

Patient and Community Advocacy and Education

Making a Difference in Your Community
Denise DiPrimio Kalman, DO, FAAAAI

Patient and Community Advocacy Where to Start

- Participate in organized medicine
 - Local and state allergy societies
 - Join your state medical society
- Identify your interest
- Partner with lay organizations
- Get involved

The Role of Organized Medicine

- Meet with like-minded physicians who want to support public policy issues that impact your patients and community
- Identify opportunities for multi-specialty collaboration
- Utilize resources, contacts and lobbyists

Patient and Community Advocacy:
Where to Start?

- Local Allergy Society:
 - Greater Washington Allergy, Asthma & Immunology
- Local Medical Society:
 - Medical Society of the District of Columbia

Patient and Community Advocacy
Where to Start?

- State Allergy Society
 - Asthma and Allergy Society of Virginia
- State Medical Society
 - The Medical Society of Virginia

National Organizations

- American Academy of Allergy, Asthma & Immunology
- American College of Allergy, Asthma and Immunology

Identify Your Interest: National Legislative Actions

- HR4662: School-based Asthma Management Plan Act
- S1972: Airline Access to Emergency Epinephrine Act

Identify Your Interest: National Regulatory Actions

- 2016 Medicare Fee Schedule and Payment Issues
- USP Proposed Compounding Requirements

Partner With Lay Organizations

- Allergy and Asthma Network
- American Latex Association
- American Partnership for Eosinophilic Disorders (APFED)
- Asthma & Allergy Foundation of America (AAFA)

Partner With Lay Organizations

- Campaign Urging Research for Eosinophilic Disease (CURED)
- Food Allergy & Anaphylaxis Connection Team (FAACT)
- Food Allergy Research & Education (FARE)
- Immune Deficiency Foundation (IDF)

Partner With Lay Organizations

- International FPIES Association (I-FPIES)
- The Mastocytosis Society (TMS)
- US Hereditary Angioedema Association (HAEA)

Learn!

- Learn about the issue
- Learn how to build relationships
- Learn how to communicate with stakeholders

Immune Deficiency Foundation
www.primaryimmune.org



Sign Up For Action Alerts



Advocacy Campaigns



Immune Deficiency Foundation

IDF Action Alert tool alerts advocates to important issues that affect the PID community.

Reaches out to public officials via email.

Customizable

www.primaryimmune.org

Sign Up For Action Alerts



Immune Deficiency Foundation

Affordable Care Act
Cadillac Tax

HR1600: Patient's
Access to Treatments
Act

www.primaryimmune.org

Advocacy Campaigns



Immune Deficiency Foundation
www.primaryimmune.org

How to Advocate Effectively



Tune in to our Advocacy Channel

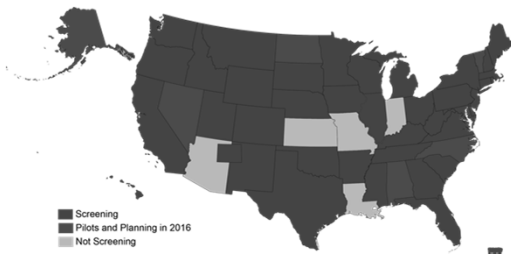


Immune Deficiency Foundation
www.primaryimmune.org

IDF SCID Initiative



Immune Deficiency Foundation
June 2016
www.primaryimmune.org



Asthma & Allergy Network

- Build your advocacy skills
 - Relationship building
 - Communicating with legislators
 - Town Hall meetings
 - Coalitions

Allergy & Asthma Network

www.allergyasthmanetwork.org



Allergy & Asthma Network

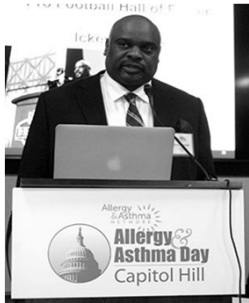
www.allergyasthmanetwork.org



Allergy & Asthma Network
www.allergyasthmanetwork.org



Allergy & Asthma Network
www.allergyasthmanetwork.org



GET INVOLVED

Highlight Your Efforts

- Tweet
- LinkedIn
- Facebook
- Web-page
- Local news
- Plaque

Practical Food Allergy Management: Resources for Families



Michael Pistiner, MD, MMSc
Pediatric Allergist, Harvard Vanguard Medical Associates

Disclosures

- I am co-founder and content creator of AllergyHome.org, free educational material
- I do not intend to discuss an unapproved/investigative use of a treatment/device in my presentation

point #1
the Unknown can be Scary




Families can come up with their own answers

point #2
Children **Believe** Grown-ups



point #3
With Food Allergies Can Come
Uncertainty



Without the Facts, Uncertainty
Can Lead to

fear



Food Allergy Management: A Challenging Balance

Allergic reactions can be prevented and dealt with *reasonably* while maintaining quality of life



(NIAID 5.1.10.1)

Goals of This Talk

- To discuss available resources that can
 - Provide needed support to families
 - Extend your reach beyond the walls of your clinics and offices
 - Leverage time
 - Leverage resources



Critical Roles of Parents in Food Allergy Management

- **Coordinator** (work with physicians, school, secondary care providers)
- **Advocate** (ensure that child's health and self esteem are protected at all times/in all situations)
- **Role Model** (act as role models for our children and the surrounding community)
- **Educator** (teach their children, secondary care providers, and the surrounding community about food allergy reaction prevention and preparedness)

Pillars of Food Allergy Management



These must be applied at all times and in all settings



Food Allergy Management must be Implemented in all Settings



Home



School



Restaurants



Parties and Play Dates



Alternative Care Givers

Food Allergy Management Education: Challenges

- Limited education time
 - Not enough time to become competent or confident in food allergy management
 - Large volume of information
 - Significant lifestyle changes
 - Train the trainer



Food Allergy Management Education: Challenges

- Studies of parental management demonstrate clear deficits in:
 - Competency in epinephrine administration (Arkwright, et al. Pediatric Allergy Immunology 2006;17(3):227-9) (Pouessel, et al. Pediatric Allergy Immunology 2006; 17(3):221-6)
 - Allergen avoidance (Joshi, et al. JACI. 2002;109(6):1019-21)
 - Information provision (Hu, et al. Arch Dis Child 2007;92:771-5)



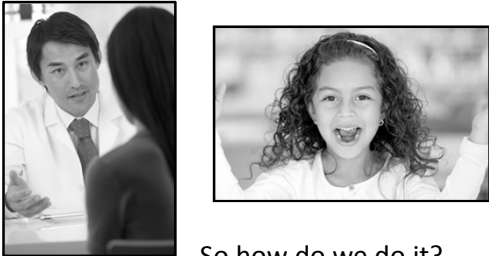
Food Allergy Management Education: Challenges

- Misperceptions and assumptions
 - Skin test size, level of IgE, air borne exposure, skin contact, danger of epinephrine, etc.





Educating, Empowering & Supporting is Critical!



So how do we do it?

The complex block contains the text "Educating, Empowering & Supporting is Critical!" at the top. Below this text are two small images: on the left, a male doctor in a white coat is talking to a patient; on the right, a young girl with curly hair is smiling broadly. Below the images is the text "So how do we do it?".

Know and Use Your Resources

- Family educational material (multiple modalities)
- Other members of your healthcare teams
- School nurses
- Patient advocacy groups
- Local support groups
- Primary care physicians and dietitians
- AAAAI
- Guidelines and guidance documents

The complex block features the title "Know and Use Your Resources" at the top. Below the title is a bulleted list of seven resources. At the bottom of the block is an illustration of two classical columns supporting a horizontal beam.

Pillars of Food Allergy Management

Prevention **Emergency Preparedness**

These must be applied at all times and in all settings

Pillars of Food Allergy Management

Prevention **Emergency Preparedness**

| | |
|---|--|
| <p>A.C.T. to Prevent Accidental Exposures</p> <ul style="list-style-type: none"> AVOID COMMUNICATE TEACH | <p>Be prepared to R.E.Act</p> <ul style="list-style-type: none"> Recognize Anaphylaxis Epinephrine Activate Emergency Response <small>Call 911. NEVER wait to give Epinephrine. Doctors and parents (as per action plan)</small> |
|---|--|

A.C.T. to prevent
Avoid Food Allergen
Ways to come in contact with allergen

Through the mouth Breathing in Touching the skin

Avoid Oral Exposure

- Each label on food should be read every time
- Understand labeling laws (FALCPA) and their limitations
- Avoid items with advisory statements (some exceptions)
- Be familiar with hidden ingredients



NIAID 5.1.5. Hefle et al. JACI 2007
Munoz-Furlong et al. Nutrition Guide To Food Allergies. FAAN. 2005





**A.C.T. to Prevent
COMMUNICATE**

- The child, all care givers, and food preparers must know about the allergy
- Have a means to contact emergency services
- Emergency identification jewelry is recommended


A.C.T. to prevent
Teach:
Parents/Children

- Age appropriate allergy management skills to give sense of control (routines, games)
- Practice scenarios (pros and cons)
- Prepare for new situations and places
- Assertiveness skills

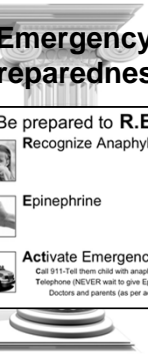
(Adapted with permission from slides of Jennifer LeBovidge, Ph.D.
Children's Hospital Boston)

Pillars of Food Allergy Management


Prevention





Emergency Preparedness



Be prepared to R.E.Act

Recognize Anaphylaxis


Epinephrine


Activate Emergency Response
Call 911- Tell them child with anaphylaxis
Telephone (NEVER wait to give Epinephrine)
Doctors and parents (as per action plan)


These must be applied at all times and in all settings

Be prepared to R.E.Act



Recognize Anaphylaxis



Epinephrine



Activate Emergency Response

Call 911-Tell them child with anaphylaxis
Telephone (NEVER wait to give Epinephrine)
Doctors and parents (as per action plan)



Food Allergy Management must be Implemented in all Settings



Home



School



Restaurants



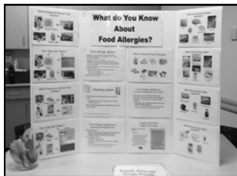
Parties and Play Dates



Alternative Care Givers

Patient/Family Educational Materials

- Appropriate reading level
- Appropriate language
- Train the trainer
- Evidence based when available
- Best practice



Patient/Family Educational Materials *Living Confidently with Food Allergy: A guide for parents and families*

- Two-year-long North American collaboration led by **Anaphylaxis Canada**; Spanish translation led by Allergy Asthma Network
- Free
- US and Canadian
- 5th-8th grade reading level
- Evidence based and best practice
- Tips to teach children
- English and Spanish (French pending)



- Designed to give parents the tools they need to keep their children with food allergies safe while addressing their emotional needs

Patient/Family Educational Materials Evaluating a handbook for parents of children with food allergy: a randomized clinical trial

Methods: 153 parents of children dg. with food allergy in the past 12 months and recruited from hospital-based allergy clinics and food allergy organizations. Randomly assigned to the handbook group (food allergy handbook after baseline survey) or at the control group (food allergy handbook at conclusion of study participation). Outcomes assessed using online surveys at baseline, 2-week follow-up, and 2-month follow-up.

- Results: Compared with controls, parents in the handbook group had:
- 1) significantly greater improvement in knowledge at the 2-week and 2-month follow-ups,
 - 2) significantly greater improvement in confidence at the 2-week and 2-month follow-ups, and
 - 3) significantly greater improvement in quality of life at the 2-month follow-up.

Parents reported satisfaction with the content the handbook.

Conclusions: The food allergy handbook evaluated in this study is an effective parent resource to supplement physician management of food allergy



Jennifer S. LeBovidge, PhD; Alexis Michaud, BA ; Ashley Deleon, BA ; Laurie Harada, BA, BEd; Susan Wasserman, MSc, MD; Lynda Schneider, MD. *Evaluating a handbook for parents of children with food allergy: a randomized clinical trial.* *Ann Allergy Asthma Immunol.* 2016 Mar;116(3):230-236.e1.

Patient/Family Educational Materials: Food Allergy & Anaphylaxis Emergency Care Plan



- Simplified criteria to identify potential allergic emergencies for use by patients, families, caregivers and school staff
- Accessible and understandable
- Strongly encourage submission to school/daycare
- Train families to use ECPs when they train others

NIAID 6.4.2.1.

www.AAAAI.org
www.foodallergy.org

Patient/Family Educational Materials: Auto-injector Trainers

- Anyone responsible for caring for a child with a potentially life threatening allergy should be trained using the specific trainer prescribed and get comfortable with use
- When developmentally appropriate children should practice with trainers as well



Other Members of your Healthcare Teams

- Utilize your staff
 - Hands on training prevention and emergency preparedness
 - Nurses , MAs, RDs, etc.
- Medical home concept reinforces the critical need for RNs to provide chronic disease management, care coordination, health risk appraisal, health promotion, and disease prevention services (American Academy of Ambulatory Care Nursing Position Paper)



School Nurses



- Critical players in school food allergy management
 - Implement and guide policy
 - Educate school community
 - Familiar with school resources and culture
 - Recognize and treat anaphylaxis
 - Create care plans (IHCP, 504 etc)
 - Serve as liaison to families
- Collaborators and partners
 - Work closely with physicians
 - Extend healthcare into the school day

Patient Advocacy and Local Support Groups

Attributes and views of families with food allergic children recruited from allergy clinics and from a consumer organization

Hu W1, Loblay R, Ziegler J, Kemp A. Pediatr Allergy Immunol. 2008 May;19(3):264-9. doi: 10.1111/j.1399-3038.2007.00644.x. Epub 2008 Jan 24.

- Parents valued consumer organizations as sources of practical information and emotional support
 - advice that did not acknowledge their individual circumstances and heightened anxiety from contact with other anxious parents were unhelpful.
- Hu and colleagues recommended to supplement the information and support provided by allergy clinics
 - "all parents should be given the opportunity to join a CO, with guidance from their clinician towards those aspects of membership which are most likely to be helpful."

Patient Advocacy and Local Support Groups

- Allergy & Asthma Network (Supporting Chapter Champions Program)
 - <http://www.allergyasthmanetwork.org/>
(free, printed resources)
- Asthma and Allergy Foundation of America/Kids With Food Allergies
 - <http://www.kidswithfoodallergies.org/>
- Food Allergy and Anaphylaxis Connection Team
 - <http://www.foodallergyawareness.org/>
- Food Allergy Research and Education
 - <https://www.foodallergy.org/>

Primary Care Team

- Develop a collaborative relationship with the referring provider
- Attempt to work in concert
 - Establish expectations as far as urgent issues, anticipatory guidance, school forms, etc.
- Offer expertise and guidance to assist primary care teams to implementing guidelines (e.g., NIAID, LEAP, etc.)

https://www.aap.org/en-us/Documents/practicesupport_lets_buddy_up.pdf
(NIAID 6.4.2.5)

Dieticians

- Nutrition counseling can help patients plan and consume an allergen-free and nutritionally adequate diet (NIAID Guidelines S.1.4.)



Mackenzie H, Grundy J, Glasbey G, Dean T, Venier C. Information and support from dietary consultation for mothers of children with food allergies. *Ann Allergy Asthma Immunol*. 2015 Jan;114(1):23-9. doi: 10.1016/j.anaai.2014.10.001. Epub 2014 Oct 25.

Flammarion S, Santos C, Guimber D, et al. A. Diet and nutritional status of children with food allergies. *Ped Allergy Immunol*. 2011;22(2): 161-165.

Nowak-Węgrzyn A¹, Groetch M. Nutritional aspects and diets in food allergy. *Chem Immunol Allergy*. 2015;101:209-20. doi: 10.1159/000373904. Epub 2015 May 21.



NIAID Guidelines for the Diagnosis and Management of Food

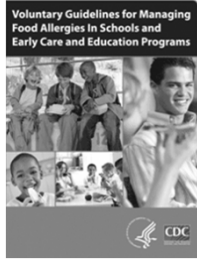


- NIAID collaboration to offer concise guidelines for healthcare professionals
- Recommendations on
 - Diagnosis
 - Testing
 - Management non-life-threatening allergic reactions
 - Diagnosis and management of food induced anaphylaxis
- Offered in full guidelines, summary for healthcare professionals and summary for parents and caregivers

<http://www.niaid.nih.gov/topics/foodallergy/clinical/Pages/default.aspx>

The Voluntary CDC Guidelines

- Guide schools and early care and education programs in the management of food allergies
- Contributions from experts experienced in school health and the management of food allergies and anaphylaxis
- Excellent foundation to implement Head Start center policies
- Allows for variation in implementation



Thank You!



Slides created by Michael Pistiner MD, MMSc and used for AAP/AAN Chapter Champion's Webinar: "Food Allergy: Epidemiology, Diagnosis and Management in the Medical Home" as well as AllergyHome educational material.

Making a Difference in Your Community



Who Are We?

"A patient-centered multidisciplinary network dedicated to ending needless death and suffering due to asthma, allergies and related conditions through outreach, education, advocacy and research."



Traditional System

- Fragmented care
- Reactive vs proactive
- Fee for Service --- volume based
- Significant disparities
- Substantial social determinants



Emerging System

- Collaborative, consistent care
- Proactive vs reactive
- Value based payment
- Coordination to link clinical, social, community orgs, public health & government programs
- Data sharing




Gaps in Understanding Remain

- Chronic conditions with serious risks
- We know what works
 - Diagnosis w/spirometry
 - Identification & avoidance of triggers
 - Good treatments
 - Monitoring tools
 - Prevention & preparedness
- Live symptom & fear free


2

Several key disconnects continue to exist...



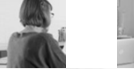
Patient perceptions of asthma control

- Subjective vs objective assessment
- Patient reality vs HCP expectations



Experience living with asthma

- Patients' attitudes about living with asthma vs limits to activities reported due to asthma symptoms



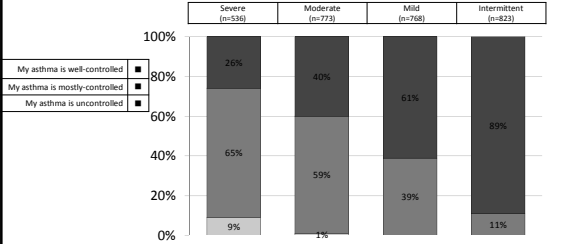
Varying accounts of office visit discussions

- HCP-reported vs patient-reported
- Specialist vs PCP perceptions of care

PR-ASTH-0027 74

The vast majority of patients believe they are well- or mostly-controlled, even among severe and moderate patients*.

Patients' Perceived Asthma Control by Severity*



| Severity | n | Well-controlled | Mostly-controlled | Uncontrolled |
|--------------|-----|-----------------|-------------------|--------------|
| Severe | 538 | 26% | 65% | 9% |
| Moderate | 773 | 40% | 59% | 1% |
| Mild | 768 | 61% | 39% | 0% |
| Intermittent | 823 | 89% | 11% | 0% |

*Among Total Patients
*Severity classified according to NAEPP Severity Assessment, based on answers to screener questions

PR-ASTH-0027

These patient-reported symptom frequencies far exceed HCP expectations.*

Mean # of Days with Symptoms in the Past 4 Weeks

| | Patient Self-Reported | | | HCP Perceptions of Their Patient Population* | | |
|---|---------------------------|-----------------------------|---------------------|--|-------------------|--------------|
| | Well Controlled (n=1,642) | Mostly Controlled (n=1,202) | Uncontrolled (n=56) | Well Controlled | Mostly Controlled | Uncontrolled |
| Wheezing | 3 | 9 | 17 | 1 | 4 | 9 |
| Coughing | 5 | 12 | 19 | 2 | 4 | 9 |
| Shortness of breath | 4 | 11 | 19 | 1 | 4 | 8 |
| Chest tightness (pain or pressure) | 2 | 6 | 15 | 1 | 3 | 8 |
| Daytime fatigue | 4 | 10 | 18 | 1 | 3 | 7 |
| Waking up in the middle of the night due to asthma symptoms | 1 | 5 | 12 | 1 | 3 | 7 |

Mean among Total Patients/Mean among Total HCPs
*Note: No known relationship between patients and HCPs surveyed

And when probed on specifics, patients reported asthma symptoms affected performing basic activities on a weekly basis.

Weekly Activity Impact - Unable to Perform/Somewhat Limited Summary -

| | Severe | Moderate | Mild | Intermittent |
|--|--------|----------|------|--------------|
| Physical Activities | | | | |
| Walking | 76% | 59% | 47% | 23% |
| Running | 93% | 86% | 82% | 60% |
| Swimming, hiking, skiing, organized sports | 85% | 75% | 66% | 40% |
| Household Chores | | | | |
| Light cleaning/dusting | 62% | 56% | 45% | 21% |
| Vacuuming | 66% | 53% | 41% | 21% |
| Family Obligations | | | | |
| Taking care of children | 54% | 35% | 20% | 9% |
| Playing with children indoors | 64% | 43% | 27% | 11% |
| Playing with children outdoors | 70% | 62% | 43% | 22% |
| Work/School | | | | |
| Productivity at work or school | 50% | 36% | 21% | 6% |
| Sufficient amount of sleep to feel rested for work or school | 68% | 61% | 41% | 17% |

The vast majority of patients (80%) reported experiencing asthma symptoms that affected at least one of these activities

Note: Activities <50% Shown
% Among Total Patients For Whom the Activity is Relevant
Floating Base Sizes (Not Relevant Excluded from Analysis)
Top 2 Box on a 4 Point Scale Where:
1 = Unable to Perform, 2 = Somewhat Limited, 3 = Not at All Limited, 4 = Not Relevant
*Severely classified according to NAEPP Severity Assessment, based on answers to screener questions

First off, it's important to know that patients are very satisfied with the HCP managing their asthma.

Overall Satisfaction with HCP Who Regularly Manages Asthma - Top 2 Box -

88% of patients are extremely/somewhat satisfied with the HCP who regularly manages their asthma



% Among Total Patients (n=2,900)
Top 2 Box on a 5 Point Scale Where 1=Extremely Dissatisfied and 5=Extremely Satisfied

During routine visits, fewer than half of moderate and severe patients say they always discuss symptoms; fewer than a third always discuss how asthma affects daily life and even fewer discuss an action plan.

Patient Reported Topics Discussed During Routine Visit with Managing HCPs in Past 12 Months - Top Box: Always -

| | Severe (n=483) | Moderate (n=702) | Mild (n=699) | Intermittent (n=726) |
|---|----------------|------------------|--------------|----------------------|
| Review your current medications | 65% | 61% | 61% | 64% |
| Symptoms | 44% | 37% | 31% | 31% |
| Talk about any recent asthma attacks | 33% | 31% | 26% | 25% |
| Steps to better control your symptoms | 28% | 24% | 19% | 16% |
| Limitations you're experiencing in daily life (examples: going to work, exercising, household chores, etc.) | 27% | 19% | 15% | 16% |
| Triggers/how to avoid to maintain better control | 21% | 19% | 14% | 12% |
| Lung function testing | 18% | 13% | 14% | 17% |
| Your personal asthma action plan | 17% | 16% | 13% | 13% |
| Spirometry tests | 17% | 15% | 14% | 17% |
| Peak flow meter testing | 16% | 16% | 16% | 16% |
| Fears or feelings you have associated with asthma | 13% | 10% | 4% | 5% |

Select Topics Shown
% Among Total Patients Who Saw HCP For Routine Visit
Top Box on a 4 Point Scale: Where
1= Never, 2= Sometimes, 3= Most of the Time and 4=Always
*Severity classified according to NAEPP Severity Assessment, based on answers to screener questions

While HCPs report regularly discussing a variety of topics, discussions about asthma's effect on patients' daily lives and action plans are less frequent.

HCP Reported Topics Discussed During Routine Visit in Past 12 Months - Top Box: Always -

| | Severe (n=859) | Moderate (n=859) | Mild (n=859) | Intermittent (n=859) |
|---|----------------|------------------|--------------|----------------------|
| Patient's current medications | 90% | 87% | 87% | 88% |
| Symptoms | 88% | 85% | 83% | 84% |
| Recent asthma attacks | 85% | 80% | 76% | 77% |
| Steps to better control symptoms | 77% | 67% | 59% | 58% |
| Patient's limitations (examples: going to work, exercising, household chores, etc.) | 76% | 64% | 55% | 53% |
| Asthma triggers | 76% | 68% | 58% | 52% |
| Patient's personal asthma action plan | 72% | 63% | 53% | 49% |
| Spirometry tests | 50% | 40% | 29% | 26% |
| Patient's fears or feelings associated with their asthma | 51% | 40% | 30% | 26% |
| Peak flow meter testing | 44% | 35% | 26% | 24% |
| Lung function testing | 46% | 37% | 27% | 23% |
| Fractional exhaled nitric oxide (FeNO) tests | 17% | 14% | 10% | 9% |

Select Topics Shown
% Among Total HCPs
Top Box on a 3 Point Scale: Where
1= Never, 2= Sometimes, But Not Every Visit, 3= Always

When we look at this HCP data by specialty, we do see specialists discussing asthma's effect on patients' daily lives more frequently than PCPs...

HCP Reported Topics Discussed During Routine Visit in Past 12 Months - Top Box: Always -

| | Severe (n=253) | | Moderate (n=253) | | Mild (n=253) | | Intermittent (n=253) | |
|---|---------------------|--------------|---------------------|--------------|---------------------|--------------|----------------------|--------------|
| | Specialists (n=253) | PCPs (n=259) | Specialists (n=253) | PCPs (n=259) | Specialists (n=253) | PCPs (n=259) | Specialists (n=253) | PCPs (n=259) |
| Patient's current medications | 91% | 90% | 89% | 86% | 89% | 85% | 90% | 87% |
| Symptoms | 91% | 85% | 90% | 82% | 89% | 78% | 91% | 78% |
| Recent asthma attacks | 87% | 84% | 84% | 77% | 80% | 72% | 82% | 75% |
| Steps to better control symptoms | 80% | 75% | 73% | 64% | 65% | 55% | 65% | 53% |
| Patient's limitations (examples: going to work, exercising, household chores, etc.) | 84% | 70% | 74% | 57% | 68% | 47% | 64% | 45% |
| Asthma triggers | 80% | 74% | 73% | 64% | 62% | 56% | 57% | 49% |
| Patient's personal asthma action plan | 73% | 72% | 65% | 61% | 54% | 52% | 51% | 48% |
| Spirometry tests | 66% | 39% | 60% | 26% | 49% | 15% | 44% | 13% |
| Patient's fears or feelings associated with their asthma | 56% | 48% | 43% | 38% | 38% | 25% | 30% | 23% |
| Peak flow meter testing | 43% | 44% | 40% | 31% | 33% | 22% | 29% | 20% |
| Lung function testing | 61% | 36% | 55% | 24% | 46% | 13% | 39% | 11% |
| Fractional exhaled nitric oxide (FeNO) tests | 24% | 12% | 20% | 10% | 15% | 7% | 13% | 7% |

Select Topics Shown
% Among Total HCPs
Top Box on a 3 Point Scale: Where
1= Never, 2= Sometimes, But Not Every Visit, 3= Always
Specialists = Allergists, Pulmonologists, PCPs = NPs, PAs, Pediatricians, PCPs

PR-ASTH-0027

81 HCPs

How do we address gaps?
Shared Decision Making

A collaborative process that allows patients and their providers to make health care decisions together, taking into account the best scientific evidence available, as well as the patient's values and preferences.

2

SHARE

- Seek patient participation & communicate options
- Help patient explore & compare options
- Assess patient values & preferences
What Matters Most?
- Reach a decision
- Evaluate the decision

2

Collaborative Care Teams

- Patients
- Caregivers
- Primary Care
- Subspecialty Care
- Allied Health
- Office Staff
- Payers
- Government/Policy makers

2

VIDEO

Still Have Work To Do....

"To end the needless death and suffering due to asthma, allergies and related conditions through outreach, education, advocacy and research."

12 Americans Die Daily

ENGAGE*EDUCATE***EMPOWER**
HOW? SHARE

10

ALLERGY STATISTICS

[HTTP://WWW.AAAAI.ORG/ABOUT-AAAAI/NEWSROOM/ALLERGY-STATISTICS](http://www.aaaai.org/about-aaaai/newsroom/allergy-statistics)

Allergic Rhinitis

- Roughly 7.8% of people 18 and over in the U.S. have hay fever.⁴
- In 2010, White children in the U.S. were more likely to have had hay fever (10%) than black children (7%).¹
- Worldwide, allergic rhinitis affects between 10% and 30 % of the population.³
- Worldwide, sensitization (IgE antibodies) to foreign proteins in the environment is present in up to 40% of the population.³
- In 2012, 7.5% or 17.6 million adults were diagnosed with hay fever in the past 12 months.⁵
- In 2012, 9.0% or 6.6 million children reported hay fever in the past 12 months.⁶
- In 2010, 11.1 million visits to physician offices resulted with a primary diagnosis of allergic rhinitis.⁷

Drug Allergy

- Worldwide, adverse drug reactions may affect up to 10% of the world's population and affect up to 20% of all hospitalized patients.³
- Worldwide, drugs may be responsible for up to 20% of fatalities due to anaphylaxis.³

Food Allergy

- Findings from a 2009 to 2010 study of 38,480 children (infant to 18) indicated:²
 - 8% have a food allergy
 - o Approximately 6% aged 0-2 years have a food allergy
 - o About 9% aged 3-5 years have a food allergy
 - o Nearly 8% aged 6-10 years have a food allergy
 - o Approximately 8% aged 11-13 years have a food allergy
 - o More than 8.5% aged 14-18 years have a food allergy

- 38.7% of food allergic children have a history of severe reactions
- 30.4% of food allergic children have multiple food allergies
- Of food allergic children, peanut is the most prevalent allergen, followed by milk and then shellfish
- In 2012, 5.6% or 4.1 million children reported food allergies in the past 12 months.⁶

General Allergy

- Worldwide, the rise in prevalence of allergic diseases has continued in the industrialized world for more than 50 years.³
- Worldwide, sensitization rates to one or more common allergens among school children are currently approaching 40%-50%.³
- In 2012, 10.6% or 7.8 million children reported respiratory allergies in the past 12 months.⁶

Insect Allergy

- Worldwide, in up to 50% of individuals who experience a fatal reaction there is no documented history of a previous systemic reaction.³

Sinusitis

- Roughly 13% of people 18 and over in the U.S. have sinusitis.⁴

Skin Allergy

- In 2010, Black children in the U.S. were more likely to have had skin allergies (17%) than white (12%) or Asian (10%) children.¹
- Worldwide, urticaria occurs with lifetime prevalence above 20%.³
- In 2012, 12.0% or 8.8 million children reported skin allergies in the past 12 months.⁶

References

1. Bloom B, Cohen RA, Freeman G. *Summary health statistics for U.S. children: National Health Interview Survey, 2010*. National Center for Health Statistics. Vital Health Stat 10(250). 2011.

2. Gupta, R, et al. The Prevalence, Severity and Distribution of Childhood Food Allergy in the United States. *Pediatrics*2011; 10.1542/ped.2011-0204.

3. World Health Organization. *White Book on Allergy 2011-2012 Executive Summary*. By Prof. Ruby Pawankar, MD, PhD, Prof. Giorgio Walker Canonica, MD, Prof. Stephen T. Holgate, BSc, MD, DSc, FMed Sci and Prof. Richard F. Lockey, MD.

4. *Summary Health Statistics for U.S. Adults: National Health Interview Survey, 2010*. By Jeannine S. Schiller, M.P.H., Jacqueline W. Lucas, M.P.H., Brian W. Ward, PhD and Jennifer A. Peregory, M.P.H., Division of Health Interview Statistics.

5. Summary Health Statistics for U.S. Adults: National Health Interview Survey, 2012, table 3, 4.

6. Summary Health Statistics for U.S. Children: National Health Interview Survey, 2012, table 2.

7. National Ambulatory Medical Care Survey: 2010 Summary Tables, table 13.

LAY ORGANIZATIONS

The AAAAI places a high value on its relationships with patient advocacy organizations in support of our mutual concern for the needs of people with allergy, asthma & immunologic disease and their families. In particular, the AAAAI has an ongoing relationship with a group of organizations with whom we partner on various projects as needs and opportunities arise. We encourage you to visit these organizations' websites for more information on their initiatives and missions.

ALLERGY & ASTHMA NETWORK

Allergy & Asthma Network is the leading nonprofit organization whose mission is to end the needless death and suffering due to asthma, allergies and related conditions through outreach, education, advocacy and research. Since 1985, we have helped thousands of individuals and families with practical, real-life tips and solutions.

8229 Boone Blvd., Suite 260

Vienna, VA 22182-2661

Phone: (800) 878-4403

Fax: (703) 288-5271

<http://www.allergyasthmanetwork.org>

AMERICAN LATEX ALLERGY ASSOCIATION

The mission of the American Latex Allergy Association is to create awareness of latex allergy through education and to provide support to individuals who have been diagnosed with latex allergy.

63334 Lohmann LN

Eastman, WI 54626

Phone: (608) 874-4044

Toll Free: (888) 972-5378

E-mail: alert@latexallergyresources.org

www.latexallergyresources.org

Follow us on Twitter and Facebook.

AMERICAN PARTNERSHIP FOR EOSINOPHILIC DISORDERS (APFED)

APFED is a non-profit organization dedicated to patients and their families coping with eosinophilic disorders. APFED strives to expand education, create awareness, and support research while promoting advocacy among its members.

P.O. Box 29545

Atlanta, GA 30359

Phone: (713) 493-7749

www.apfed.org

mail@apfed.org

ASTHMA & ALLERGY FOUNDATION OF AMERICA (AAFA)

AAFA is a not-for-profit, voluntary health organization dedicated to improving the quality of life for people with asthma and allergies and their caregivers through education, research and advocacy.

8201 Corporate Drive, Suite 1000

Landover, MD 20785

Phone: (800) 7-ASTHMA (800) 727-8462 or (202) 466-7643

Fax: (202) 466-8940

www.aafa.org

Alaska Chapter: www.aafaalaska.com

Greater Kansas City Chapter: www.aafakc.org

Maryland/Washington DC Chapter: www.aafa-md.org

Michigan Chapter: www.aafamich.org

New England Chapter: www.asthmaandallergies.org

St. Louis Chapter: www.aafastl.org

CAMPAIGN URGING RESEARCH FOR EOSINOPHILIC DISEASE (CURED)

It is the hope of CURED that we raise substantial funding, as well as, public awareness to aid in research for this complex disease. Presently, very little is known about Eosinophilic Disorder. It is our heart-felt belief and mission that CURED can make a difference for the individuals and their families who are touched by this disorder. Our ultimate goal is that everyone affected by this condition is CURED!

P.O. Box 32

Lincolnshire, IL 60069

Phone: (847) 361-3292

www.curedfoundation.org

ellyn@curedfoundation.org

Follow us on Facebook and Twitter

FOOD ALLERGY & ANAPHYLAXIS CONNECTION TEAM (FAACT)

FAACT's mission is to educate, advocate, and raise awareness for all individuals and families affected by food allergies and life-threatening anaphylaxis.

P.O. Box 511

West Chester, OH 45071

Phone: (513) 342-1293

Fax: (513) 342-1239

info@foodallergyawareness.org

www.foodallergyawareness.org

FOOD ALLERGY RESEARCH & EDUCATION (FARE)

FARE works on behalf of the 15 million Americans with food allergies, including all those at risk for life-threatening anaphylaxis. This potentially deadly disease affects 1 in every 13 children in the U.S. – or roughly two in every classroom. Formed in 2012 as a result of a merger between the Food Allergy & Anaphylaxis Network and the Food Allergy Initiative, FARE’s mission is to ensure the safety and inclusion of individuals with food allergies while relentlessly seeking a cure. We do this by providing evidence-based education and resources, undertaking advocacy at all levels of government, increasing awareness of food allergy as a serious public health issue and funding world-class research that advances treatment and understanding of food allergies.

FARE National Headquarters
7925 Jones Branch Drive, Suite 1100
McLean, VA 22102
Phone: (800) 929-4040
info@foodallergy.org
www.foodallergy.org

IMMUNE DEFICIENCY FOUNDATION (IDF)

The IDF is the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research.

110 West Road., Suite 300
Towson, MD 21204
Phone: (800) 296-4433 or (410) 321-6647
Fax: (410) 321-9165
www.primaryimmune.org

INTERNATIONAL FPIES ASSOCIATION (I-FPIES)

I-FPIES is a non-profit organization that funds research and provides education, support and advocacy for patients and families affected by Food Protein-Induced Enterocolitis (FPIES). We strive to bridge the gap between patient, family and physician while also bringing non-IgE allergies to the forefront of medical interest on par with IgE allergies. I-FPIES is the worldwide leader in resources and information for FPIES patients and families and is supported by a multi-disciplinary, international panel of Medical Advisors.

319 Richmond Avenue
Point Pleasant Beach, NJ 08742
www.fpies.org
contact@fpies.org

THE MASTOCYTOSIS SOCIETY (TMS)

TMS is a nonprofit organization dedicated to supporting patients affected by Mastocytosis/ Mast Cell Activation Disorders as well as their families, caregivers, and physicians/health care providers through research, education, and advocacy. TMS offers educational materials, a quarterly newsletter, a written resource guide for physicians/health care providers who need assistance in diagnosing a patient with a suspected mast cell disorder, an email list, and support groups. We hold an annual conference that includes a Walk-a-thon to raise funds for mast cell research and education, and is attended by patients and mast cell disease specialists.

The Mastocytosis Society, Inc.

P.O. Box 129

Hastings, NE 68902-0129

Phone: (508) 842-3080 or (952) 905-6778

Fax: (508) 842-2051

tmsbod@tmsforacure.org

www.tmsforacure.org

US HEREDITARY ANGIOEDEMA ASSOCIATION (HAEA)

The US HAEA is a non-profit patient advocacy and research organization. Our organization provides a wide range of patient services, educational programs and peer-to-peer support for patients with all forms of hereditary angioedema and their caregivers. We further advance our mission to help HAE patients achieve life-long health via our Scientific Registry – Patient Driven Research for a Cure.

The US Hereditary Angioedema Association

c/o Janet Long, Vice President

Seven Waterfront Plaza

500 Ala Mona Blvd., Suite 400

Honolulu, HI 96813

www.haea.org