

MOCHA

Mothers of Children Having Allergies



www.MOCHAllergies.org

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Meeting Dates:

MOCHA meets on the second Monday of the months of September, November, January, March, and May at Highland Park Hospital, 777 Park Avenue West, Highland Park, IL 60035, Meeting Room 2 in the basement, 7-9 pm. Upcoming meetings:

- September 14, 2009
- November 9, 2009
- January 11, 2010
- March 8, 2010
- May 10, 2010

Non-Allergic Food for Thought:

The world is not Milk, Egg, Peanut, Tree nut, Wheat, Soy, Fish, Shellfish-Free. It is our job as parents to give our children the **Education, Encouragement, Experience and Enthusiasm** to get out there and live their lives to the fullest—safely.

Disclaimer:

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HAPPY HOLIDAYS! The holiday season is upon us and with it the need to remain vigilant against increased exposure to food allergens. So many special foods associated with this time of year are made with tree nuts, milk, eggs, etc., so it goes without saying that we need to take extra care to know what our kids are eating.

MEMBERSHIP INFORMATION: We'd love to have you join MOCHA! You'll be included in our email list – you'll receive all the communications we distribute throughout the year. Please email membershipinfo@MOCHAllergies.org with your name, address, phone number and email address to be added to our membership list.

DUES UPDATE: In light of the country's struggling economy and the personal impact it has on so many families, MOCHA has decided to discontinue collecting membership dues! We want to provide support and information to all those who need it, without placing any financial burden on families already struggling to meet the needs of their food-allergic members. MOCHA will no longer send out the large bi-yearly paper mailing packets. We will continue to produce periodic newsletters, however, which will be posted on the MOCHA website, www.MOCHAllergies.org, as well as emailed to the MOCHA-Talks email list.

UPCOMING MEETINGS:

MONDAY, JANUARY 11, 2010: We will be debuting the brand new Food Allergy Initiative/Children's Memorial Hospital video "What I Wish You Knew About My Food Allergies," followed by a short presentation by Katy Schmeissing, M.S., R.N., Food Allergy Community Educator, and Christine Szychlinski, APN, NP, Manager, Food Allergy Program. We'll also have an open forum on school issues and what the new state guidelines may bring. Come with questions and couple of extra hankies for viewing this very special video.

UPDATE HB281 Becomes Public Act 096-0349: www.ilga.gov Success! The Illinois School Code has been amended to provide that not later than July 1, 2010, the State Board of Education in conjunction with the Department of Public Health, shall develop and make available to each school board guidelines for the management of students with life-threatening food allergies. The guidelines will include education and training for school personnel, procedures for responding to life-threatening allergic reactions to food, a process for the implementation of individualized health care and food allergy action plans for students with life-threatening food allergies, and protocols to prevent exposure to food allergens. Each school board will be required to implement a policy based on the guidelines by January 1, 2011. To read the full text of the amendment, go to: www.ilga.gov/legislation/publicacts/fulltext.asp?Name=096-0349.

FOOD ALLERGY STUDY: Children's Memorial Hospital Food Allergy Study Update

The Children's Memorial Food Allergy Study is gaining momentum and gearing up for a big push in 2010 to reach its goal of having 1,000 families participate in the study.

Here's what's new:

- The Study recently received a groundbreaking new grant from the National Institute of Health to do genetic analysis that will be the first of its kind in the country.
- As of November 2009, nearly 600 families have enrolled so they are still looking for **another 400 families** to participate in the next year.
- Study visits are now being conducted at Glenbrook Hospital in Glenview.
- Evening appointments now available at the main hospital (as late as 5:00 pm).
- Saturday appointments offered once a month.
- The study is able to coordinate the blood draw with your pediatrician or allergist so there is only one poke.
- Funding from National Institutes of Health (NIH), the Chicago Community Trust, The Food Allergy Initiative and other generous donors.

The study team is seeking families from and all over the U.S. to join, not just the Chicago metropolitan area. An eligible family has at least one food allergic child under the age of 21, and both biological parents willing to participate. Participation consists of a **one-time visit** at Children's Memorial Hospital in Chicago, with optional follow-up visits every one to two years. Visits last only about two hours, medical care or insurance are not affected in any way, and participation is completely voluntary. Participants receive Target gift cards, validated parking, and goody bags for the kids as well as this beautiful keychain.



Children's Memorial Hospital Food Allergy Study Update (cont'd)



What is the situation?

- Peanut allergy occurrence has doubled in the past 5 years.
- Food allergy now affects an estimated 6-8% of children in the United States.
- With the incidence of food allergies increasing so rapidly, the triggers and underlying causes of this condition need to be identified.
- Diagnostic tools are unreliable.
- Avoidance of food allergens is currently our only solution.
- We don't understand the who, why, or when of food allergy.

Why are 1,000 trio families needed for the study?

- To do a unique genotyping analysis, the first of its kind in the country
- To have sufficient statistical power to do a genetic analysis and be able to study more than a million genetic markers and environmental exposures that potentially affect food allergy.
- To build a solid foundation on which to determine the causes, find better diagnostic and treatment methods for, and eventually maybe even find a cure for food allergy.
- To research the role of genetics, the environment AND the immune system on food allergy

What can you do?

- Enroll your family in the study.
- Tell someone about the study. Do you know a friend, relative, neighbor or acquaintance with food allergic kids (anywhere in the country)? Share your experience!
- Pass out the study's brochures at your local health food store, allergist's office, school, day care, support group meeting or pediatrician's office.
- Put a blurb about the study on your blog or favorite food allergy website; ask your favorite group or organization to include info about the study in their next newsletter.

So the next time you see a friend, family member, or doctor who shares your concerns about raising kids with food allergies, ask them to call 1.888.573.1833 or email allergystudy@childrensmemorial.org for more information. **The study needs to reach its goal by the end of 2010!** Doing something that simple can have a big impact on our understanding of the causes of food allergies in children. Let's get the word out!

Call Deanna Caruso at 312-573-7755 to sign up. Direct online link is www.childrensmrc.org/allergy/study. Leslie Lesner, Community Outreach Coordinator for the Food Allergy Study, is available to speak to your local support group about the study and the urgent need to participate. She can be reached at 312-579-7919.

FOOD ALLERGY INITIATIVE (FAI): The 12th Annual Food Allergy Ball was held on December 7th in New York at the Waldorf Astoria. The evening raised \$3.9 million to benefit FAI's research activities and educational programs aimed at effectively treating and raising awareness of life-threatening food allergies. This year's event honored Charles Koppelman, Executive Chairman of Martha Stewart Living Omnimedia. Emeril Lagasse, the celebrated chef, restaurateur, and television personality, received the FAI Lifetime Achievement Award. Conor Kennedy, the son of Mary Richardson Kennedy and Robert F. Kennedy, Jr., accepted the FAI Legacy Award, which honored the late Senator Edward M. Kennedy for his commitment to the food-allergic community.

FAI Chicago's 2nd Annual Benefit was a great success, raising more than \$1.1 million for food allergy research and education. The benefit was orchestrated by co-chairs Suzanne and David Friedland, Susie and Chris Hultquist, and Eun Lee and David Calicchia, along with a tireless benefit committee. Ginger Zee, who anchors the weather for NBC 5 Chicago, welcomed some 500 guests. Michelle and Darren Anixter, parents of children with food allergies, were honored for their dedicated advocacy on behalf of the food-allergic community. The FAI Chicago Lifetime Achievement Award was presented to Charlie Trotter, world-renowned chef and philanthropist, for his commitment to culinary excellence and his sensitivity to the needs of food-allergic patrons. Dr. Hugh Sampson, MD (Mount Sinai School of Medicine, New York, NY), a prominent allergist, gave an update on the progress of research.

The annual FAI Spring Benefit Luncheon will be on Wednesday, April 21, 2010 at Cipriani 42nd Street in New York. For more information, contact Anne MacGillivray at 212-207-8795 or check the website, www.faiusa.org.

FOOD ALLERGY AND ANAPHYLAXIS NETWORK (FAAN): FAAN has a new website. See their new look at: www.foodallergy.org/. View the events calendar under the About Us section to stay informed of FAAN's upcoming events. The Chicago FAAN Conference is scheduled for Saturday, May 22, 2010. Keep checking back with the FAAN website to register for this event.

Eleanor Garrow-Majka, Illinois' POCHA founder, is now the Vice President of Education and Outreach for FAAN! Congratulations to Eleanor! We wish her all the best in her new position with FAAN.

FAAN's Chicago 2008 walk raised over \$88,000, with more than 1,000 people participating. Thank you to all the walkers and workers who made this event a success.

KEYCHAIN FOR A CURE: As a personal expression of thanks for donating \$100 or more in honor of MOCHA to Children's Memorial Hospital Division of Allergy & Immunology; FAI Chicago; or FAAN, Denise Bunning would like to give donors a special food allergy keychain that she designed in collaboration with She Beads. The key-chain is comprised of nine colorful beads, each denoting one of the nine most common food allergens.



milk



egg



tree nut



shellfish



peanut



fish



soy



wheat



seeds

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GETTING MORE INFO:

We suggest making sure to spend some time visiting these websites. Especially if you're new to MOCHA!



www.FAIUSA.org

www.ChildrensMemorial.org/Depts/Allergy

www.Allergists-Asthma.com

www.AllergyMoms.com

www.MedicAlert.org

www.FoodAllergy.org

www.POCHAofWillCounty.com

www.KidsWithFoodAllergies.org

www.AllergicLiving.com

www.LivingWithout.com

www.IllinoisFAEA.org

www.POCAofDuPage.org

www.ThriveAllergyExpo.com

www.Divvies.com

www.CIFAN.org

www.FoodAllergyWis.org

www.MinnesotaFoodAllergy.org

www.SanDiegoFoodAllergy.org

www.FoodAllergySmart.org

www.AllergicChild.com

www.FoodAllergyAdvocate.com

www.VermontFoodAllergyOrg.org

www.PAKCharlotte.org

www.BestAllergySites.org

www.FoodAllergySupport.net

www.AAFA.org

EE: Eosinophilic Esophagitis—Check out www.apfed.org and www.curedfoundation.org for more info.

REMEMBER: Always consult with your own doctor about information you receive on the internet. If it sounds too good to be true, unfortunately it probably is not true.

PREVIOUS MEETINGS: All of these presentations are available on the www.MOCHAllergies.org website under the Meetings tab.

NOVEMBER 19, 2009: Kelly Newhall, MD, Chicago Family Asthma & Allergy, discussed H1N1 and seasonal flu and their effects on the asthmatic/allergic child. Christine Szychlinski, APN, NP, demonstrated the new, redesigned EpiPen which now features a roll-proof barrel and a guard to cover the needle after use. There is a link on the left side of the www.epipen.com home page on how to use the EpiPen Auto-Injector.

SEPTEMBER 14, 2009: Our guest speaker was Dr. Rachel Story, Attending Physician, Allergy & Immunology Department at Children's Memorial Hospital, who presented on Food Allergy Research.

MAY 11, 2009: Our speaker was Ruchi Gupta, MD, pediatric physician at Children's Memorial Hospital of Chicago. She presented results of her research into Food Allergy Knowledge and Beliefs among the General Public, Primary Care Physicians and Parents of Children with Food Allergy. It was a fascinating look at food allergy perceptions from various perspectives. Dr. Gupta has been named one of the 15 most promising physician-scientists in the United States, and this honor will help support the continuation of her research.

MARCH 9, 2009: Our speaker was Mary Beth Feuling, RD, MS, CNSD, Registered Dietician at Children's Hospital of Wisconsin. Mary Beth works with food allergy patients and children who have various types of gastrointestinal issues including EE (Eosinophilic Esophagitis). Mary Beth has been instrumental in helping many families navigate the nutritional challenges of our food-allergic children, and we were very encouraged by her presentation.

SCHOOL RESOURCE GUIDES: We have links to examples of school guidelines for Illinois Districts 39 and 67 for supporting children with life-threatening allergies on the MOCHAllergies.org website under the Resources tab. Consult your local school district's website for the procedures in place for your child's school.

504 PLANS: If you are interested in purchasing a CD with Sample 504 plans, POCA of DuPage has a CD they prepared. Please send your name/address/phone number to Kristin Miller, Co-Leader of POCA of DuPage, by emailing her at: kamonmiller@comcast.net.

POWER EMAIL: Thanks to Tom Donovan for helping to keep us all informed. If you are not getting your power emails, your email address is changing, or you wish to be deleted from the email list, please send an email to membership-info@MOCHAllergies.org.

MOCHA WEBSITE: We are continually updating the MOCHA website, and we want your suggestions for upcoming speakers, restaurants, camps, etc.! What should we include that would be most helpful? Send your suggestions to Denise at dbunning@comcast.net, with "Website Suggestions" in the subject line. Thanks!

ARTICLES TO SHARE: Please continue to send articles that you'd like to share with the group to Denise at dbunning@comcast.net.

ALLERGY FRIENDLY RESTAURANTS: Please continue to send us information on local, Illinois allergy friendly restaurants.

As always, stay safe. See you soon!
Denise and Anne



milk



egg



tree nut



shellfish



peanut



fish



soy



wheat



seeds

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