



Farewell from Vicki McCarrell

As you can see from this issue, "Moebius Syndrome News" has a new editor, Marcia Abbott from Piedmont, California. After 10 years of editing the newsletter I felt it was time to put my efforts (and limited time!) to other uses in the Foundation and Marcia graciously readily agreed to edit the newsletter when I asked her.

We're all working to bring together a host of professionals for the 5th Moebius Syndrome Conference in North America July 19-21 in Chicago. We hope to see all of you there!

I look forward to continually



hearing from all of you and urge you to send articles and photos to Marcia for upcoming newsletters. Our mailing list has grown from 30 in 1991 to over 1000 worldwide (and that doesn't include the many individuals in support groups around the

world), so getting the newsletters out is a **big** job!

Our need for donations to keep the newsletters and conferences going is greater than ever. Remember to send your donations to our 501 c 3 organization to the address listed below.

Many thanks for your unending support. See you in Chicago in July. . .

Vicki McCarrell

PO Box 147
Pilot Grove, MO 65276
660-834-3406
vmccarrell@mid-mo.net

Hello from Marcia Abbott

Welcome to the first issue of our new newsletter. This will be a team effort, with Natalie Abbott assisting with format and the other technical aspects of the newsletter, and hopefully many of you who will be submitting material for the newsletter.

Please also send in suggestions on what you want in the newsletter as well as articles and questions for professionals that you would like answered.

I would like to welcome Jessica

Roach as the new Editor of the Kids' Page, beginning with this issue, and thank Natalie Abbott for her years of creating the Kids' Page for the Moebius Syndrome News. Jessica lives in Texas, is (not quite) 13, and is a homeschooler in seventh grade.

Please send your submissions, comments, and questions to our new address:

The Moebius Syndrome News
PO Box 20354
Oakland CA 94620-0354

In this Issue

From the Editors.....	Page 1
2002 Conference.....	Page 2
Italian Conference.....	Page 4
Scrapbook.....	Page 5
Question & Answers.....	Page 6
Birth Day.....	Page 6
Kids' Page.....	Page 7
Contribute.....	Page 8

Moebius Syndrome News

Marcia Abbott, Editor

Mailing Address:
P.O. Box 20354
Oakland CA 94620-0354

510 835-1318
moebiusca@aol.com

Lori Thomas,
Printing & Mailing
38883 Foxholm Dr.
Palmdale, CA 93551

661 267-2570
Lorismile@usa.net

Moebius Syndrome Website

www.moebius syndrome.com

Moebius Syndrome Foundation

Board of Directors

Marsha Roach, President

Rich Campbell, Vice President
Matthew Joffe, Vice President
Vicki McCarrell, Secretary
Paul Frelich, Treasurer
Marcia Abbott
Kathi Campbell
Lori Thomas
Natalie Abbott, Junior Member

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.

Conference 2002

1994 in Los Angeles....1996 in New York...1998 in Toronto... 2000 in Boston.....and now.... 2002 in Chicago!!

Registration packets will soon be mailed for the 2002 Conference. If you live outside the U.S. and Canada and plan to attend, please call or email Sharon Deveney to have a registration packet mailed to you:
Sbdeveney@hotmail.com or
540 752-7834

The 2002 Conference will take place:

Friday July 19 through Sunday July 21, 2002

Pheasant Run Conference Center
4051 East Main St.
St. Charles, IL
1 800 4-Pheasant
630 584-6300
www.pheasantrun.com
Hotel Rate: \$120 per night

There will be child care, and special programs for children including Joan Fleitas (Bandaides and Blackboards) and Scott Graham (Kids4Kids).

St. Charles is an hour west of Chicago in the Fox River Valley. Transportation options from the airports will be provided in the registration packets. Monday excursion to Chicago is in the planning.

For more information:
www.visitstcharles.com
www.enjoyillinois.com
www.choosechicago.com
www.cityofchicago.org/tourism

The Conference programs and speakers are now being finalized. Confirmed speakers include:

- Dale Delisle, keynote
- Ronald Zuker, M.D.
- Rickie Anderson, Aboutface
- Sara Rosenfeld-Johnson
- Steve Clarke
- Jody Berlin Morrow
- Holly Benkert
- Laura Heller
- Joan Fleitas
- Scott Graham

Programs so far plan to cover:

- Bodybrushing
- Surgery (smile, hands)
- Sign Language Adult Issues
- Sleep Disorders
- Homeopathic panel
- Scoliosis, respiratory, assistive technology
- Possibly: A 'makeover clinic' and consultant from InStyle Magazine
- Canine Companions (assistance dogs)
- Saturday night entertainment

Adult Issues:

Your input is requested. The "Kissing Doctors" Holly Benkert and Jodie Berlin Morrow are (thankfully!) returning, and there is a panel on alternative medical approaches. Also being considered are more psychologically oriented issues. Email your ideas to Matthew Joffe at **msj@nyc.rr.com**.

The history of Moebius Syndrome is being documented in a timeline for the conference. Email information you may have to contribute to Matthew Joffe.

Conference 2002

Conference Donations & Journal Ads

The 2002 Conference registration packets will contain forms for everyone who wishes to request donations from friends, relatives or businesses, or to sell Journal Ads for the 2002 Conference Journal.

To provide the opportunity to begin selling journal ads or request donations now, forms are enclosed in this newsletter as inserts. They are:

- Sample letter to send friends and relatives
- Explanation of Journal Ads
- Journal Ad Form
- Journal Ad sizes

The forms can be copied and used with your own personal letter. The 2002 Journal will again be a fabulous resource for adults, families, and professionals affected by Moebius Syndrome.

Extra copies of the 2002 Journal will be available for purchase after the July conference. Information on how to purchase the Journals will be in the next newsletter.



“Vintage 2000” Sturbridge, Mass. Conference

We now have “Vintage” T-Shirts, Conference Bags, and Conference Journals from the 2000 Conference in Sturbridge, Mass. to sell at cost.

The Moebius Syndrome Foundation Conference Journals from July 2000 in Sturbridge, Mass. contain a wealth of information on resources and presentations from the last conference.

Prices include postage. They are:

2000 Journal:	\$5
T-Shirt (Adult):	\$5
Canvas Bag	\$5

Special: All 3 for \$10

T-Shirt sizes are *only*:
Adult Extra-Large or Large

Specify T-shirt size.

To order, send check made out to the Moebius Syndrome Foundation to:

Elisa Schumacher
22 Winthrop Ct. Apt B
Wappingers Falls NY
12590-5614

Questions? Contact Elisa at
eschumacher@slh-tch.org

Regional Support Groups

Please contact Vicki McCarrell with the contact information of your regional support group. The list of all support groups will be compiled for the 2002 Journal. Send information to Vicki at vmccarrell@mid-mo.net or 660 834-3406.

Conference Contacts:

Alan Blowers
ablowers@Ballhelix.com

Vicki McCarrell
vmccarrell@mid-mo.net

Marsha Roach
roachml91@hotmail.com

Sharon Deveney
sbdeveney@hotmail.com

Elisa Schumacher
eschumacher@slh-tch.org

Matthew Joffe
msj@nyc.rr.com

Lori Thomas
lorismile@earthlink.net

Peggy Bakalo
bakalo@bc.edu

Marcia Abbott
marciaabb@aol.com



Italian Moebius Syndrome Conference



Thanks to the hard work of Renzo De Grandi, President of the Associazione Italiana Sindrome De Moebius, the first Moebius Syndrome Conference in Italy was held July 13-15, 2001 at Venice International University on the Island of San Servolo, Venice.

I attended to represent the US Moebius Syndrome Foundation thanks to the gracious invitation and funding by the Italian Association. I showed slides of various US Moebius get-togethers, shared the history of our Foundation and gave warm congratulations from all of us in the US.

It was exciting to meet so many other families from around the world affected by Moebius and the many physicians, therapists and other professionals in Europe who share our goal of educating others about Moebius and finding ways to bring hope and empowerment to individuals and families who share this common bond. Among those attending were Carmen Leal and Julian

Calabria who founded the Moebius Foundation in Spain and attended our conference in Toronto in 1998; Dr. Ronald Zuker and Susan Organek from the Hospital for Sick Children in Toronto; Joan Fleitas, Ed.D, from Fairfield, CT; Sara Rosenfeld-Johnson, speech pathologist from South Salem, NY; Steve Clarke from Manchester, England and a host of other professionals from Europe.

Renzo is working to unite all Moebius Syndrome Associations, Foundations and support groups worldwide under the international statute "Altogether for a Smile." His goal is to allow a better coordination between associations worldwide, an international data base and coordination of research work, as well as cooperation in organizing conferences, meetings and events. For more information their website is www.moebius-italia.it

I'm constantly amazed and proud of how far we've all come in the last 10 years. Thanks to the internet, increased interest in Moebius

Syndrome by medical professionals and the media, and endless hard work of the individuals who have Moebius and their families, we have brought Moebius out of the dark. Congratulations to Renzo and all of the others in Italy who put together such a wonderful conference. Over 40 people with Moebius came together for the first time in Italy for the conference.

Vicki McCarrell
vmccarrell@mid-mo.net

Pictured in photo above, left to right: Dr. Ronald Zuker, Gail Zuker, Susan Organek, Sara Rosenfeld-Johnson, Phil Johnson, Joan Fleitas, Gail Clarke, Steve Clarke, and Vicki McCarrell

Thank You

The Moebius Syndrome Foundation would like to thank the following for their generous donations:

In memory of Leon Kulis, step-father of Leslie Van de Carr:
Ronald and Dorothy Hutchins
Stacey Shaheen
Donald and Dawn Johnson
Gary and Alice Cox
Kimi Folaron
L. Roy Briggs

Pfizer Foundation Volunteer Program

Questions & Answers

Q: Has anybody else (parents of Moebius children) tested positive for Prothrombin Mutation? It is also called Mutation 2021A or Factor II Mutation. It can be found through a simple blood test, but is a rare condition so doctors usually don't test for it unless a patient actually develops a severe blood clot that is not responding to normal treatment.

Sandra Kenkel, Schaumburg, IL
kenkel@megsinet.net

Please submit questions and responses to the Moebius Syndrome News,
moebiusca@aol.com

Ask A Professional

Submit any questions you have for a professional, and we will make every attempt to find several to respond to your question. Send questions to the Moebius Syndrome News.

Ask Us...

Submit questions or ideas for others with Moebius Syndrome or parents of children with Moebius Syndrome to respond to. Again, send to the Moebius Syndrome News.

Birth Day

We were told by the head of Jefferson's neo-natal unit to "go home and take care of your first born. Place this baby in an institution. There is no way you can care for him." Mikey stayed at Jefferson Hospital for almost five months while we waited placement for him in an institutional hospital/school. We visited him daily, we prayed. He needed round-the-clock care and I had no medical training whatsoever. Mike showed no brain-wave activity at all as an infant. We would visit him once a month while he resided at North Jersey Training School and constantly ask when he was going to be well enough for us to bring him home. We insisted that

Mike's club feet be casted to turn them around. This we did even though we were told there was no indication that Mike would ever walk. I said that should Mike ever decide to walk, I wanted his feet to be pointed in the right direction so he could! Even though Mike was in a vegetative state we kept putting crib toys and mobiles all around his crib. My theory was, if he had any inkling to reach out and touch something, I wanted him to have a lot of choices of what to touch.

At age 3 Mike only weighed 13 lbs. and still was nonfunctioning. Between 5 and 6 years, Mike decided to start reaching out and moving around. He never crawled. He stood up in his crib and began throwing the toys out! This turned out to be the best institutional care I have ever encountered. They had play mats on the floor and spent individual time playing with each of the infants. By the time Mike left in 1986 he had graduated out of his wheelchair and was totally ambulatory without any aids. He has had surgery for scoliosis, learned sign language, and dresses/undresses himself. He now communicates with a picture board, swims, rides a horse, and has competed in the Special Olympics. He has been elevated from 'profoundly' to 'mildly' retarded. Mike has been on a waiting list for group home placement for over 10 years. Our goal now is for good group home care, to get Mike settled into a 'family' type atmosphere.

Nancy Karam
nkaram@home.com

Kids' Page!

By Jessica Roach, Editor

Bodybrushing!

I am Jessica and I am now doing the Kids' Page instead of Natalie Abbott. I would like to do this first article on bodybrushing or as some call it neurostimulation.

The person who invented this is named Steve Clarke. He is from Manchester, England. When I first heard about it I thought it was very weird and brushed it off as another thing my mom wanted me to try at the Moebius Conference in Boston.

I must tell you you have to be screened first to see if you are a candidate for the treatment. So I went and got screened. It turns out I was a candidate for it. Then I started going to the website and read stories of how children with Moebius might smile, move their eyes, suck, and close their mouths too.

I looked forward to the

treatment and started in December of 2000. Since then I have missed a couple of appointments but people say I can talk better, and my lips are closer together. I have better balance, and more confidence; also, what little of a Moebius smile I have is now going up more.

I know it sounds weird and it does require a lot of traveling. If you are screened and are a candidate you should try it. For more information go to:

Your ideas for the Kids' Page

Please send your ideas, articles, poems, word games, and drawings to me for the Kids' Page to me:

Kroac2@aol.com

Or

Jessica Roach
200 River Bend Dr. #606
Georgetown, TX
78628-3363

Moebius Pen Pal Group

If you have Moebius and would like to have a Pen Pal with Moebius, please mail your name, age, and where you live, and your hobbies.

I will try to match you up with a Pen Pal as soon as possible.

Send to:

Pen Pals
Jessica Roach
200 River Bend Dr. #606
Georgetown, TX
78628-3363

Bodybrushing

Bodybrushing a ticklish thing
It looks like a brush but does a different thing

I time how long it takes like it was a race

But in return I get a wrinkle in my face

It has some side effects

But it will get rid of a reflex

It makes me bloody minded

I try to be kind when reminded

Bodybrushing will come to an end

But Steve Clarke will still be my friend