

Angels at Bethesda

Charitable medical air transportation serving patients of the National Institutes of Health

Smiles Belie Child's Serious Condition

By Jenny Fields, Volunteer Correspondent



Sarah (pronounced sorra) is a beautiful young girl, five years of age, with a rare genetic disease of the nervous system called Angelman Syndrome (AS).

Sarah displays the characteristic AS features of delayed development, speech impairment (she is non-verbal) and problems with movement and balance (she is not yet walking).

Popular with Everyone

Children with AS typically have a happy, excitable demeanor with frequent smiling, laughter and hand-flapping movements. Sarah is very

popular with everyone who knows her and is loved by all. She lives with her mother, Mariam, two brothers (ages 10 and 17) and one sister (age 9) in Las Cruces, New Mexico.

Treatment Unavailable

Mariam and her husband are Egyptian/American and lived in Egypt for sixteen years. All four of their children were born there. The family decided to return to America when Sarah was diagnosed so she could receive the necessary treatment and services that were not available to them in Egypt.

They moved to Las Cruces to be near their family for emotional and spiritual support.

Referred to Mercy Medical Airlift

Last year Mercy Medical Airlift (MMA) provided Mariam and Sarah with a flight via Southwest Airlines to San Diego, California for participation in a six-year natural history study funded by the National Institutes of Health (NIH) at Rady Children's Hospital.

The referral to Mercy Medical Airlift came through the Rare Diseases Clinical Research Network (RDCRN), which combines the resources of research hospitals across the country to better

undertake clinical studies for rare disorders.

According to Mariam, everyone connected to AS knows about Mercy Medical Airlift! Marita Eddy



at the National Institutes of Health in Bethesda, Maryland, worked with Mariam on flight arrangements.

Details Handled with Care

When asked to describe her MMA experience, Mariam said it was handled by warm, caring and thoughtful people.

Mariam and Sarah's most recent flight was to San Diego on March 25, where the girl participated in session two of the study.

Mercy Medical Airlift stands ready to assist this family with future flights as needed.

Rare Day Raises Public Awareness



Ed Boyer

February 29, 2012 was a "rare day." Mercy Medical Airlift along with people worldwide joined patients, advocacy groups and researchers in celebrating the fifth annual Rare Disease Day.

Rare diseases affect between 25 and 30 million Americans. MMA is involved because 42% of patients assisted by MMA suffer from rare cancers and other rare disorders.

I had the privilege of personally representing MMA at events in the Washington, DC area sponsored by the National Organization of Rare Disorders (NORD), the National Institutes of Health (NIH) and the Food and Drug Administration (FDA).

MMA is closely involved with all these parties—that we may better know how to serve patient travel needs to gain access to specialized treatment facilities nationwide by providing free flights on commercial airlines.

Through the Office of Rare Diseases Research, MMA has a dedicated transportation coordinator at NIH for patients needing travel assistance to the Clinical Center. Marita Eddy can help patients with rare and common conditions. You can reach her by calling 301-451-9646 or sending an email to meddy@mail.nih.gov.

During 2012 MMA will arrange or provide transport for upwards of 15,000 persons. Thank you for making possible our service to those in need.

Ed Boyer is the CEO and President of Mercy Medical Airlift, the parent organization for Angel Flight.



Angels at Bethesda is published by Mercy Medical Airlift. Editor, Suzanne Rhodes. **Contact Marita Eddy** at the NIH Office of Rare Diseases Research, 6100 Executive Blvd., Suite 3A07, MSC 7518, Bethesda, MD 20892. Ph.: 301-451-9646 Fax: 301-480-9655 Email: meddy@mail.nih.gov

Parents Grateful for Flight



"Your generosity in travel arrangements for us to take our daughter to NIH Clinical Center was a blessing beyond words. Leaving our other children behind to seek answers to our baby's illness was very emotional, but your help lessened our stress on all of the unknown issues we have... Thank you so much for financially helping us get to our destination, as the time & extra expenses of driving would have been overwhelming." (Parents of child with Muckle Wells Syndrome).

Do you have unused frequent flyer miles?
Save lives by donating them today!
 Visit www.DonateFrequentFlyerMiles.org
 Mercy Medical Airlift partners with these airlines:



25,000
 Frequent Flyer Miles equals 1 round-trip ticket

ATTENTION! US Airways has opened its annual Dividend Miles Match campaign. From April 9-May 12, US Airways will make a 1,000-mile donation, up to 25,000 miles, for every 5,000 miles donated to Mercy Medical Airlift: Please donate via www.DonateFrequentFlyerMiles.org. THANK YOU.