



RareConnect New Online Community For Moebius Syndrome

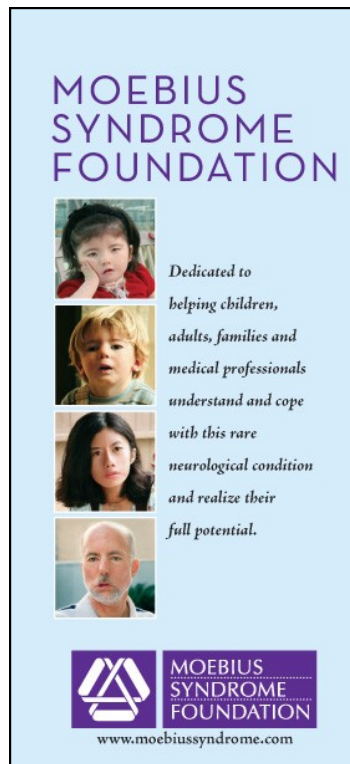


NORD, the National Organization for Rare Disorders and EURORDIS, the European Rare Disease Organisation, have launched a new website for specific, rare conditions called RareConnect. It is an online social network for patients and their families to connect with one another to support and share important experiences in various aspects of living with a specific rare condition. Its purpose is to help people to understand their condition, connect with others with the same condition, and to provide tools for living with their disorder. It includes patient stories, links to news items, and questions and answers.

When you access the site for the first time, you will need to register. It is available in five languages, including Spanish, French, Italian and German. Find RareConnect at www.rarediseasecommunities.org.

New Moebius Syndrome Brochure

An updated brochure from the Moebius Syndrome Foundation is now available. It is online and can be downloaded at



www.moebius syndrome.com.
Copies may be requested by sending a self-addressed stamped business size envelope to:
Moebius Syndrome Foundation
PO Box 147
Pilot Grove 65276

Cover and other photos in the brochure are courtesy of Rick Guidotti of Positive Exposure. For more information, please visit www.positiveexposure.org.

Moebius Syndrome Foundation Financial Summary 2011

Income

Donations	\$143,202.81
Interest	\$ 1,953.85
NORD reimbursement	\$ 300.00
Watch sales	\$ 150.00

Total income **\$145,606.66**

Expenses

Research	\$ 48,870.60
Newsletters	\$ 9,478.73
Postage	\$ 2,462.35
Website	\$ 2,035.06
Tax Preparation	\$ 1,250.00
D&O insurance	\$ 744.00
Board travel / Hotel / meals (1 face-to-face meeting)	\$ 6,125.37
Bd members to NORD	\$ 1,112.27
Auction expenses	\$ 2,642.00
Genetic Alliance	\$ 675.00
NORD dues	\$ 200.00
Supplies	\$ 71.07
Stop payment fee	\$ 25.00

Total expenses \$ 75,891.45

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Moebius Syndrome Foundation

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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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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.

Letter from the President

Spring 2012

Greetings,

As the 10th Moebius Syndrome Conference draws near, we are working furiously to put the final details on the many aspects of the conference so that you will all have a wonderful experience July 13-15 in Philadelphia. As you may realize, it takes 'a village' to put together a conference for over 400 attendees, including coordinating 35 speakers, childcare for nearly 100 children, meals, photos, developing the conference brochure, coordination of volunteers to handle registration, sales, a raffle - the list goes on and on. Many thanks to the conference committee: Co-chairs Dawn Ang and Emmet Linn, and Monica Woodall and Marcia Abbott for their tireless work. People are constantly amazed that the Moebius Syndrome Foundation has no paid staff. All of our work is accomplished by volunteers. We are also grateful to the speakers who donate their time and knowledge.

We are thrilled to be able to fund research thanks to the donations that we receive from all of you. Research currently being funded by the Moebius Syndrome Foundation includes:

"Genetic Studies of Moebius Syndrome" Co-principal investigators: Ethylin Wang Jabs, MD and Bryn D. Webb, MD; Mt. Sinai School of Medicine, New York

"Oral Placement Therapy for Improved Feeding Skills and Speech Clarity in Children with the Diagnosis of Moebius Syndrome" Principal investigator: Renee Roy Hill, MS, CC-SLP

"Genome-wide Epigenetic Profiling in Moebius Syndrome" Principal investigator: Rosanna Weksberg, MD, PhD, FRCP(C), CCMG, The Hospital for Sick Children, Toronto

"Pilot Service Delivery Model for Early Detection and Intervention for Risk Markers of Social Communication Disorders in Very Young Children with Moebius Syndrome" Principal investigator: S. Wendy Roberts, MD, FRCPC; Co-principal investigator: Shelley Mitchell, MSLP, PhD Candidate; Co-investigators: Irene Drmic, PhD; Jennifer Levine, BSc, The Hospital for Sick Children, Toronto

Warmest wishes to all of you. Keep educating others about Moebius syndrome! We look forward to seeing you in Philadelphia.

Sincerely,



Vicki McCarrell, President

vickime@iland.net
www.moebius syndrome.com



2012 Moebius Syndrome Conference
Friday July 13 – Sunday July 15, 2012
Sheraton Philadelphia Downtown Hotel
Hotel room rate valid: July 10 – July 18, 2012

By Emmet Linn, 2012 Conference co-chair

Haven't booked your hotel room? Here's a reason to act fast

Time flies. Before you know it, you'll wake up in Philadelphia, ready to attend the 10th Moebius Syndrome Conference. But will you wake up in the hotel where the conference takes place, or a hotel down the street or across town?

The conference site, the Sheraton Philadelphia Downtown Hotel, is also the site of a large conference that starts Monday, July 16. Rooms are expected to go fast.

If you haven't registered for the conference yet, please do so soon at

www.regonline.com/10thmoebiussyndromeconference. Register by June 15 to get the early registration discount.

Perhaps more important, June 15 is also the deadline to secure the hotel's special conference rate. That is, if rooms are still available. Book your room today. You can do so at the conference registration website under the "Hotel and Transportation" tab or at <http://www.starwoodmeeting.com/Book/10thIntlMoebiusConf>.

To reserve your room by phone, call 215-448-2000. Be sure to request the special conference rate of \$119 (\$137.09 including all tax) by informing the hotel that you are attending the Moebius conference. The special conference rate can be applied to stays of any length from July 10 through July 18.

When you register a family online ...

... be sure to register an adult first, and repeat the adult's e-mail address when registering children. If you're a parent requesting consultations for your child with Moebius, be sure to do so only for your child, and not in your own phase of online registration. Don't forget to pay, either with a credit card or check.

Child care and teen bowling

Child care and teen bowling consent forms are required to participate in those activities but are not part of the online registration process. If you plan to register online or have already done so, please fill out the consent forms ahead of time and bring them with you to the conference. Better still, mail your completed forms today to Moebius Syndrome Foundation, PO Box 20354, Oakland, CA 94620-0354.

Forms are available in the registration packet that you should have received in the mail and on the registration website under the "Conference Program" tab. They're also available on the Moebius Syndrome Foundation website at www.moebiusyndrome.com. Go to the 10th Moebius Syndrome Conference section and scroll down to "Conference Forms."

For Sale at the Conference

In addition to t-shirts and other items, there will be wristbands and Moebius syndrome teddy bears for sale at this year's conference, with a choice of two t-shirts: the conference logo and "I'm smiling on the inside!"



Conference logo

While you're on the foundation's website and registration site, you'll see our wonderfully colorful 2012 conference logo. The logo was designed by Nick Ciotti, owner of Ciotti Imaging in Temecula, Calif., and father of 3-year-old Luke, who has Moebius syndrome.

The image will appear on conference T-shirts and other materials. If you meet Nick at the conference, be sure to say thanks for the beautiful design!

Just for dads, moms ... and grandparents

Our "Just for Dads" and "Just for Moms" sessions have been a big hit at recent conferences, especially for parents attending a Moebius conference for the first time.

Based on your feedback, we're holding these very informal sessions on the first day of the 2012 conference. They're a great opportunity to make friendships and to connect with parents who have faced some of the very same challenges that you're facing and can seem so overwhelming.

And this year, for the first time, we're offering a "Just for Grandparents" session, where grandmothers and grandfathers can talk about their unique challenges of being parents of parents of children with Moebius.

Focus group study for teens

Kathleen Bogart, a newly minted Ph.D. and Moebius Syndrome Foundation board member, will join Rhonda Robert in conducting "The Social Side of Moebius: A Focus Group Study for Teens." Drs. Bogart and Robert will lead teens with Moebius in discussing experiences with friends, at school and with bullying.

A similar focus group study was conducted at the 2010 conference with adults with Moebius, and the results have been published in the *Journal of Health Psychology*. If you'd like a copy of the article, please contact Dr. Bogart. (Her contact information is at the end of this section.)

The 2012 focus group is open to teens with Moebius ages 12-18. (Sorry, no parents allowed.) Teens and their parents will sign a consent form before the study begins. The focus group will be audiotaped. Information will remain confidential and will be compiled into a scientific article. The study is intended to help parents, educators and health-care practitioners better understand issues that teens with Moebius face, and will help develop a social skills workshop for children with Moebius.

Consent forms will be available at the conference registration table, by contacting Dr. Bogart, or at the beginning of the focus group session. To learn more about the study or to participate, please contact Dr. Bogart at kathleenrbogart@gmail.com or 225-266-8638.

Program updates

For an updated list of speakers, conference sessions and other activities, please visit the conference registration website at www.regonline.com/10thmoebiusyndromeconference and go to the "Conference Program" tab. More frequent updates will be available on Facebook. Search for "10th Moebius Syndrome Conference" **events page**.

Monday excursion

Our Monday excursion is always bittersweet. We've become enlightened and rekindled friendships, and then it's time to say goodbye. This year's event will be a double-decker-bus tour of Center City Philadelphia. If you're staying on in Philadelphia, it's a great opportunity to take note of places you'll want to see.

We'll ride the bus around town and stop at the famed "Rocky steps" of the Philadelphia Museum of Art, in case you want to make your own triumphant run or walk up the steps. You'll also have a couple of hours where you can choose to visit Independence Hall, the Liberty Bell, the National Constitution Center or the Betsy Ross house, all within walking distance of our bus drop-off point.

The bus will have us back to the hotel by 4 p.m.

This letter, by Lisa Lawton, a mother of a child who is participating in the research and consult services by Sara Rosenfeld-Johnson of TalkTools: Improving Feeding Safety and Speech Clarity for Clients with Moebius Syndrome, was received by the Moebius Syndrome Foundation. For an update, go to <http://www.moebius syndrome.com/go/research/oral-motor-research-for-children-3-to-10>.



My son Ty is 4 years old and was diagnosed with Moebius at about 4 months old. I wanted to send a letter to you, thanking the Moebius Syndrome Foundation for funding the research study that my son is currently participating in, SRJ Therapies, through Talk Tools by Sara Rosenfeld-Johnson. Renee Roy Hill is one of the therapists that we work with.

I just wanted to say THANK YOU. Thank you for the opportunity for us to be involved in this research study. Thanks to the Moebius Syndrome Foundation for funding it. This letter comes from a mother who is doing everything I can to help my son be successful and succeed in life and will do anything I can to help him. Hearing doctors say your son will never be able to do this, your son will never be able to do that just doesn't sit well with me. I didn't know anything about Moebius nor what options and opportunities were out there. Ty started this study in April 2011 and it wasn't but 2 weeks later, he started to blow bubbles by himself for the very first time. He's always tried to do this in the past but was unsuccessful. I could tell by listening to how he was blowing on the wand that he didn't have enough wind nor was it strong enough for him to blow the bubble. He would get frustrated, so we bought him bubble guns that he could shoot instead. Now he has a really nice even flow of wind when he blows air out of his mouth which has also helped him to blow his nose; he is now also able to blow on horns. He can blow a flute and is currently using a harmonica successfully. He gets so excited as do we when he gets to use a new instrument to make noises, meaning the different horns. Something HUGE for us happened on Ty's 4th birthday: He got to blow his candles out by himself for the first time! Besides the birth of Ty that was probably close to one of the biggest days of my life, to see him gaining the ability to do the things we were told he'd never be able to do and to get to watch him blow out his candles for the first time.

Ty's mouth closure has gone from 8mm to 6mm, possibly even more. I'm finding that people who don't know Ty are understanding him a lot better now. His speech is so much clearer now. The only sound he still has a hard time with, but I can tell is getting better, is his B's. He moves his tongue around so much better in his mouth. I actually got to watch him use his tongue to clean the insides of his cheeks to get the food out. Until now he always used his hand to push the food out of his cheeks. Even when he spits his gum out and can get it into a ball and spit it out without all the excess saliva, the drooling has stopped. He can slurp now to hold the saliva in his mouth and has better control of it. He can now chew bazooka gum which is hard to chew. Before this study I gave him a piece of gum a few times but was scared to do so, afraid he would choke; but he only chewed it for a few minutes and complained that his jaw hurt and it was a mess, the saliva everywhere just didn't go over very well. Now he asks non-stop to chew gum, and I allow him to because it only helps strengthen his jaw.

I just wanted to share all this with you because I wanted you to know how happy I am with the results we, the Lawson family, have got to see with this research study and wanted to thank whoever it is we need to thank for funding this. Without this study Ty would not be doing all the things he's able to do now, and have as much control over his mouth (at least that's how my husband Jamey and I feel, as well as my parents and Jamey's parents). We are all seeing the difference. So again, Thank you, and just know that at least one family has seen a noticeable difference. This is helping Ty! Thank you, from the Lawson Family, Lisa, Jamey and especially Ty Lawson



FUNDRAISING FOR THE MOEBIUS SYNDROME CONFERENCE

EVERYONE IS ENCOURAGED TO PARTICIPATE IN FUNDRAISING FOR THE CONFERENCE. USE THIS LETTER AS A GUIDE IN WRITING YOUR OWN LETTER. ATTACH COPIES OF THE DONATION FORMS ON THE FOLLOWING PAGES, OR PRINT THEM FROM THE CONFERENCE WEBSITE.

March XX, 2012

Dear XXXXXX,

Imagine the things that can make you smile – a frolicking puppy, bursting bubbles, or the ice cream truck traveling down your street on a hot summer evening.

Imagine NOT being able to smile.

For individuals with Moebius syndrome, that is what they cannot do, but their smiles come from within.

As a parent of a child with Moebius syndrome/As an individual with Moebius syndrome, one of my driving forces is to educate the general public on this rare neurological/craniofacial disorder that manifests itself primarily in facial paralysis. Individuals with Moebius syndrome cannot smile, frown or blink, and do not have lateral eye movements. Many individuals with Moebius syndrome also have Poland syndrome, which results in limb abnormalities.

I have/my son/daughter has both Moebius and Poland syndromes. DESCRIBE YOUR OWN EXPERIENCES IN ONE PARAGRAPH

We are actively involved with the Moebius Syndrome Foundation because every individual who has Moebius syndrome is part of our extended family. Moebius syndrome is so rare – there are about 1,000 people in the United States who have this syndrome.

Between July 13-15, 2012, the 10th Moebius Syndrome Conference will be held in Philadelphia. Typically, the conference is a place for people with Moebius syndrome, and their families, to learn about the latest research into this rare neurological condition, and is also a social outlet for those with Moebius. It reminds these special individuals that they are not alone in confronting their challenges. Typically, about 400 people attend the conference.

I am asking you to please consider taking on a sponsorship towards our conference. Attached to this letter is a listing of the sponsorship levels. We have a goal of raising \$50,000 towards this conference, so that we can keep such conferences affordable to all who attend.

I thank you in advance for your consideration. Please do not hesitate to contact Dawn Ang, the conference chair if you have any questions. She can be reached at 215 301 0832 or by email at dawnang@moebiussyndrome.com.

Sincerely,

Your Name



SPONSORSHIP OPPORTUNITIES

Please consider supporting the 2012 Moebius Syndrome Conference with a sponsorship. Your generous contribution can be put towards the cost of the conference or towards the conference scholarship fund for first time attendees who have a financial need. The Moebius Syndrome Foundation is a 501 c (3) charitable organization, and your sponsorship will be tax-deductible to the fullest extent of the law.

o **PREMIER SPONSOR** - \$10,000

As the premier sponsor you will receive a full page (7" x 9.5") color Journal Ad in the inside or outside back cover of the Conference Journal, be included (with your logo) on the inside front cover of the Journal, and be acknowledged as a premier sponsor at the conference. Your organization or company's logo will be featured on the back of our conference t-shirts.

o **SPIRIT SPONSOR** - \$5,000

As a spirit sponsor you will receive a full page (7" x 9.5") color Journal Ad in the inside or outside back cover of the Conference Journal, be included (with your logo) on the inside front cover of the Journal, and be acknowledged as a spirit sponsor at the conference.

o **SPONSOR** - \$1,000 and above

Amount: \$ _____

As a sponsor you will receive a full page (7" x 9.5") color Journal Ad in the Conference Journal, be included (with your logo) on the inside front cover of the Journal, and be acknowledged as a sponsor at the conference.

o **SUPPORTER** - \$500-\$999.99

Amount: \$ _____

As a supporter you will receive a full page (7" x 9.5") black and white Journal Ad in the Conference Journal, be included in the listing of supporters in the Journal, and be acknowledged as a supporter at the conference.

o **JOURNAL AD** – Your Ad will be featured in the Conference Journal and your donation will be acknowledged in the Journal.

- o Half Page (7" x 4.75") \$ 350
- o Quarter Page (3.5" x 4.75") \$ 200
- o Business Card (3.5" x 2.5") \$ 100
- o Listing of Friends: \$ 50 (Name & 1-Line Message)

Name: _____

Message (90 characters maximum): _____

o **OTHER DONATION** You will be acknowledged in the Conference Journal.

Amount: \$ _____





SPONSORSHIP OPPORTUNITIES

o CONFERENCE SCHOLARSHIP FUND - Amount \$ _____

This fund will be used to provide conference scholarships to waive registration fees for adults and families with Moebius syndrome who are attending a conference for the first time and have a financial need. You will be acknowledged in the Conference Journal.

o Mail form and payment by check (made out to Moebius Syndrome Foundation) to:
 Moebius Syndrome Conference
 PO Box 20354
 Oakland CA 94620-0354

OR

Make payment through www.moebiusyndrome.com through the Donate button:

o Payment made through PayPal via Moebius Syndrome Foundation website:

Date: _____ 16 Digit Receipt Number: _____

OR

If you are registering for the Moebius Syndrome Conference, you may enter your donation online at the time of your registration through the Conference Website.

o Payment made through the Conference Website with my Conference Registration

Date Registered: _____ Registration ID Number: _____

o Paid Online **OR** o Paid by check (check number: _____ and date: _____)

PLEASE SUBMIT YOUR DONATIONS BY MAY 15, 2012 SO THAT WE CAN BE SURE TO INCLUDE YOUR JOURNAL AD AND ACKNOWLEDGE YOUR DONATION IN THE CONFERENCE JOURNAL. THANK YOU.

HOW TO GET YOUR JOURNAL AD TO US: You may email your completed Journal Ad to Marcia@moebiusyndrome.com. If you have paid online, you may email this form with your Journal Ad. If you need to have your Journal Ad designed, you may email or mail us your text and photos along with this form and the payment.

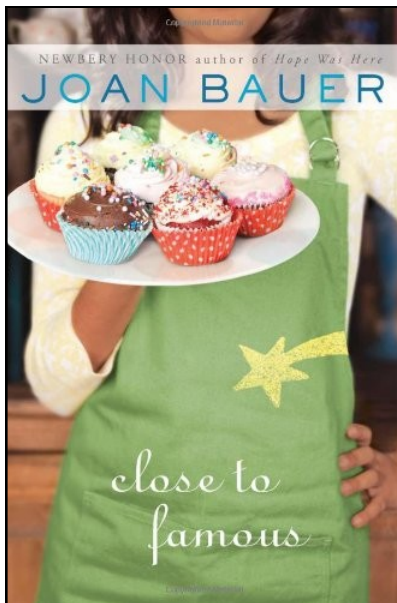
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Questions? Email Marcia@moebiusyndrome.com or phone 510 304-2302.

Kids' Page

Schneider Family Book Awards

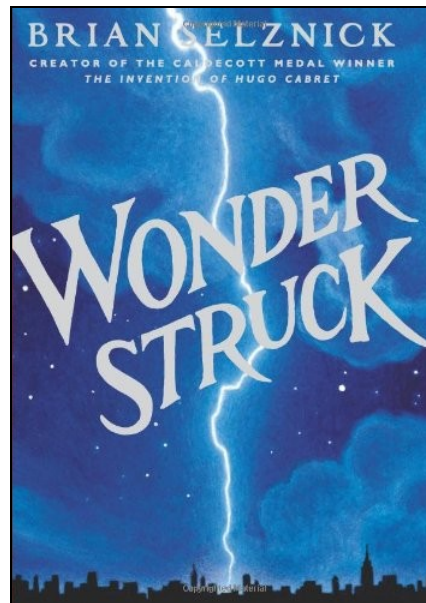
The American Library Association awarded the 2012 Schneider Family Book Award for books that “embody an artistic expression of the disability experience”:



Close to Famous

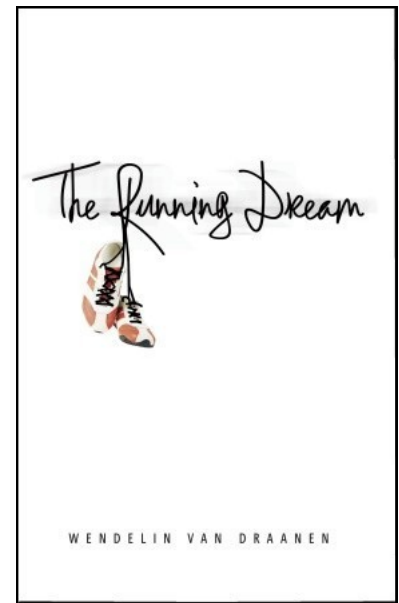
‘Close to Famous’ is a novel for middle-school age 9 to 12. It’s about a girl who has a very serious learning disability (she cannot read) and who is an extraordinary baker. The story involves her mother and her new friends.

After reading it you will want to bake some cupcakes, or at least get to Magnolia Bakery to eat one.



Wonderstruck

‘Wonderstruck: A Novel in Words and Pictures,’ also for middle schoolers, is a magnificent novel. It’s long but is a fast read since one of the two related stories is told in drawings, and the other written. Characters in each story are deaf, and while that is important to the stories, there is so much more to them. This is a book teens and adults will appreciate as well.



The Running Dream

‘The Running Dream’ is the novel that won the award in the teen level, grades 7 to 10. The main character, Jennifer, is a track star who loses a leg in an accident. In the novel she faces her disability and rehabilitation as well as recognizing others (especially a new friend with cerebral palsy) who happen to have a disability.



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.

In Memory of Tracy Ann Baxter
Stephen & Donna Allen

In Memory of Capt. Roland Bienvenu Sr.
Anne Broussard

In Memory of Hannah Jade Devine
Susan Knox

In Memory of Terrance Garbuzinski
Patricia Garbuzinski
Linda McDaid

In Memory of Burton Minow
Elaine Burton-Resnick
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Glenda Roberts-Lush

In Honor of Avery Marie Giannini
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<http://www.facebook.com/moebiussyndrome>



Follow us on Twitter:
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<http://twitter.com/MoebiusSyndrome>

Will you contribute to the Moebius Syndrome Foundation?

Your support is always appreciated, and will help the Moebius Syndrome Foundation fund important efforts 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 at www.moebiussyndrome.com. Please call us at 660 834-3406 with any questions.

EIN # 13-3753992