

CONNECTICUT NUTMEGGERS

June 24, 2009
Volume 1

SUPPORT GROUP NEWS

Inside this issue:

| | |
|------------------------------------|-----|
| Support Group News | 1 |
| Next Meeting | 1 |
| San Francisco | 1-2 |
| Virtual Support Group Telecalls | 2 |
| What's New In Washington | 2 |
| Upcoming Education Days | 2 |
| Education Days | 3 |
| In The News | 3 |
| Website Resources | 4 |

Reminders

OCTOBER 2-4

Autumn Escape Bike
Trek — Cape Cod, MA

Greetings from Jo Anne!
I am officially your new
Support Group Leader.

Ed will still be here for you
as always. I will be taking
over the communications
and planning sessions. I
look forward to bringing
you informative and
enjoyable meetings.

Please let me know if you
have anything you would
be interested in learning
about or if you know of a
good speaker for Alpha-1.
ctnutmeggers@yahoo.com
or 860-739-4331.

Change in Nutmegger Meeting Date

We are postponing the
July 18th Support
Group Meeting until
August. Tentatively
we picked Saturday,
August 15th. If not
good for majority, we
will pick another date.

It will be at our home
to just socialize, share
our experiences and get
to know each other
better.

(See attached Flyer)

Meat, soda, iced tea
and lemonade will be
provided. If you would
like to bring alcoholic
beverages of your
choice that is OK.

If you want to, you can
bring one dish for the
potluck. It usually
works well if everyone
brings their favorite
food. Please call me or
email me what you are
bringing so we don't
have duplicates.

Alpha 1 National Education Conference

Alphas Gathered in San Francisco !

On June 5th, over 450 attendees (including 108 first-time attendees) gathered at the Hyatt Regency San Francisco Airport to kick off the 18th Annual National Education Conference. Walter Bortz, M.D., the keynote speaker, addressed the audience about the importance of healthy living and how to live a long life. From Friday through Sunday, every session provided something new for everyone to take away including new friends. Attendees learned how to drum in unison and created wonderful beats together during the Friday night dinner. Saturday sessions were devoted to support and education about Alpha-1. The conference ended on Sunday, with Dr. Robert (Sandy) Sandhaus dispelling the myths about Alpha-1 and explaining its realities and a panel of experts on access and reimbursement facilitated by Miriam O'Day.

Alpha 1 National Education Conference

I attended the Support Group Leader Training session on Sunday afternoon. I met other support group leaders from all over the country and heard their ideas on what makes a good support group leader.

PowerPoint presentations from the conference will be available to listen to and view on the Association's website www.alpha1.org, under E-Education by July

We are grateful to our 18th Annual National Education Conference Sponsors:
2009 Core Program Sponsors - AlphaNet, Baxter, CSL Behring and Talecris Biotherapeutics, Center for Education and Science and Major Conference Sponsor - Centric Health Resources

Virtual Support Group Telecalls

For those who cannot make support groups, you will be able to join and participate in the Virtual Support Group Meetings to be held in June and July via telephone. To participate on the call, please dial: 1 (888) 550-5602 and enter **7924 4120**. **For quick access, go to <https://www.spiderphone.com/79244120>** (This link will help connect both your browser and telephone to the call) All calls will be held at 9:00pm EST at the meeting dates below.

- June 23** Alpha-1 Buddies Support Group
- June 30** Alpha-1 Families Support Group
- July 17** Pre and Post Transplant Support Group

For more information, please call Cathey Horsak at: 877-346-3212 or chorsak@alpha1.org.

Upcoming Education Days

- August 8, 2009: Denver, Colorado
- August 29, 2009: Hershey, Pennsylvania
- September 12, 2009: Boston, Massachusetts
- November 14, 2009: Ann Arbor, Michigan

Please remember that members of the Alpha 1 Association and individuals in the Alpha 1 Foundation and Alpha Net Mailing list will receive an invitation to education days in their area four to six weeks prior to the event. It will also be posted on www.alpha1.org

What's New in

IMPORTANT PROTECTION FOR RARE DISEASES INCLUDED IN SENATE BILL S 1213 INTRODUCED LAST WEEK

The Alpha-1 Foundation and Alpha-1 Association is pleased to announce that recent legislation introduced in the Senate entitled the "Patient-Centered Outcomes Research Act of 2009" includes a special provision to protect rare diseases. S 1213 addresses Comparative Effectiveness Research and is intended to be included in any Senate introduced comprehensive healthcare reform legislation. S 1213 establishes an "expert advisory panel for rare disease" which will assist in the design of rare disease comparative effectiveness research and in the evaluation of the research studies. Inclusion of a rare disease advisory panel will allow individuals with expertise in that particular disease state to inform the process; such as physicians, scientists, patients and manufactures. The Foundation and Association will continue to advocate for the same type of special protection in House legislation.

Education Day in our Area

The Alpha-1 National Education Series is co-sponsored with the Alpha-1 Foundation to provide access to current medical information and resources for Alphas and their families and are held in a variety of regions in the US. The next one in our area is:

September 12, 2009
Marriot Boston Burlington
One Burlington Mall Road
Burlington, MA 01803
To make hotel reservations
please contact the
Marriott Boston Burlington at
800-228-9290 or 781-229-6565.

Tell them you are attending the Alpha-1 Education Day. The Group rate is \$99 plus tax. Reservations must be made by August 14, 2009 to guarantee rate. The booking code is Alpha-1 Patient Education Day.

You can register for this Education Day on line at: www.alpha1.org.

AARC Accreditation

This learning activity has been approved by the American Association for Respiratory Care (AARC) for 6 hours of Continuing Respiratory Care Education (CRCE).

In The News

CSL calls Off Talecris Biotherapeutics Merger 6/19/2009

WASHINGTON (CN) - CSL Limited will not proceed with its proposed \$3.1 billion acquisition of Talecris Biotherapeutics, CSL said Monday. The Federal Trade Commission went to court to block the merger, claiming it would reduce competition in the U.S. markets for four plasma-derivative protein therapies - Immune globulin, Albumin, Rho-D, and Alpha-1.

The therapies are used to treat patients suffering from illnesses such as primary immunodeficiency diseases, chronic inflammatory demyelinating polyneuropathy, alpha-1 antitrypsin disease and hemolytic disease of the newborn.

Kamada files BLA for alpha-1 antitrypsin deficiency drug candidate 6/10/2009

Jun 03, 2009 (Datamonitor via COMTEX) -- Kamada, a biopharmaceutical company, has submitted a biologics license application to the FDA for its lead clinical candidate, intravenous alpha-1 antitrypsin, for the treatment of alpha-1 antitrypsin deficiency. Kamada has developed a unique, high purity, liquid, ready-to-use human plasma derived alpha-1 antitrypsin indicated for the treatment of alpha 1 deficiency. The product is produced using a chromatographic purification method.

David Tsur, CEO of Kamada, said: "The submission of our intravenous alpha-1 antitrypsin (AAT-IV) biologics license application (BLA) is an important milestone for Kamada, as it positions us one step closer to bringing our product to the US and European markets.

"We believe that the data supporting the BLA for our AAT-IV are strong and we look forward to working with the FDA to bring this important and advantageous therapy to market for the benefit of the patient population."



Website Resources

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|---------------------|-------------------------------------|
| www.alpha1.org | Alpha-1 Association |
| www.alphaone.org | Alpha-1 Foundation |
| www.aoa.org | Administration on Aging |
| www.caps4caregivers | Children of Aging Parents |
| www.caregiver.org | Family Caregiver Alliance |
| www.nhlbi.nih.gov | National Heart Lung Blood Institute |
| www.nih.gov | National Institutes of Health |
| www.lungusa.org | American Lung Association |

Check Handouts area at meeting for complete list with descriptions

Pharmacy & CoPay Assistance

| | |
|---------------------|---|
| www.caringvoice.org | Caring Voice Coalition |
| www.pparx.org | Partnership for Prescription Assistance |
| www.uneedpsi.org | A,C,C.E.S.S. by PSI |

The Big Fat Reference Guide is quick and easy to use. After navigating to the AlphaNet web site at www.alphanet.org, click on BFRG. A simple registration allows the BFRG to be personalized to the specific needs of the user.

YOUR BEST VACATION

We are adding this as a new section to our Newsletter. Please let me know if I have your permission to supply your name with your story. Please submit a short story about the best vacation you've taken. Just some highlights: Place, Points of Interests, Favorite Restaurant and any other interesting facts and a couple favorite pictures.

IMPORTANT PHONE NUMBERS

Marlene Erven, Executive Director

1-800-521-3025

Miriam O'Day,

Senior Director of Public Policy

1-877-829-8488

COPD Information

1-866-316-COPD (2673)

Here's our most recent!

SAN FRANCISCO, CA

Golden gate bridge, Alcatraz, 39 mile drive all around SF, 17 mile drive to Carmel and Monterey, U.S. 1 drive to Carmel along the ocean, Sausalito. The Zoo. There were lots of baby animals especially a gorilla. The Silverback male put on a great show.



CAREGIVERS

The mission of our support group is not only to help Alpha-1 patients but also to give support and information to their caregivers.

If you have questions or would like to talk to another caregiver, call the C.O.P.D.Foundation's caregiver information line at 1-866-316-COPD (2673), Monday-Friday 9a.m.to 9 p.m. EST. Ask for speak to a caregiver and your message will be forwarded to a trained caregiver who will call you back.

Alpha-1 falls under the umbrella of COPD.

Jo Anne Brailey

Support Group Leader

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860-739-4331

Cathey Horsak

A1A Director

Community Programs

horsak@alpha1.org

877-346-3212