

VACC CAMP IS “PARADISE” FOR KIDS WITH VENTILATORS

“It’s a week where he gets to feel special – treated like royalty,” said Mario Ortegon about his son Elliot’s experience at the Miami Children’s Hospital Ventilation Assisted Children’s Center (VACC Camp).



Elliot “Spiderman” Ortegon at VACC Camp.

Elliot has attended the week-long camp every year for the last seven years. Now 19 years old, he was diagnosed with transverse myelitis, a neurological disorder caused by inflammation of the spinal cord, two months before his 11th birthday. It left him paralyzed from the tongue down and ventilator-assisted through a trach.

“He is nonverbal, so it gives him happiness to go and interact with people,” said Ortegon. “He totally enjoys it.”

VACC camp is a free, week-long, community-based camp program providing

recreation and social support for families with children who need to use oxygen and/or ventilators long term.

And a full week it is. Campers and their families are kept busy with activities including music and shows, pizza and pajama parties, movies, a Hawaiian luau, a day at the beach, boat rides, bowling, art and games, to name a few. A volunteer staff of nurses and respiratory therapists and local teenagers are on hand to provide parents and families with some leisure time.



2011 Camps for Ventilator-Assisted Kids

March 12-18. Ventilator-Assisted Children’s Center (VACC) Camp, Miami, Florida. Contact Bela Florentin, VACC, Miami Children’s Hospital, 305-662-8222, bela.florentin@mch.com, www.vacccamp.com.

May 29-June 5. Camp Pelican, Lion’s Camp, Leesville, Louisiana. Contact Cathy Allain, 985-764-0343, cathyallain@cox.net, www.camppelican.org.

June 1-5. Light the Way Camp, Children’s Harbor, Alex City, Alabama. Contact Kara Bishop, 205-370-9605, karabishop@ventkidsofalabama.com, www.ventkidsofalabama.com.

June 5-10. Trail’s Edge Camp, Camp Fowler, Mayville, Michigan. Contact Mary Buschell, RRT, Camp Director, 231-228-3371, mkbuschell@yahoo.com, www.med.umich.edu/mott/trailsedge/index.html.

June 8-12. Camp Inspiration, Double H Hole in the Woods Ranch, Lake Luzerne, New York. Contact Tara Bogucki, Admissions Coordinator, 518-696-5676, ext. 222, theranch@doublehranch.org, www.doublehranch.org. *Admissions deadline: April 15 (later admissions accepted if there are vacancies).*

June 12-17. Fresh Air Camp, Camp Cheerful, Strongsville, Ohio. Contact Kathy Whitford, MSN, RNP, Cleveland Clinic Foundation, 216-721-7159, whitfok@ccf.org, www.freshaircamp.org.

June 19-23. CHAMP Camp, Bradford Woods, Indianapolis, Indiana. Contact Jamie Mitchell, 317-679-1860, admin@champcamp.org, www.champcamp.org.

June 26-30. PA Vent Camp, Camp Victory, Millville, Pennsylvania. Contact Robin Kingston, MSN, CRNP, 717-531-5337, rkingston@hmc.psu.edu.



Elliot relaxes at the beach with camp volunteers.

“Camp is an extraordinary experience for everyone involved – the staff, the campers and their families, and all the volunteers, adults and teens. Your life perspective changes after experiencing VACC Camp for the first time. I know that through camp we all make a difference in every camper’s life and that of their families too. You just have to see the smiles on the children’s faces to understand,” said Bela Florentin, VACC Camp Program Coordinator.

“That week at camp is paradise for Elliot,” said his father. ▲

CONFERENCE CALENDAR 2011

March 24-26. FOCUS on Respiratory Care and Sleep Medicine Annual Conference. The Town and Country Resort, San Diego, California. www.foocus.com

April 28–30. “A Breath of Fresh Air” Canadian Respiratory Conference. Sheraton on the Falls Hotel & Conference Centre, Niagara Falls, Ontario, Canada. www.lung.ca/cts

May 13-18. American Thoracic Society International Conference. Denver, Colorado. www.thoracic.org

June 23-26. FSMA Family and Professionals Annual Conference. Walt Disney World Swan and Dolphin Resort, Orlando, Florida. www.fsma.org

June 29–July 2. CCHS Family Conference, San Diego, California. www.cchsnetwork.org

July 6-10. Parent Project Muscular Dystrophy Annual Conference. Baltimore, Maryland. www.parentprojectmd.org

August 31 – September 2. “Post-Polio Syndrome – A Challenge of Today.” Copenhagen, Denmark. The Danish Society of Polio and Accident Victims, and European Polio Union. www.poliocconference.com

September 24-28. European Respiratory Society Annual Congress, Amsterdam, Netherlands. www.ersnet.org

October 22-27. CHEST, American College of Chest Physicians Annual Conference. Honolulu, Hawaii. www.chestnet.org

November 5-8. AARC International Respiratory Congress. Tampa, Florida. www.aarc.org

Join IVUN! ...and receive Ventilator-Assisted Living, IVUN's bi-monthly newsletter.

The eight-page newsletter will be sent electronically in February, April, June, August, October and December. (IVUN Members without email access may request print copies by contacting IVUN). Members will also receive an electronic *IVUN Membership Memo* in alternate months. To become a Member, complete this form. *Memberships are 100 percent tax-deductible.*

\$30 Subscriber – Bi-monthly *Ventilator-Assisted Living* and *IVUN Membership Memo* (both delivered electronically).

Yes, I want post-polio news, too.

\$55 Subscriber Plus – *Ventilator-Assisted Living* (bi-monthly; electronic) AND *Post-Polio Health* (quarterly; print)

\$100 Contributor ALL the benefits of Subscriber Plus AND *Resource Directory for Ventilator-Assisted Living* and *Post-Polio Directory*; discounts on special publications and meetings sponsored by IVUN

\$150 Sustainer ALL the benefits of Contributor AND one additional complimentary gift membership to:

- Person of your choice (include name and address) or
- Person who has expressed financial need to IVUN.

Yes, I want to support IVUN's mission of education, research, advocacy and networking and its comprehensive website, www.ventusers.org.

Membership at the following levels includes ALL benefits PLUS special recognition in IVUN publications:

- \$250 Bronze** Level Sustainer
- \$500 Silver** **\$1,000 Gold** **\$5,000 Platinum**
- \$10,000 Gini Laurie Advocate**

Name _____

IMPORTANT: Email _____

Affiliation (optional) _____

Address _____

City _____ State/Province _____

Country _____ Zip/Postal Code _____

Phone (include area/country code) _____

Fax (include area/country code) _____

I am enclosing a check for \$_____ made payable to "Post-Polio Health International." (USD only)

Please charge \$_____ to this credit card:

VISA MasterCard Discover Card

No. _____ Exp. Date _____

Name on Card _____

Signature _____

Send this form to: Post-Polio Health International,
4207 Lindell Blvd, #110, Saint Louis, MO 63108-2930 USA,
314-534-0475, 314-534-5070 fax