



Sitta Sang-rod with respiratory nurse Thitida Chaisupamongkollarp.

Ventilator Donation to Thai Hospital

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Sitta Sang-rod is now 11 years old. He has inoperable congenital heart disease. His left diaphragm is paralyzed due to phrenic nerve injuries from one of his heart surgeries. Sitta used a Puritan Bennett 2801 ventilator donated by Walgreen Health Initiatives for five years, but in 2005, Sitta had a leak around his trach which caused a false alarm. Sitta was readmitted to the hospital and switched to a PLV®-100 (Respironics, Inc.) ventilator, a donation from Post-Polio Health International and the family of Lew Gumerman. (The 2801 ventilator was sent out for maintenance.) Sitta is currently doing well. He uses the ventilator only during the night; he can breathe spontaneously through his tracheotomy without ventilator support during the day.

Registries

■ The **ALS Registry Act**, introduced in Congress last year (H.R. 4033/S. 135), would authorize the Centers for Disease Control and Prevention to create and maintain a nationwide registry of people with ALS. The ALS registry would bring together existing collection and surveillance entities, maintain information over time, and track the progress of people with ALS, helping researchers to determine causes and potential treatment. For the legislative status of the act, go to www.alsa.org/policy and click on "Legislative Priorities."

■ The **International Spinal Muscular Atrophy Registry** helps researchers gain statistical data to benefit others with SMA. The registry is coordinated by the Department of Medical and Molecular Genetics at Indiana University. To participate, contact Connie Garland at Indiana University, 317-274-5745, cjgarlan@iupui.edu. Registry forms are available online: www.iupui.edu/~medgen/hereditary/sma.html.

Calendar 2006

JULY 2-7. Eleventh International Congress on Neuromuscular Disorders. Istanbul, Turkey. Contact icnmd2006@flaptour.com.tr or visit www.icnmd2006istanbul.org.

JULY 13-16. Parent Project for Muscular Dystrophy (PPMD) 2006 Annual Conference. Cincinnati, Ohio. Contact PPMD, 800-714-KIDS, 513-425-9907 fax, www.parentprojectmd.org.

JULY 14-15. Families of Spinal Muscular Atrophy (FSMA) Families and Professionals Conference 2006. San Diego, California. Contact FSMA, 800-886-1762, 847-367-7623 fax, www.fsma.org.

AUGUST 2-6. ALS Nursing ... For the Americas 2006. Chicago, Illinois. Contact Jennifer L. Armstrong, RN, BSN, 312-695-5886, 312-695-3166 fax, jarmstrong@nmff.org, www.lesturnerals.org.