluated by many doctors. It was a visit to Children's Hospital in Chicago where I was diagnosed. After observing me for 30 minutes the neurologist came out and looked at my parents who were in tears (or so they say), put her hand on my dad's shoulder and said, "He has Moebius." So the journey began: One question was answered and many more remained.

I started walking when I was three



years of age and that was an interesting story. I never crawled or "practiced walking." One day my brother and his friend were watching "wrestling" and my brother was running around and mimicking Hulk Hogan in a really loud voice. I became irritated by the loud noise and started chasing my brother; although I fell a few times, I kept getting up and began chasing my brother, kind of like Forest Gump. I still remember being very annoyed with him and this is probably one reason I hate Hulk Hogan even to this day. For many children walking comes naturally, however for me it did not. For years my parents and my brother crawled in front of me in order to get me to crawl, but due to the low muscle tone in my legs it was very difficult for me. Instead, as my brother was crawling in front of me, I would pat him on the head. My parents were concerned that I would never walk, so they took me to Dr. Tajan, a world renown physician who wrote a book and is recognized by many as "one of the best." After observing my boring face for two hours, he told my parents that "This child will walk one day. I can write it down anywhere you want me to that this child will walk."

One positive side to Moebius is

that since it is so rare society may constantly ridicule you or claim you cannot do several things, but when you finally prove them wrong, it makes you feel rather good inside. Walking is one example of how I gradually developed and eventually successfully engaged in the particular behavior. Throughout my academic career I have been told that due to my disability I could not perform at the level of other students, and due to this underperformance I needed to be placed in basic level courses. When my dad expressed his interest in sending me to a university at a school Individual Education Plan (IEP) meeting, the instructors laughed at him, and asked if he was serious. My dad (being the determined man that he is) fired back with two words I will never forget and which further showed me the extent one parent would go for his child. These two words were "Watch me."

It was my dad who kept me going during turbulent times. In high school I would become very frustrated and often go home and cry because I felt that I was being underappreciated and not being challenged by the school system.

I would finally find someone who would appreciate my work, someone who behind the still face saw me differently, my basic English instructor. According to my dad, this instructor told him, "Rak writes better than me." This was the hammer that hit the nail on the head and the season finale of this saga. The IEP hesitantly placed me into academic, so I guess I proved them wrong. During the summer I received a very exciting letter from the University of Illinois at Chicago.

Continued on Page 7

Continued from page 7

After staring at the letter for a few minutes wondering how a university rejects a student, my heart started throbbing, the blood started circulating upwards as I read the entire letter and the words "You have been accepted." Is this a dream, I asked myself? Will I wake up in a few minutes just like I did that one time when dreaming about the Cubs winning a world series? To those who asked "Are you serious?" you have been proven wrong yet again.

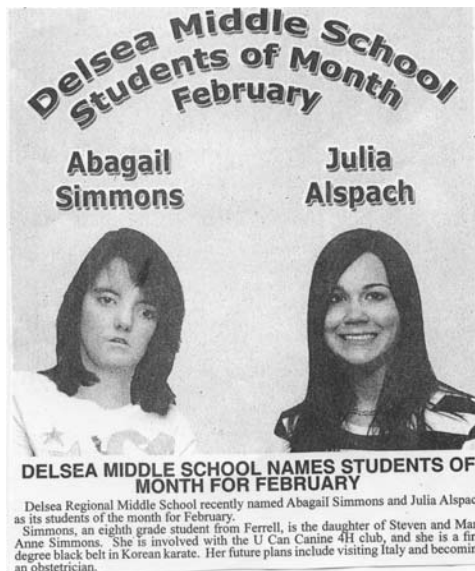
I am currently a senior at the University of Illinois at Chicago and I graduate this May with a BA in Psychology with special emphasis on Neuropsychology. I hope to attend graduate school next year. I hope my beloved Cubs do not jinx me. UIC has been so kind to me and during my undergraduate career here. I have developed many everlasting friendships. I think it is pretty corny that we do not have a football team but I am happy to be a part of the university.

The point of my story is not to celebrate my life, but to provide a backbone for others who have Moebius syndrome. The ability to smile is a basic sociological construct that everyone possesses. If you lack this ability you may be

Abigail Simmons of New Jersey was recently Student of the Month at her middle school.

perceived as abnormal or deviating from societal norms. This is the initial reaction, and there are two things we can do as parents of those with Moebius and as children with it: 1) We can accept the ridicule and do not try to improve our condition or 2) We can fight the system, challenge the questions and overcome the obstacles. As a person who has done the latter I can assure you it feels a whole lot better. In order to accomplish this we need to have a stable support system and the willingness to improve. If it were not for my parents who defended me and encouraged me to achieve my potential, my brother who I thought was cute with his "crawling rehearsals," my grandfather who spent every hour of the day with me and even the educational system that initially helped me achieve success (when I was in elementary school I could not do certain things; the IEP has some positive points to it, they just tend to undermine the students' potential) I would not be where I am today.

dabhoi@gmail.com



Gene Talk: What do we Expect from Families and their Doctors?

Members of the Moebius Syndrome Foundation have been asked by the Genetic Alliance to be involved in a research study which has potential to improve medical care for our community.

Gene Talk: What do we expect from Families and their Doctors? is a US national study sponsored and funded by the National Institute of Health. The purpose of the study is to collect thoughts, opinions, and beliefs from patients and providers about who has responsibility for sharing genetic risk information within families, and when it is morally acceptable not to share information. One of the unique things about this study is that a quarter of the data will come from individuals who belong to support groups. The investigators believe that the opinions of people who actually live with these situations are key to their research.

If you would like to participate, please go to an online survey to fill out your contact information. Once you have done this, the survey will be mailed to you. It is important to note that the researchers will not have access to your email address. All information will remain confidential and that names will not be connected to answers.

Go to the survey at:

https://www.surveymonkey.com/s.aspx?sm=C_2fGj736r_2fLAHxJnp1YMBRQ_3d_3d

There is also a link to the survey on the Moebius Syndrome Foundation web site.

Questions and Answers

A: Autism & ADHD

In the Spring 2009 newsletter, a parent asked about struggles with school work with a diagnosis of Autism or ADHD and Moebius syndrome.

When I read your question in the Moebius Syndrome News I thought of my nine year old daughter. Although she has never been diagnosed with autism or ADHD she has extreme difficulties doing math. For years she has struggled to understand the concepts, she gets very agitated, she won't pay attention, and she rebels against anything having to do with numbers or quantity. This year she had IQ testing. At last it seemed that she finally reached an age where her intelligence could more accurately be tested. We were relieved to know that the areas where she does well she scored highly on the test and in all areas of math and reasoning she did very poorly. We realized that her struggles, agitation, and rebellion really had to do with her inability to understand. Perhaps your son is in a similar situation. Although age six is young for testing, time will be on your side. For now I would recommend giving him only simple concepts. More complicated concepts may only make his behavior worse for lack of understanding.

Donna Kremer, BOTZWANNA@aol.com

Q: Joint Problems

My daughter's doctor has recently diagnosed her as having joint problems. Have any other children with Moebius syndrome been diagnosed with joint problems?

Sneakybitter@yahoo.com

Q: Lower Lip

In the winter of 2008 I submitted a question, but did not receive any replies. In August of 2009 I will be 72 years old. I still have not found a doctor who can help me in Arizona. I do not want cosmetic surgery as my insurance will not cover that. It will cover constructive surgery though. My lower lip droops down a lot because of my age and the Moebius I have in my face. My facial muscles don't work. I don't really need a smile. I want my lower lip fixed so it won't droop. It is hard to control my saliva and when I eat food or drink. I am moving to Texas next year to be near my daughter, Is there a medical professional in Texas who can help me? Thank you.

Mary Arlene Smith

Please send responses to the Moebius Syndrome News, and we will forward to Mary Arlene Smith.

Q:

Asperger's and College Resources

What resources are available for college students with Asperger's?

A:

AHEAD, the Association on Higher Education and Disability, is a nonprofit that provides information. Check their web site at www.ahead.org. Another resource is the book "Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum" by Ruth Joyner Hane, Kassiane Sibley, Stephen Shore and Roger Meyer.

Q:

Chewing on Fingers

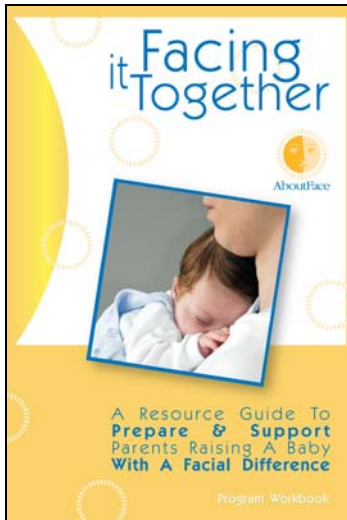
My 12 year old daughter is trached, tube fed and nonverbal. She is showing signs of chewing on her fingers. We have an appointment with ENT to see if this is about eating or speaking. Are there parents who have any suggestions of what can be used to give children with Moebius to chew on, like a pacifier? We don't want her to break the skin on her fingers because of infections. Thank you.

Leigh Webb

leighwebb@comcast.net

Please respond to the Moebius Syndrome Newsletter at newsletter@moebiussyndrome.com so we can include your response in the next newsletter. Thank you.

AboutFace Resource for New Parents



'Facing It Together: A New Resource Guide for Parents'

Facing It Together: A New Resource Guide for Parents Raising a Baby with a Facial Difference is offered by AboutFace International, Inc. in Canada.

This new program consists of a workbook and a DVD. It addresses the challenges facing parents and is designed to help parents manage social and emotional situations they will face during the first few years of raising a baby with a facial difference.

The workbook walks parents through important strategies in dealing with difficult situations, and encourages exercises to document personal strategies.

A preview of the workbook and the DVD are on AboutFace's web site, www.aboutface.ca. Check their web site for additional information or to order the workbook and DVD. The cost is \$15 plus shipping. AboutFaceInternational can also be contacted at 416 597-2229.

Our Life with Emily

By Barbara Thomson

In 2000 I was asked to take care of Emily until her birth mother or father could get their lives back together. Emily was beautiful but fragile. She was on a feed pump and respirator and needed to be suctioned every few hours. Our family consisted of my husband and me and our two daughters. After we agreed to take Emily, the whole family became hers. Emily's doctor thought she would only live about five years. We decided to do everything to give her the best chance to be happy. I took her to therapy, doctor appointments and clinics every week. She had several surgeries and was diagnosed with Autism. Most people I came across thought that I was taking on a task that was too difficult and an institution would be better to care for her. I felt she deserved a home, not a hospital.

When Emily was three she started school. I needed to be there due to her trach. She loved to be with her friends and began to walk. To help with her swallowing she was given lollipops. We played an exercise game to help with her tongue movements. Whenever we were looking at each other, we would stick out our tongues. I was often told that I was teaching my child bad habits, but I usually took the time to explain why we were doing this!

We knew when Emily was happy and when she was mad: her eyes would sparkle when she was happy and her cheek would quiver when she was mad. At four Emily had her G-tube removed and could eat a soft diet. Her teachers were willing to learn and help Emily with sign language which was challenging with

her motor skills and stubbed fingers. Her trach was removed at age five. When Emily was seven, her birth father came to live with us and took on the responsibility of caring for Emily. He did very well and I felt comfortable that I was there in case of a serious problem. Emily's birth mother also started to visit her more often. Emily moved with her father when she was eight and had to start a new school. They had a fire in their house and nowhere to live, so they returned to our home to live.

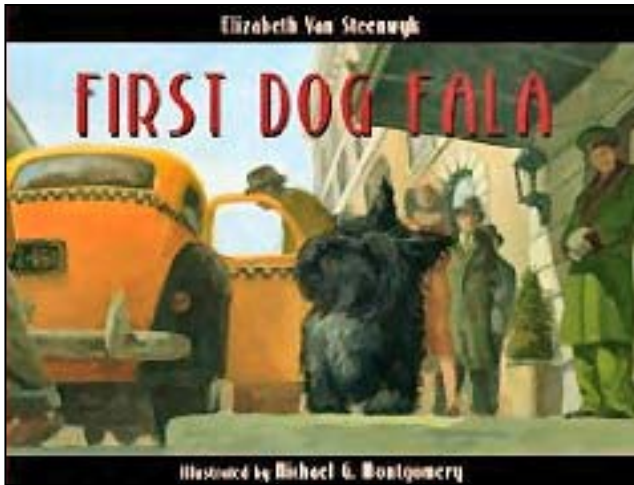
In the fall of 2008 my daughter with Autism went off to college. I helped Emily's father with school shopping, and she was so excited when she got a new shirt with her favorite singer on it and a book bag. Shortly after that Emily developed a respiratory infection and received medicine from the clinic at her school. She and her father went on a bike ride, then she bathed and went to bed. That is the last night I hugged and kissed her goodnight. The next morning when her father tried to wake her, he found that she had passed away.

I miss Emily every day. I find myself crying and saddened when I think of all the things I should have done differently. If you have a child with a disability, fight every day to make the best day possible. Emily was always living life to her fullest. She brightened every room she entered and showed me that with all the difficulties that you might face, look hard enough and you will find a way around it. Both of our daughters are now in college and our oldest is planning to get married. Emily's death is the hardest thing that I have ever dealt with. I am willing to talk to anyone who has a child with special needs; I know that is what Emily would want me to do.

tomsdoall@live.com

Kids' Page

Here are some very interesting new books about dogs and cats:

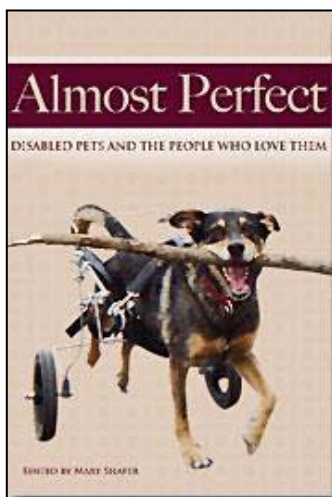


First Dog Fala

By Elizabeth Van Steenwyk;
illustrated by Michael G.
Montgomery

Peachtree Publishers, LTD., 2008;
40 pages: \$16.95

First Dog Fala is a new picture book for ages 4 to 8, or anyone who likes stories about Franklin Delano Roosevelt and his very much loved dog, Fala. Fala is a black Scottish Terrier who is the President's "best friend." Their loving relationship clearly shows as Fala gets into scrapes around the White House and offers the President relief from the real concerns of the day including World War II. Another important fact is discussed in a straightforward way with an illustration, that FDR had polio and used a wheelchair.



Almost Perfect: Disabled Pets and the People Who Love Them

Edited by Mary A. Shafer

WordForge Books, 2008.
128 pages: \$12.95

Almost Perfect: Disabled Pets and the People Who Love Them is a collection of eleven essays about cats and dogs who have disabilities themselves, and the humans who love them. The stories are heartwarming and show how the animals are courageous and rise to the challenges of living with a disability. Available at bookstores, libraries and amazon.com. For more information and to read sample pages from the book, go to the WordForge web site at www.WordForgeBooks.com.

Thank You

The Moebius Syndrome Foundation would like to thank the following for their generous donations. Donations listed have been received since the last newsletter was published. If we have missed you, please let us know so that we can acknowledge your generous gift. All donations are used to achieve the mission of the Moebius Syndrome Foundation.

In Memory of Avery Cheney

Chuck & Becky Cheney

In Memory of Brooklyn Clarke

Scott Erdman

In Memory of Hannah Devine

MW & SE Knox

Susan & Mark Knox

In Memory of Christine Dowdle

Ruth Dowdle

In Memory of Matthew Frecon

Alice Frecon

In Memory of Bill Greene

Paul Casey

Margaret King

Margaret Murphy

Mary Murphy

In Memory of June Moore

Diane & Henri Breton

Robert & Beverly Williams

In Memory of Patricia Quaiife

John & Sheila Buswell

In Memory of Frank Robinson

Helen Schwartz

In Memory of Alaisha Rosa

Sheri Brown

In Memory of Eric Washer

Holly & Chris Kahle-Washer

In Memory of Caleb Wilson

Joseph & Dorothy Bartkowski

Louis & Patricia Bartoshesky

David Belasco

Marge Delhey

Joan Dembkrowski

Edwin & Sara Gray

Cynthia & Donald Greenamoyer

Kenneth & Peggy Hall

Dolores Hughes

Francis & Diane Klonowski

John & Jean Lewis

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In Memory of Caleb Wilson

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Donna & Larry Sorrell

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Donald Vavrosky

John & Karen Weyrauch

Jeffrey & Mary Wolff

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Loretta Lisowski

In Honor of Natalee Ballanger

Lee & Jada Ballanger

In Honor of Kimberly Banning

Diane & Kevin Moran

In Honor of Kimberly Banning &

Leslie Dhaseleer

Cheryl & David Banning

In Honor of David Belasco

ATK, Minneapolis

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Roland Bienvenu

Anne Broussard

In Honor of Chuck Cheney

Julie McGirt

In Honor of Leslie Dhaseleer

Leslie Cunningham

In Honor of the Frady Family

Dennis & Carol Frady

In Honor of Mike Garbuzinski

Arbella Charitable Foundation

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Jacob & April Iverson

In Honor of Tad & Hillary Law

David Law

In Honor of Miriam Licht

Fredman Family Charitable Trust

Margie & Brad Hartman

Merck Partnership for Giving,

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The mission of the Moebius Syndrome Foundation is to provide information and support to individuals with Moebius syndrome and their families, promote greater awareness and understanding of Moebius syndrome, and to advocate for scientific research to advance the diagnosis and treatment of Moebius syndrome and its associated conditions.

Would you like to contribute to the Moebius Syndrome Foundation?

Your support is always appreciated, and will help the Moebius Syndrome Foundation fund important activities such as the conferences and research grants. The Moebius Syndrome Foundation is a 501(c)(3) non-profit organization. Please use the enclosed envelope to donate. Contributions are also accepted online on our web site at www.moebius syndrome.com. Please call us at 660 834-3406 with any questions. Thank you.

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