

ASTHMA & ALLERGY

BULLETIN

ASTHMA AND ALLERGY FOUNDATION OF AMERICA • NEW ENGLAND CHAPTER

Stop the FLU from getting YOU!

People with asthma are at increased risk for serious complications from the flu, including life-threatening pneumonia.

The best time to get your flu shot is in the fall, before the New England flu season begins. Contact your physician, local health department or pharmacy now for information about getting your whole family protected.

The CDC recommends flu vaccinations for everyone ages 6 months and older, and especially for people with chronic conditions (such as asthma) and those who live with or care for them. Ask your doctor about new protocols and vaccines for people with a history of egg allergy.

RESEARCH UPDATE

Bullies Target Children with Food Allergies

By Frank J. Twarog, MD, PhD

Bullying is a common problem in the current culture, and we can now add food allergy as one part of this troublesome trend. A study published recently in the journal *Pediatrics* reminds us that parents and children with food allergies may be concerned not only with avoiding the allergenic food but also about social/psychological issues that they must learn how to handle.

In a survey of children and adolescents 8 to 17 years of age, 31.5% of children and 24.7% of their parents reported bullying relative to food allergy. The nature of the bullying ranged from being

teased to actually being touched by the allergenic food. Most episodes occurred in the school setting. This activity affected the quality of life not only for the child who was being bullied but also for the parents, who may have had increased anxiety because of the child's food allergy and risks.

(Continued on page 2)



**Women
and
Asthma**
(see page 2)

SHARE YOUR STORY

Personal Picture Book Paves the Way to Understanding

By Carla Uzzell

In 2008 when my 17 month old daughter went into anaphylactic shock after putting a cashew in her mouth, the worries of Kindergarten were very far from my mind.



Instead, I focused on the day to day toddler playgroups, birthday parties and the relatives that just didn't understand how serious potentially life-threatening food allergies truly are.

For all of these hurdles, the Asthma and Allergy Foundation of America, New England Chapter guided me through. Shortly after Jessica's life threatening reaction, I started attending every single support group event that was held within a 45 mile radius that AAFA New England offered. From the experts: allergists and parents in

attendance, I learned how to read labels carefully, how to educate family members who were still in denial, and in case of an emergency I practiced administering expired epinephrine injectors in every orange the guest speakers passed to me.

Fast forward 3 years from that fateful night when my baby was at death's door due to a food that I have always enjoyed. Kindergarten was on the horizon. By this time, I felt comfortable with our day to day life. Our family of four had our routines down at the few safe restaurants that we braved attending. During the few hours I did work each week our sitter was well trained with how to keep Jessica safe and how to use an epinephrine injector in the confines of our home. Jessica was now nearly 5 years old and very good at hand washing before eating and saying "No thank you, I have food allergies" if offered a lollipop at the post office or a piece of cake at a birthday party.

(Continued on page 6)

RESEARCH UPDATE (continued from page 1)

The authors of this study, who are based at the Mt. Sinai Jaffe Food Allergy Institute, acknowledged that the patient population they surveyed may not be representative of all children with food allergies. Nonetheless, it provides another insight into parental concerns regarding food allergy.

In a recent issue of this newsletter (Spring 2013) we reviewed concerns that adults with food allergy experience while dining out. Bullying in various forms is another source of stress for families with food allergies.

Source: Shemesh, E. et al. Child and parental reports of bullying in a consecutive sample of children with food allergy. *Pediatrics*, 131:e10, 2013.

What can you do about bullying?



Educate: Enlist the school nurse, PTO and others to help improve awareness about food allergies and create a more supportive environment. In addition to classmates, teachers and other school staff can also act like bullies sometimes, so everything you can do to help people understand food allergies and take them seriously improves the school climate and helps prevent bullying.

Teach: Raise your child with the self-confidence that we all need to muster when picked on, and give your child the skills (what to say, who to tell, etc.) to respond appropriately if bullied.

Advocate: Make sure your school has effective policies and programs in place to prevent bullying and respond appropriately.

For other tips, see “Teasing and Bullying: Don’t let your child be a victim” in the Food Allergy section of our website (www.asthmaandallergies.org).

Find other helpful resources and tools at these websites:

www.stopbullying.gov www.stopbullyingnow.com www.AllergyHome.org

Hormonal Changes May Affect Women with Asthma

Although childhood asthma tends to be more frequent in boys, the opposite is true for adults. Hormonal changes may be a factor in adult women, as asthma is more frequent in this population, and up to 30% of adult women experience unstable or increased asthma symptoms before their menstrual periods.



A recent study surveyed 756 women who are part of the Severe Asthma Research Program. (In our region, Brigham & Women’s Hospital is a participating center for this important effort.) Most of the women were in the third decade of life. Between 50 and 60% were Caucasian and 30-35% were black.

The women who had more frequent symptoms related to their

menstrual cycle, which is called “perimenstrual asthma” (PMA), also had increased asthma severity, aspirin sensitivity, high body mass index (BMI, a rough indicator of “fatness”), increased frequency of acid reflux (or gastroesophageal reflux disease, known as GERD, a chronic heartburn-like condition), and lower lung function. Severe asthma was identified in 53% of those with PMA, while it was present in 30% of those without PMA.

PMA had previously been associated with more frequent emergency room visits for asthma flares and more frequent near-fatal asthma episodes, although other studies have not identified PMA with this higher frequency. For example, in a United Kingdom sample it was found in only 8.5% of women.

Women who have PMA should receive more aggressive controller therapy for their asthma. Factors such

as aspirin sensitivity identified in this population would suggest that they avoid nonsteroidal anti-inflammatory drugs. In the future, more targeted treatment may become available. An older study from Japan suggested that pranlukast, a medicine related to montelukast (Singulair®) was particularly effective in controlling PMA. Similar observations have not been established with other treatments, however.

Source: Rao, Chitra et. al. Characteristics of perimenstrual asthma and its relation to asthma severity and control: Data from the Severe Asthma Research Program. *Chest*. 143:984, 2013.

Frank J. Twarog, M.D., Ph.D., is an allergist in Brookline and Concord, MA, and serves as President of the Asthma and Allergy Foundation of America, New England Chapter. He is a Clinical Professor at Harvard Medical School.

ASK THE DOCTOR: Does Asthma Worsen in the Fall?

Q. Many children seem to have increased asthma symptoms during the fall season. Is there really a higher incidence of asthma in the fall? What are the reasons why this may happen? Does this lead to increased trips to the hospital? What can parents do to help prevent asthma flare-ups?

A. Children often have increased asthma symptoms in the fall. There are many possible reasons for this. The fall season brings about a change in weather. The cooler weather is a definite trigger for asthma attacks.

In addition, certain outdoor triggers such as ragweed pollen and mold counts increase in the fall. The combination of allergens with damp, cold environments provides a double trigger that can flare asthma. We often see children in the emergency room for asthma after raking leaves or going “trick or treating” on Halloween, when they are out in the cold, damp environment and exposed to moldy piles of decomposing leaves and damp grass.

The fall season usually marks the start of children returning to school, where colds and flu illnesses are easily passed from one child to the next, triggering asthma attacks. School time often includes increased involvement in organized sports and group activities. Exercise in high pollen or cold, damp environments can trigger asthma. Poor ventilation

and pets or other allergens in the classroom can also lead to asthma symptoms.

Parents can help decrease asthma flare-ups by watching carefully for early signs and symptoms of an attack. Coughing, wheezing and shortness of breath should be treated early with albuterol and a quick call to the pediatrician if symptoms don’t improve.



Sometimes maintenance medications such as inhaled steroids are increased in dosage during the fall and winter as a preventive measure. In addition, you and your doctor should work out a

written asthma action plan for how to deal with early symptoms and to know when further interventions such as oral steroids may be helpful.

The goal is to catch the attack early, and avoid emergency room visits or hospitalizations. Based on your child’s asthma history, you and your doctor should work out a personalized written asthma action plan. Peak flow meters can be helpful for some older children, and should be used in conjunction with the action plan.

Other preventive tips include:

- Avoid piles of damp leaves. Children allergic to mold should probably avoid raking leaves.
- Teach your child to wash his/

her hands frequently to prevent the spread of colds.

- Avoid excessive use of humidifiers since moist environments are conducive to mold and dust growth.
- Avoid triggering allergens such as ragweed and mold, which are common in the fall.
- Consider having ducts professionally cleaned before turning on the home heating system, to decrease dust mite and other allergen exposure.
- If your child has exercise-induced asthma, work out a plan for pre-exercise asthma therapies to prevent attacks.
- Consider an evaluation by an allergist to identify allergies in your child that may trigger asthma.
- Become educated in environmental control measures to decrease exposure to allergens that are problematic in your child, both at home and at school or child care.

All these measures can help make fall and winter a safe and asthma-free time for your child.

Wanda Phipatanakul, MD, MS is a Pediatric Allergist and Immunologist at Children’s Hospital, Boston, and Associate Professor of Pediatrics at Harvard Medical School. Contact her if you are interested in learning about opportunities to participate in asthma and allergy research projects: asthma@childrens.harvard.edu or 857-218-5336.

LIVING CONFIDENTLY with FOOD ALLERGY: A Guide for Parents and Families

This excellent new publication offers accurate and practical information about managing food allergies, including how to avoid allergens and how to recognize and treat a reaction. It offers many helpful suggestions for daily life at home and in various situations (dining out, play dates, childcare, school, and more) and discusses the challenges of living with food allergies. There are sections devoted to teenagers and people with asthma, and recommendations for how to educate your child and others.

Download the booklet free or read it on-line at: <http://www.allergyhome.org/handbook/>

This beautifully designed easy-to-read handbook was published by Anaphylaxis Canada and written by a multi-disciplinary team that included Boston Children’s Hospital affiliates Jennifer LeBovidge, PhD and allergist Michael Pistiner, MD, a member of AAFA New England’s Board of Directors.

Special offer: We will mail a copy of the gorgeous full-color printed version of *Living Confidently with Food Allergies* to all new and renewing members. Send a check, call with your credit card, or donate on-line and mention that you want a copy of the book.

FROM THE BOOKSHELF: Advocacy at School

by **Laurel Francoeur**

The Merriam-Webster Dictionary defines an advocate as someone who (1) pleads the cause of another; specifically: one that pleads the cause of another before a tribunal or judicial court; (2) defends or maintains a cause or proposal; (3) supports or promotes the interests of another.

Anyone has the power to be an advocate. You can plead your child's case, and it is your job to support and promote the interests of your child. You don't need a fancy degree or influential connections. You do need confidence in yourself. As a parent, you are used to being the voice for your child. You need to take that same voice and be willing to use it in whatever context is necessary to keep your child safe and happy.

The following are the qualities you need to be a successful advocate:

1. Be Knowledgeable

A good advocate is someone who is knowledgeable and passionate about his subject. Educate yourself about food allergies in general and also the specifics about your child's allergy. The more you know, the better you can address all the needs your child will face.

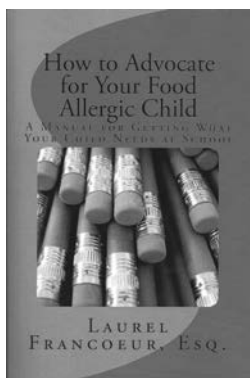
2. Be Passionate Without Being Obnoxious

If you do not believe in your cause, no one else will either. Speak from the heart and let the school know why the issues are important to you. Let them know that you are afraid for your child's safety and mental well-being. However, don't go overboard and get too emotional. Do not act mad or mean – just passionate.

3. Know Your Rights

An advocate knows what rights are available and who is in charge of enforcing those rights. Read as much as you can about your rights and even

consult an attorney if necessary. For example, your child is entitled to a free and appropriate education. If your child has a disability, he may be entitled to receive accommodations from the school under federal law.



He has the right not to face discrimination. A good place to start your research is with the U.S. Department of Education Office of Civil Rights, which has a nice summary of rights at <http://www2.ed.gov/about/offices/list/ocr/know.html>.

4. Know the Players

Identify who at your school is responsible for overseeing your child. Learn the names of the main players like the school nurse, the principal, and the teacher. Use every opportunity available to familiarize yourself with these people so you can understand their personalities. Pay attention at parent/teacher conferences and school activities to how the players act and treat children. Ask other parents about their dealings with the school.

5. Write Everything Down and be Organized

Any time your child encounters a problem at school, make a written note about it, listing as many of the facts and circumstances as possible. Take notes when you have meetings with the teacher, nurse or principal. Make all formal requests to the school in writing. Keep copies of all reports and letters about your child. Make sure all your documents are organized so that you can find them quickly and easily when you need them.

6. Anticipate Objections

You need to be like a good chess player who can anticipate his opponent's moves. Try to think of the problem from the school's perspective. What things do you think they will find objectionable? What reasons might they give to deny your requests?

7. Offer Solutions

After you have thought about what objections the school may have, try to think of solutions that will be mutually agreeable. For example, if the school does not want to have to pay for hand wipes for the children to use after lunch, suggest that the students hand wash in the sink for free. If you cannot think of solutions on your own, ask the school personnel to help you brainstorm. Bringing a prepared form can help. In order to create the form, you have already thought about the best solutions for your child. Having the form prepared ahead of time can also help you to think about what objections the school may raise.

8. Be a Teacher

Approach every interaction as if you were a teacher whose job it is to educate your child's caregivers. Good teachers are patient. You will get better results if you view your role as helping the school to learn about your child and his or her needs than by being a bully who demands your own way.

I want to make it clear that I am not talking about becoming a lawyer. Lawyers are advocates who receive training and are able to practice law in courtrooms and the like. You can be an advocate for yourself and your child without practicing law. However, do not be afraid to hire a lawyer if the issues get too complicated.

Your role as a parent already qualifies you to be a good advocate. Have confidence in yourself, and you will help your child to get what he needs.

Laurel Francoeur, Esq., is co-leader of the AAFA NE Metro-Northwest Suburban Boston Educational Support Group. She has a child with food allergies, and is co-founder of Greenlaurel Documents, which provides on-line food allergy advocacy tools. This is an excerpt from her book "How to Advocate for Your Food Allergic Child: A Manual for Getting What Your Child Needs at School," which is available for \$9.99 at the "Classroom" section of her website: www.greenlaureldocuments.com.

See page 5 for more resources.

AAFA New England

EDUCATIONAL SUPPORT PROGRAMS

provide you with opportunities to

- Learn from experts • Get your questions answered
- Meet others who share your concerns • Find resources and confidence

FOR MEETING DATES AND TOPICS:
see our website (www.asthmaandallergies.org) or call 781-444-7778.

METRO-BOSTON ALLERGY & ASTHMA SUPPORT GROUP

Newton, MA
Meets at Newton-Wellesley Hospital,
2014 Washington St. (Rt. 16)

NORTHWEST SUBURBAN BOSTON AREA SUPPORT GROUP - Lexington, MA

Meets at Beth Israel and Children's
Hospital Medical Care Center,
482 Bedford St.

FOOD ALLERGY GROUP OF THE NORTH SHORE Salem, MA

Meets at Salem Hospital, 81 Highland
Ave. (Davenport Conference Area)

MERRIMACK VALLEY ASTHMA & ALLERGY SUPPORT GROUP

Meeting site: TBD

METRO-WEST ALLERGY & ASTHMA SUPPORT GROUP Framingham, MA

Meets at Allergy & Asthma Treatment
Specialists, 475 Franklin St., Suite 206

PIONEER VALLEY FOOD ALLERGY SUPPORT Ludlow, MA

Meets at St. John the Baptist Pastoral
Center, 201 Hubbard St.

SHORESIDE ASTHMA & ALLERGY EDUCATIONAL SUPPORT GROUP

Kingston, MA
Meets at Wingate - The Inn at Silver
Lake, 21 Chipman Way

CAPE COD ASTHMA & ALLERGY GROUP Yarmouth Port, MA

Meets at Allergy & Asthma Center for
Cape Cod, 244 Willow St.

The following groups are currently temporarily inactive:

NASHOBA VALLEY ASTHMA & ALLERGY EDUCATIONAL SUPPORT GROUP

RHODE ISLAND ALLERGY & ASTHMA EDUCATIONAL SUPPORT GROUP

SOUTHEASTERN MASS. FOOD ALLERGY PARENT SUPPORT GROUP

Send your e-mail address if you would like to receive announcements about support group meetings and programs.

Let us know which group is closest to you.

Send to: aafane@aafane.org

Resources to help you manage food allergies at school

In addition to the book excerpted on page 4, here are a few other resources on food allergies at school:

PUBLICATIONS

Food Allergies: A Recipe for Success at School A comprehensive 318 pg. book by Jan Hanson. Available on-line and at bookstores. For more info see: www.foodallergied.com.

The Food Allergy Book: What School Employees Need to Know Published by the National Education Association in English and Spanish. See: <http://neahin.org/educator-resources/foodallergybook.html>

Food Allergies and School: A Guide to Keeping Your Child Safe and Included by Ruth LovettSmith. Available only in e-book format from Amazon.com.

WEBSITES

AllergyHome.org: See "Food Allergy Tools for Schools" at www.AllergyHome.org

Kids with Food Allergies Foundation, a division of AAFA, has a back-to-school tool kit at: <http://community.kidswithfoodallergies.org/blog/managing-food-allergies-essential-back-to-school-tool-kit>.

We are grateful to have received a generous bequest from the

Dorothy E. Stanley Trust

These funds will be used to support AAFA New England's education, community awareness and patient advocacy programs.

You can leave a lasting legacy by including AAFA New England in your estate plans.

SHARE YOUR STORY (continued from page 1)

Personal Picture Book Paves the Way to Understanding

(continued from page 1)

Still, with Kindergarten looming, I was counting the hours each day that my daughter would be without my careful eye noticing which kid was eating nuts, who hadn't washed their hands well, and which adults need to be informed of my precious daughter's potentially life threatening food allergies. Full day Kindergarten equals 6.5 hours per day. This seemed like way too many opportunities for mess ups.

Then I remembered something I had heard at one of the many, many AAFA New England meetings I had attended. A mom of a school age boy told us that she had made a book specific to her son's allergies. She then asked the school nurse and the classroom teacher to read this book to the boy's classmates so they could all be well versed in their classmate's allergies and how to keep him safe. I remembered thinking this was a brilliant idea, but it was so many meetings ago that I had tucked the idea away.

Armed with this great idea and just weeks before the start of school, I got busy scripting each page and making notes of the images I thought the 5 year olds should see. I wanted to include images of my daughter's allergens; peanuts, tree nuts and sesame so every classmate would know what to keep away from Jessica. I wanted the children to know how to clean their hands; soap works but hand sanitizer does not, if they have eaten Jessica's allergens. I also wanted her peers to know that Jessica has many interests and hobbies that have nothing to do with allergies. She is a fun, kind, playful child who happens to also have allergies to some very common foods. This part was important to include because although I wanted to educate her peers, I did not want them to be afraid to befriend this classmate.

With each page scripted, I decided what picture would best illustrate the important written message. Then 5 year old Jessica and her 4 year old sister were excited to participate in the photo shoots! I got advice from other moms of soon to be Kindergarteners about if the information was clear and if there was anything else they wondered. Size was important; I didn't want the book to be too long, in case the classmates lost interest. Also I did not want the book to be too small so that the photos would be clear. I opted for 12x12 so that every peanut, tree nut and sesame seed was very visible on the page. After all of the edits and revisions, it was time to make the book in its final form.

When we met Jessica's Kindergarten teacher and school nurse in August of 2011, just days before the first day of school, I brought along the book I had made. I kindly

asked if they would read this book to the class on the first day of school. They were very impressed with the compilation of information in a kid-friendly manner and agreed to read the book to Jessica's class on the first day of school and the other Kindergarten classes in the first week of school, so all of the students in her grade would be able to work together to keep their classmate safe.



Food allergies stormed into my life the day my baby girl fought to breathe with little to no relief. This we have no choice about. My life's goal has been to live being prepared, not paranoid. Sometimes, I know there is a fine line between the two when it comes to keeping those we love safe. This tidbit about creating a food allergy book specific to my child to be shared

with her peers that I gathered at an AAFA New England meeting years ago helped me be prepared, not paranoid.

The same book I created was read again in Jessica's first grade class. Today, Jessica is gearing up for second grade. Her love of learning is awe inspiring. She is a wonderfully artistic, opinionated, clever little girl who has her whole life ahead of her. I wonder if she'll allow me to share this book with her second grade teacher.... Time will tell.

Please share YOUR story.
How have you handled "real-life" challenges of living with allergies or asthma? Let us know what happened and how everything worked out.
(Send to: sharons@aafane.org or call 781-444-7778.)

GOLF for a good cause!

**AAFA New England
Dr. Paul J. Hannaway
Memorial Golf Classic**

Sept. 16, 2013

Tedesco Country Club - Marblehead, MA

Call for information (781-444-7778) or visit
www.asthmaandallergies.org.

We help schools, restaurants, child care providers and health professionals help YOU manage asthma and allergies

Dr. Maureen George, nationally renowned lecturer at the University of Pennsylvania School of Nursing, will present another of our popular **"Asthma Management and Education"** seminars for nurses and respiratory therapists on Sept. 18, 2013 in Lowell, MA. Call for details: 781-444-7778.



Tell your local restaurant owners, managers and chefs about the AllergyEats 2nd Annual **Food Allergy Conference for Restaurateurs**, so they can become more knowledgeable and accommodating about food allergies. The conference will be held this November in Boston. It is the brainchild of AAFA New England Board member Paul Antico, founder/CEO of AllergyEats, food allergy advocate, and father of three food-allergic children. The conference features a prestigious panel of industry and medical experts who will provide valuable information that will help keep you and your family safer when you eat out. For details visit www.allergyeats.com.

AAFA New England will be offering six **"Asthma and Allergy Essentials for Child Care Providers"** workshops this year thanks to a grant from the Blue Hills Community Health Alliance, a public health network that covers 13 towns to the south and southwest of Boston. Our training program, which we can bring to your community, helps keep children safe and healthy when they are cared for outside their homes.

School nurses: AAFA New England can provide you with spacers and peak flow meters for teaching purposes and for use by students whose families can't afford them. We also have teaching tools and activity books.

BECOME A MEMBER OR RENEW YOUR MEMBERSHIP NOW!

Membership in AAFA New England helps you and others with asthma and allergies to enjoy fuller lives.

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- ◆ Newsletters mailed to you (Multiple copies to Professional members)
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- ◆ 10% discount on books

Send your check payable to AAFA New England to 109 Highland Ave., Needham, MA 02494. MC/VISA accepted by phone or on-line at www.asthmaandallergies.org.

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Please remember to ask your company for a matching contribution to AAFA NE.

ASTHMA & ALLERGY BULLETIN

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The Asthma and Allergy Foundation of America, New England Chapter, is dedicated to helping people with asthma and allergic diseases, and those who care for them, through education, support for research and an array of services.

Information contained in this newsletter should not be used as a substitute for responsible professional care to diagnose and treat specific symptoms and illness. Any reference to available products and procedures should not be construed as an endorsement. AAFA New England, including all parties to or associated with this newsletter, will not be held responsible for any action taken by readers as a result of the newsletter. ©2013. All rights reserved. Material may not be reproduced without permission of the publisher.

Honor your friends and relatives by making a donation to AAFA New England

Donations have recently been received in memory of:

Donald Cook

Amye Lorina

Jean Michaels

Donations have recently been received in honor of:

Kathleen and Carver Porter

Donations can also be made in honor of family, friends, or healthcare providers, or to mark special occasions.

To contribute a memorial gift or tribute in honor of a special person or a birthday or other event, please send a check payable to AAFA New England. MC/VISA accepted by phone, mail or on-line: www.asthmaandallergies.org. Please include the name of the person being honored or memorialized, and let us know who to notify of your donation.



Asthma and Allergy
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NEW ENGLAND CHAPTER

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Did you pick up this newsletter in your doctor's office?

To receive future issues at home, become a member of AAFA New England. (See page 7)

How do your schools measure up?



Every year the
Asthma and
Allergy Foundation
of America
(AAFA) evaluates
how well state

policies support people with asthma, food allergies,
anaphylaxis risk and related allergic diseases in U.S.
elementary, middle and high schools.

Four of the seven states and the District of Columbia
that meet AAFA's criteria to be listed on the Honor
Roll in 2013 are in New England (CT, MA, RI and
VT). But that doesn't mean that our work is done!

Get Involved! Find out where your school stands on
making and enforcing policies that protect students
and staff with asthma and allergies.

You'll find the full report, the standards you should
be looking for, plus back-to-school tips and tools, at
www.StateHonorRoll.org.

Shopping?

Start your AMAZON.COM

shopping from our website

When you do, a portion of what you spend will be
donated to our organization at no extra cost to you!
This is an easy way to help support asthma and food
allergy education and advocacy.

Go to our home page (www.aasthmaandallergies.org)
and look for the Amazon.com search box.

Simply type in the "keyword" for the specific item or
category of item that you are shopping for and then start
shopping as normal.

Please bookmark this on your computer and share this
information with family and friends.

Thanks, and happy shopping!



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