

Alpha-1 Nor'Easter a Support Group Newsletter (April/May 2012)

Serving the North Eastern US for the most part!

DATE	TOPIC	PLACE	CONTACT	
Sat 6/2	Fundraiser: Alpha Run	Cherry Rum Plaza, Greenfield MA	Frank	413. 475. 0502
6/8-9-10/12	Annual Alpha-1 National Conference	Seattle, WA	A1A	(800) 521-3025
Thur 6/21	MA S/G Meeting: New COPD Treatments	Wingate Nursing Home, Needham, MA	Sheila	(978)468-7704
Sat 8/11	MA S/G Meeting: BBQ & Pool Party	homes of Joanne Mellady & Joyce Smith	Sheila	(978)468-7704
Sat 8/18	New England Area Alpha-1 Education Day	Dartmouth Medical Cntr, Lebanon, NH	A1A	(800) 521-3025

UP COMING ALPHA EVENTS (more info: see "SUPPORT GROUP NEWS " Page 2)

We would hope and recommend that everyone receiving this notice is a member of the Alpha-1 Association (A1A) and has enrolled in the Alpha-1 Foundation (A1F) Registry. If you don't receive the A1F Research Registry Update you are NOT part of the cure for Alpha-1 (shame! shame!). Even if you receive a copy of the Alpha-1 News you are NOT necessarily a member of A1A. Call them just to be sure. 1 (800) 521-3025 ext 11. Another great publication is the Alpha-1 magazine; contact the Alpha-1 Foundation to get a copy.

Alpha-1 Association (A1A)	1 (800) 521-3025	www.alpha1.org	Support
A1A Genetic Counselor	1 (800) 785-3177	courtesy of A1A	Family Concerns
Alpha-1 Foundation	1 (888) 825-7421	www.alphaOne.org	Research
Alpha-1 Coded Testing (ACT)	1 (877) 886-2383	AlphaOne@musc.edu	Free coded (confidential) testing
Alpha-1 Registry	1 (877) 886-2383	http://www.musc.edu/alphaoneregistry/	Be part of the cure
Baxter Healthcare	1 (800) 423-2090	www.Baxter.com/ Aralast.com	Aralast & Glassia
Talecris	1 (800) 243-4153	www.Prolastin.com	Prolastin
CSL Behring	1-866-936-2472	www.Zemaira.com	Zemaira
Accredo	1 (866) 625-7421	www.Accredotx.com	Aralast/Zemaira
AlphaNet	1 (800) 577-2638	www.AlphaNet.org	Prolastin/Zemaira
Prolastin Direct (Centric)	1 (800) 305-7881	www.ProlastinDirect.com/	Prolastin
Coram Healthcare	1 (866) 367-2174	www.CoramHealthcare.com	Aralast/Glassia/Zemaira
A.C.C.E.S.S. provided by PSIA	1 (888) 700-7010		disability help for Alpha-1 patients

IMPORTANT PHONE NUMBERS: if all these numbers confuse you give me a call 201-444-7839

WORLD WIDE WEB

Most of the following information was gathered at the ALPHA-1 MAILING LISTS. As with everything else in this meeting notice take it with a grain of salt. Remember we do edit some of these E-mail posts and we select which to print. There is much more on the lists. Some of which is very interesting. If you have any questions contact me < JoeReidy@Verizon.net >. Alpha-1 International Support Groups are email networks which Alphas use to rapidly exchange information, support, suggestions, questions, plans, activities; nearly anything that comes to our minds. Many of us have had to reduce our activities and contacts; the Alpha1 contacts are a great way to maintain contact with others. It is also a big psychological boost to know that we are not alone. Here is a list of the E-mail groups to which I (Joe) subscribe:

While the above used to be true with the advent of social media such as Facebook and Twitter and especially with the passing last year of our ace reporter, Peter Duttweiler, much of the information was gathered at the Alpha-1 Foundation web site.

#	Mailing List Name:	enrollment	owner(s)	TO JOIN: E-mail to:
1	Alpha-1 International	open to most interested in Alpha-1	Connie Storey	ALPHA-1-REQUEST@home.ease.lsoft.com
2	Alpha-1 LIVER	open to most interested in Alpha-1	Nancy Cropper	ALPHA-LIVER-REQUEST@home.ease.lsoft.com
3	Alpha-1 Lungs & Life	open to most interested in Alpha-1	Sally Turner	Alpha1 Lungs and Life-subscribe@yahoogroups.com

INDEX	SUPPORT GROUP NEWS	PAGE 2	TESTING INHALED AUGMENTATION THERAPY	PAGE 4
	AUGMENTATION THERAPY	PAGE 2	NEW COPD DRUG	PAGE 4
	LUNG TRANSPLANT NEWS	PAGE 3	IRONIC TWIST?	PAGE 5

Support Group News

Support Group Leader Messages

Alpha Opportunities Eastern PA

From: "Larry & Marian Hoffman" <alfalfaalphagroup@gmail.com>

Date: April 27, 2012 9:35:14 AM EDT

Subject: Save the date

Dear Group members,

We are planning a meeting in Oaks Pa, hopefully on June 30 which is tentative at this point. We are also having our Holiday meeting at Maggianos Restaurant in King of Prussia on Dec 1 2012 which is confirmed. We will follow with more info later.

Thanks , Larry & Marian Hoffman

Connecticut Support Group

From: STEPHEN PETTY <srpchief@sbcglobal.net>

Date: May 6, 2012 10:25:58 AM EDT

Subject: Support Group Meeting

Good Morning All, Greetings from South Carolina.

The next Connecticut support group meeting will be held on 7/21/12 The topic will be announced at a later date. Steve

Massachusetts Support Group

From: Sheila Favazza <slfavazza@yahoo.com>

Date: May 20, 2012 10:19:39 AM EDT

Subject: Alpha-1 Events

Hi Folks,

Summer is almost here & with that comes several Alpha events for which I have attached flyers....

- This years Alpha Motorcycle Run Fundraiser is on June 2 in Greenfield.
- The June Support Group meeting has been moved to June 21 to allow those attending Nat'l Conference to get home & have time to regroup.
- Our summer BBQ / Pool Party is on August 11 & will again be held at the homes of Joanne Mellady & Joyce Smith. We had a small group last year but it was a great time...I hope many more can fit it into their schedules this year.
- And, on August 18, the New England Area Education Day will be held at Dartmouth Medical Center in Lebanon, NH.

Please add these events to your calendar to keep the dates open.

EVENT DESCRIPTIONS

Massachusetts Support Group

DATE: Thursday, June 21, 2012

TIME: 7pm to 9pm

PLACE: Wingate Nursing Home
589 Highland Ave.
Needham, MA

EVENT: Alpha-1 Support Group Meeting

TOPIC: New COPD Treatments

RSVP: to Sheila
(978)468-7704 slfavazza@yahoo.com

Refreshments provided by Talecris Biotherapeutics

Please RSVP so we can plan for food:

Alpha Run Helping Research for a Cure

A Benefit Outing sponsored by Mohawk Ramblers Motorcycle Club

All proceeds donated to the Alpha-1 Foundation to support the research for a cure for Alpha-1 Antitrypsin Deficiency

Saturday, June 2nd, 2012 at Cherry Rum Plaza, Greenfield MA

9:30 - 10:30 am Registration,

10:30 am Run Starts at Mohawk Ramblers / Lake Pleasant

11:00 am Grounds open

5:00 pm Grounds close

Food • Fun • Music • 50/50 Raffle

\$20 suggested donation

includes free hamburger , hot dog & soft drink
(First 50 to sign in receive a FREE event T-shirt)

For more information, call Frank : 413. 475. 0502

(Please! No Pets and No Glass)

Massachusetts Support Group

DATE: Saturday, August 11th (rain date Sunday, Aug. 12)

TIME: 12 noon to 6pm

PLACE: the homes of Joanne Mellady & Joyce Smith
38 Wild Rose Drive
Andover, MA 01810

EVENT: Alpha-1 BBQ & Pool Party
Bring Family, Bring Friends

Refreshments Hamburgers, Hotdogs, & Soda will be provided
Bring your favorite pot-luck to round out the menu
Munchies Salads Side Dishes Desserts

RSVP: with your pot-luck choice to Sheila
(978)468-7704 slfavazza@yahoo.com

NATIONAL CONFERENCE ALERT!

Found on A1F web site.

Alphas, families attending national conference in Seattle urged to get immediate booster shot for whooping cough

Posted: Friday May 18, 2012 under News Announcements

Alphas and their families who plan to attend this year's Alpha-1 Association National Education Conference are urged to consider receiving a vaccination for whooping cough as soon as possible.

AUGMENTATION THERAPY

Found on A1F web site.

Kamada announces positive interim results for trial of Alpha-1 protein as treatment for juvenile diabetes

Posted: Tuesday April 17, 2012 under A1F News Announcements

Globes

Israeli biopharmaceutical company Kamada Ltd. announced that it has received a positive interim report on the preliminary results of the Phase I/II clinical trial of D1-AAT, which uses the Alpha 1 antitrypsin protein, for the treatment of Type 1 diabetes (juvenile diabetes).

The trial found stabilization and even improvement in diabetes measures of the patients, and a high safety profile in the 20 children and adolescents tested. Kamada cautions, however, that the trial was limited in time and that the patient sample was small. These facts should be taken into account when drawing conclusions from the interim report. The company expects to publish the final report on the clinical trial in late 2012.

The Alpha-1 protein is used as an intravenous infusion to treat lung disease caused by Alpha-1 Antitrypsin Deficiency. Kamada manufactures Glassia, an Alpha-1 treatment approved by the U.S. Food and Drug Administration (FDA). The FDA has approved "orphan drug" status for the use of the Kamada for Type 1 diabetes.

This is the first time that Kamada's drug with the Alpha-1 protein has been given to children and adolescents, which highlights the importance of the safety issue. The safety and tolerability data of D1-AAT have been very positive to date, Kamada said. Diabetes measures in most of the patients showed stabilization and even slight improvement.

The interim report includes data collected in the 10 months since the start of clinical trial in June 2011, during the three months of continuous treatment of the children and adolescents who had recently developed Type 1 diabetes. Kamada is conducting the clinical trial at Schneider Children's Hospital and Assaf Harofeh Hospital in Israel.

Found on A1F web site.
Posted: Thursday April 19, 2012 under News Press Releases
Baxter announces \$1 billion Georgia plant to manufacture plasma products
Fiercehealthcare.com

DEERFIELD, IL — Baxter International Inc. today announced it will build a new state-of-the-art manufacturing facility in Georgia to support growth of its plasma-based treatments. These therapies include treatments for immune disorders, trauma and other conditions including Alpha-1 Antitrypsin Deficiency.

Baxter expects capital investments at the Covington, Ga., site to exceed \$1 billion over the next five years and to result in the creation of more than 1,500 full-time positions in Georgia and more than 2,000 jobs in total across multiple U.S. locations.

Baxter manufactures and distributes Aralast NP, and also distributes Glassia, manufactured by the Israeli biopharmaceutical company Kamada, both infusion products for treating Alpha-1 Antitrypsin Deficiency.

LUNG TRANSPLANT NEWS

Found on A1F web site. Posted: Tuesday May 8, 2012 under News
<http://consumer.healthday.com/Article.asp?AID=664124>

Vitamin D May Affect Lung Transplant Success

Vitamin deficiency associated with higher rates of rejection, infection and death, study shows

FRIDAY, April 27 (HealthDay News) -- Vitamin D is important for the health of lung transplant patients, a new study suggests.

Researchers from Loyola University Health System in Chicago found that vitamin D deficiency is associated with an increase in lung transplant rejection and infections.

"Patients who undergo lung transplants are at risk for rejecting the organ, and two-thirds of these patients are vitamin D deficient," Dr. Erin Lowery, the study's first author and assistant professor in the department of pulmonary and critical care medicine at Loyola University Chicago Stritch School of Medicine, said in a health system news release.

For the study, researchers examined 102 lung transplant patients. The participants had their vitamin D levels checked within 100 days of their surgery or 100 days after the operation.

Normal vitamin D levels were found in 21 patients, but 81 transplant recipients were deficient. The rejection rate in the deficient group was more than twice as high as the group with adequate levels of vitamin D. The deficient group also had more than twice as many infections, and their mortality rate was nearly five times higher one year post-transplant.

The study authors said 52 percent of the transplant patients received a vitamin D supplement before their surgery. One year later, 75 patients had normal levels of the nutrient and 27 did not.

"Given the high prevalence of vitamin D deficiency in lung transplant patients and the growing evidence that this supplement helps the immune system tolerate the organ, optimal levels of vitamin D are critical for positive outcomes in these patients," Lowery said.

The study was published recently in the Journal of Heart and Lung Transplantation.

The body uses sunlight to make vitamin D. Other sources include dairy products and fatty fish, such as tuna and salmon, and supplements.

More information: The U.S. Office of Dietary Supplements provides more information on [vitamin D](#). - Mary Elizabeth Dallas

SOURCE: Loyola University Health System, news release, 4/24/12

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<http://consumer.healthday.com/Article.asp?AID=664124>

Z-Pack warnings?

Found on A1F web site. New York Times

Popular antibiotic azithromycin may increase risk of death in adults, especially those with heart disease

A new study finds that a widely used antibiotic, azithromycin, may increase the likelihood of sudden death in adults, especially those who have heart disease or are at high risk for it. The increased odds of death are small, but significant enough that the authors of the study say doctors should consider prescribing a different drug, like amoxicillin, for high-risk patients who need antibiotics.

People at high risk include those with heart failure, diabetes or a previous heart attack, and those who have undergone bypass surgery or have had stents implanted. In such patients, the drug may cause abnormal heart rhythms that can be fatal. Just how the drug might disrupt heart rhythm is not known, the researchers said.

Complete story:

http://www.nytimes.com/2012/05/17/health/research/popular-antibiotic-may-raise-risk-of-sudden-death.html?_r=1

ODDS & ENDS

The Record e-Newsletter: Health E-ssentials, from North Jersey

Why kids need dirt to stay healthy? 4/3/12

It's official. Kids need to get dirty.

It's something that all kids seem to know instinctively and most parents need to be reminded of. A little dirt is a good thing. And a new study has finally found that exposure to dirt might just make our kids healthier in the long run.

Health experts have known for years that kids who grow up on farms are less likely to have immune system disorders such as asthma, allergies and inflammatory bowel disease than kids who grow up in cities. It's called the "hygiene hypothesis," but even though it's generally accepted, health experts have never understood why it works — until now.

A new study from an international team of researchers led by scientists at Brigham and Women's Hospital may finally have found a biological explanation for the hygiene hypothesis. The study, recently published in the journal Science, found that exposure early in life to microbes helped to train certain immune cells to resist disease later in life. Exposure to those same microbes as an adult did not have the same effect.

The immune cells affected were generally those in the lungs and intestines. No microbe exposure meant that the immune cells were not properly "trained," leading to respiratory and digestive disorders later in life.

So there you have it. A little dirt early in a child's life can help protect him from all sorts of diseases. Go ahead; toss out that bottle of hand sanitizer and let your kids play in the dirt.

Think before you drink

Consider carefully what liquid you wash medication down with: Some beverages can interact with drugs, lessening their effectiveness or even posing health hazards.

- Grapefruit juice: This citrus slows enzyme activity needed to process more than 50 drugs.
- Milk: Calcium makes it harder for the body to absorb some prescriptions, such as thyroid pills.
- Orange juice: Look out for symptoms of too much potassium in your system, like muscle cramps.
- Green tea: Vitamin K can decrease the effect of blood thinners such as warfarin (Coumadin).

By The Record staff, with content from The Associated Press

Send questions or comments to hospitals@northjersey.com

Thank you,

Joe Reidy

A Coordinator with the
NY/NJ Alpha-1 Support Group

66 Moore Ave

Waldwick, NJ 07463

1 (201) 444-7839

JoeReidy@Verizon.net

NY/NJ Alpha-1 Support Group
Joe Reidy
66 Moore Ave.
Waldwick, NJ 07463
1 (201) 444-7839
E-mail JoeReidy@Verizon.net

OPEN CAREFULLY

Alpha-1 Nor'Easter (April/May 2012)

NY-NJ Alpha-1 Support Group From A1F web site.

A record 200-plus walk to raise funds and awareness at the 5th annual George Washington Bridge Walk

A record 200-plus walkers took part in the 5th annual George Washington Bridge Walk last Saturday. Alphas from New York, New Jersey, New England and even farther away teamed up with the Alpha-1 Foundation and the James P. Mara Center for Lung Disease at St. Lukes/Roosevelt Hospital in New York City to raise awareness and funds for Alpha-1 research programs.

The number of walkers was a huge gain over last year, when 130 people participated (a record at that time). Besides the awareness — the walk was featured on local television — the walk raised more than \$30,000, also a record for the event. Team R2J and Team Telschow were the largest fundraisers, between them raising more than \$6,000.

Among the largest teams participating were Team Carmel led by Alexandria Corrado, with 37 walkers; and Team Golder led by Kimberly Golder Gagnaniello, with 18 walkers. Both teams have participated in four of the five bridge walks.

Team Carmel is named in honor of Carmel Casella, Alexandra's grandmother, an Alpha who died at 72 after taking part in the first George Washington bridge walk. The team also walks to honor Carmel's sister, Agnes English, an Alpha who died in 2011.

Team Golder is named for Buddy Golder, Kimberly's father, who died in 2006 after living 14 years with a lung transplant.

Gerry Turino, MD, and Edward Eden, MD, of St. Lukes/Roosevelt Hospital Center, and John Walsh and Angela McBride of the Alpha-1 Foundation, all addressed the crowd at lunch about the importance of their participation, and thanked them for their efforts to raise Alpha-1 awareness and funds for Alpha-1 research programs.

Alpha Larry Hoffman and his wife Marian of Shoemaker, PA, attended with their grandson, Owen Dubble. Owen came with his racing go-kart, which displays a prominent Alpha-1 Foundation logo. Owen won the 2011 Pennsylvania Dirt Kart Series in the Junior Championship at age 12, and is about to begin a new series of racing.

Lori Tartell of St. Luke's/Roosevelt and Joe Reidy, New York-New Jersey Alpha-1 support group leader, spearheaded the walk again this year, as they have every year.

Bridge walkers met at the Fort Lee, NJ, side of the bridge, had a light breakfast before the walk, and lunch afterward. The bridge walk, about a mile long, is always "at your own pace" and participants were welcome to turn back at any point.

Some walkers chose an alternative, Fort Lee Historic Park, for their walk. The park, just south of the bridge, has wonderful scenery from the Palisades above the Hudson River. The park walk is about half a mile, including a hill. **To see a TV story on the bridge walk go to:**

<http://www.ny1.com/content/161115/gw-bridge-walkers-raise-money-for-lung-disease-research?ap=1&MP4>

To see some photos of the GW Bridge Walk go to:

http://www.bradhess.com/ALPHA%5FGW%5FBRIDGE/ALPHA_GW_BRIDGE/index.html

The NY/NJ Alpha-1 Support Group
(not this newsletter) is endorsed by the:

Alpha-1 Association



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