



Allergy  
& Asthma  
NETWORK

The logo graphic for the Allergy & Asthma Network, featuring a stylized sunburst or flower-like shape composed of several yellow, teardrop-shaped petals radiating from the right side of the text.

2017  
Annual Report

**MISSION:** To end needless death and suffering due to asthma, allergies and related conditions through outreach, education, advocacy and research.





Allergy & Asthma Network is the leading national patient-centered nonprofit organization advocating on behalf of the 60 million Americans with allergies, asthma and related conditions. Founded by Nancy Sander in 1985, its mission remains the same: To end needless death and suffering due to asthma, allergies and related conditions through outreach, education, advocacy and research.

The Network takes a proactive and collaborative approach to developing quality asthma and allergy education, advocacy and community outreach programs.

The organization's patient-centered philosophy makes an empowering difference for individuals seeking asthma management advice in consumer-friendly language. From newsletters, magazines, websites and a support toll-free helpline, the Network speaks to patients' needs in a way that achieves quantitative and qualitative results. Through these services, the Network gets direct input about specific community needs.

The goal of the Network's strategic plan is to fulfill its mission by working with leading experts and building patient-centered collaborative care teams to achieve optimal health outcomes.

This report highlights the Network's 2017 programs, initiatives, partnerships, resources and other activities.

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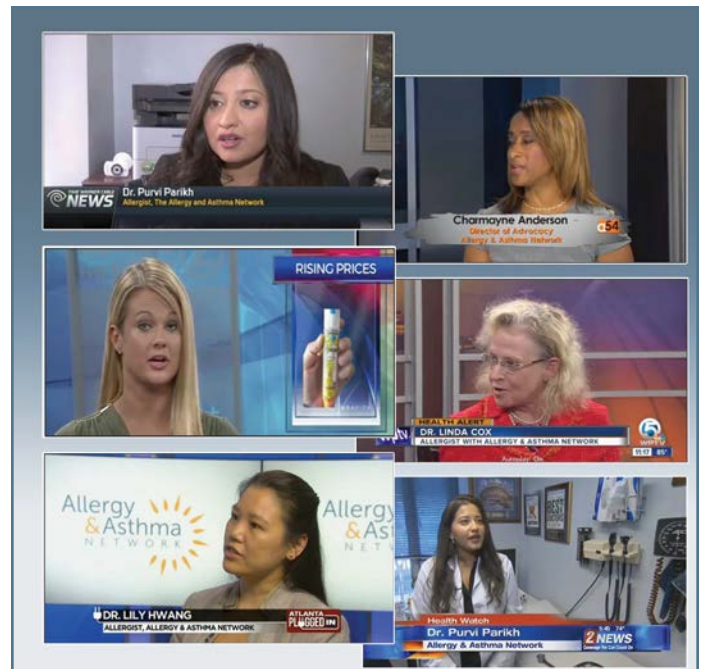
## MISSION AREA: OUTREACH

Allergy & Asthma Network reaches out to patients, families, caregivers, healthcare providers, industry partners and communities across the country to educate and expand awareness about allergies, asthma and related conditions. In 2017, the Network participated in over **40** outreach activities, attended **18** medical professional meetings and recruited more than **7,000** new members. The Network's public relations efforts achieved more than **800M** impressions in traditional and social media.



## MEMBERSHIP

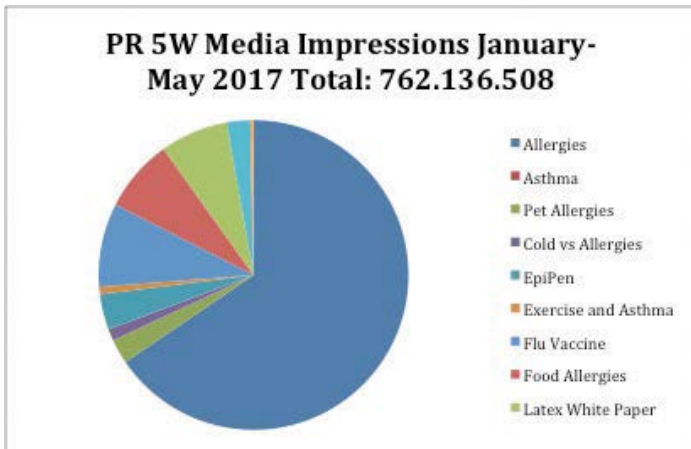
The Network has more than 2 million members, including patients, families and healthcare providers. Becoming a member is easy: individuals can join for free or pay an annual fee. All members have access to our toll-free helpline, monthly E-newsletter and all the Network's educational materials, including print and digital versions.



## PUBLIC RELATIONS

Allergy & Asthma Network works with 5W, a PR company located in New York, to raise awareness of the Network and asthma and allergies. To accomplish this goal, 5W uses media platforms including national and regional broadcasts, print and top online outlets on topics such as May's World Asthma Day and Food Allergy Awareness Week, among others. In addition, 5W connects with various regional and national allergists/immunologists regarding secured and potential opportunities and interviews.

In 2017, the Network was featured in **261** outlets totaling **762,136,508** impressions. "Allergies" was the topic with most impressions, followed by "Asthma," "Meat allergy" and "Pet allergies."



The Network's communications team writes press releases to inform patients and families about the latest trends in allergy and asthma care, important disease prevention policies, outreach and screening events, food and latex allergy safety tips and new mobile apps and digital tools to help improve asthma management, among others. To disseminate press releases, the staff uses PR Newswire, the Network's website and social media.

PR Newswire: 4 press releases. Total views and hits: **13,452**

Network website (<http://www.allergyasthmanetwork.org/category/press-page/>): 12 press releases. Total views and hits: **463**

## OUTREACH SERVICE COORDINATOR PROGRAM

Allergy & Asthma Network's national headquarters is in Vienna, Virginia, but its local presence depends on the community volunteers we call Outreach Service Coordinators (OSCs).

OSCs are moms, dads, grandparents, respiratory therapists, health care providers or whoever shares the same goal – educating their communities about asthma, allergies and related conditions.

OSCs represent the Network at local events and programs; distribute the Network's educational materials to schools, libraries, hospitals, free clinics or community health centers; participate in local and statewide asthma and allergy coalitions; give out information in health fairs and community events; and support the organization during exhibit time at professional meetings.

In 2017, the Network had **350** volunteers in **24** states.

## PATIENT OUTREACH



To increase outreach and engagement with patients, families and caregivers, the Network:

- Engages in social media activities
- Offers toll-free line (English and Spanish)
- Goes into local communities to conduct outreach and screening activities
- Provides educational materials to schools, hospitals, community centers and asthma camps
- Offers resources to help patients better control their disease
- Partners with different organizations to expand patient outreach



### Social Media

The Network uses social media (Facebook and Twitter) to increase outreach and engagement, informing followers on the latest asthma and allergy news as well as research studies and perspectives. Social media also allows the Network to receive valuable feedback on what patients and families are experiencing as they manage their condition.

Jan. 1, 2017 - Dec. 31, 2017

#### Twitter

- New followers: **750**
- Retweets: **1,392**
- Likes: **1,910**
- Impressions: **605,300**
- Link clicks: **1,365**
- Replies: **112**

#### Facebook

- Facebook: **1,579**
- Average reach per day: **2,512**
- Top video: Ask the Allergist – Pinpointing the Cause of Hives (with Chitra Dinakar, MD), **6,100** views
- Total Facebook Live views: **4,012**
- Top Facebook Live: Congressional Lunch Briefing Live at AADCH, **1,700** views
- Page reach: **894,272**
- Total video views: **31,378**



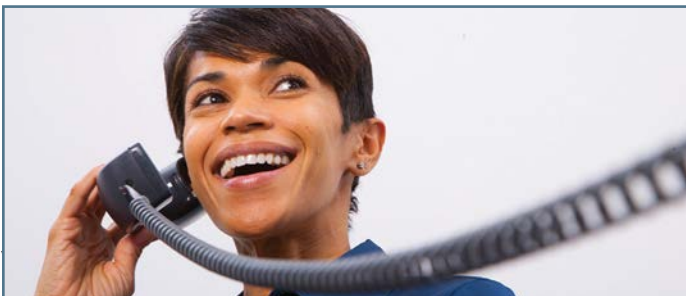
## Lifetime TV

In a “Balancing Act” video segment broadcast on Lifetime TV, Allergy & Asthma Network President/CEO Tonya Winders discussed how to be proactive with your doctor and better manage asthma, whether it’s mild, moderate or severe. In addition to appearing on Lifetime TV, the video was placed on Allergy & Asthma Network’s website, YouTube and Facebook page.

Website Page Views: **280**

YouTube Views: **275**

Facebook Views: **485**



## Contact Us & Helpline

The Network offers a direct line of communication for patients and families. This service has two components: a toll-free line (English and Spanish) and an online “Contact us” form. Both are managed by Network staff who provide answers and assistance to anyone with nonemergency questions about asthma, allergies, COPD, atopic dermatitis, anaphylaxis, medications, financial assistance, mold, tests and treatments, among others. In 2017, the Network received **1,200** calls and more than **190** e-mails. **250** of those communications were followed up with a free package of information.

## Outreach Activities

In 2017, the Network participated in more than 40 outreach activities, including health fairs, community events and asthma camps, and provided educational material for free distribution to schools nurses, respiratory therapists, state and local asthma programs, asthma coalitions and community health workers, among others. Examples include:



- Oklahoma, OK: Lung Health Experience (CHEST Foundation). OKC opened the streets of the city to vendors and had 45,000 people visiting booths and displays. The Network and CHEST conducted asthma and COPD screenings on almost **500** participants and provided educational resources on allergies and asthma.
- Nashville, TN: Lung Health Experience (CHEST Foundation). During the Country Music Awards (CMA) Festival, with more than 80,000 attendees each day, the Network and CHEST Foundation hosted a table and screened about **300** people for lung function and provided educational resources on allergies and asthma.
- Chicago, IL: Lung Health Experience (CHEST Foundation). During the Chicago Half-Marathon, the Network, CHEST and partners hosted a tent at the finish line and offered COPD and asthma screenings, reaching out to over **400** attendees. Each attendee also received educational material.
- Toronto, Canada: Lung Health Experience (CHEST Foundation). More than **300** people visited the Network and CHEST stand on Nathan Phillips Square to receive free lung screenings, interact with a Virtual Patient Tour and connect with local lung health experts.
- Charlotte, NC: Right2Breathe Event. The Network offered free respiratory spirometry tests to racing fans who attended the NHRA Four-Wide Nationals, held at Bruton Smith’s Z-Max Dragway. More than **450** attendees were screened and all received educational material.





- Orange Beach, AL: World Food Championships. Allergy & Asthma Network partnered with the World Food Championships to provide food allergy education and safety for restaurant owners, chefs, kitchen personnel and wait staff. The Network presented the Allergy Safe dining guide to more than **300** participants, along with other resources.
- Madison, WI: The Network participated as an exhibitor on the Out Run Asthma event, where more than **200** families walked to raise awareness of the disease.
- Fayetteville, SC: The Network participated in the Asthma Action Fair, which provides services for patients and families in Cumberland, Hoke, Bladen and Harnett counties. This event reached out to **250** patients and families looking for asthma education, resources, services and supplies.
- Upper Marlboro, MD: The Network partnered with Breathe DC to provide a bag with asthma educational material to **60 kids** attending Camp Breathe Happy asthma camp, just outside of Washington, DC.
- New York, NY: The Network sent educational material to a health fair at Bellevue Hospital, where **50+** families received information on allergies and asthma.
- Arlington, VA: The Network provided educational material for **100** Spanish-speaking families at the Community Health Fair hosted at the Cesar Chavez Community Center.
- Washington, DC: The Network sent educational material on allergies and asthma to **100** students at the SEED Public Charter School, as part of their annual Health Week.
- Milwaukee, WI: The Network sent **250** packages of information to a community outreach event organized by the Association of Asthma Educators.
- Woodbridge, VA: The Network sent educational material on allergies and asthma to the Marumscos Hills Elementary School Health. **150** families reached.

- San Francisco, CA: The Network participated in the Breathe California Health Fair and distributed education material to **150** families.
- Anderson, IN: The Network sent patient education materials (**100**) to the Aspire Indiana Health Center.
- Philadelphia, PA: The Network sent educational and promotional material to **150** families attending the Community Asthma Day - Asthma Day @ Nemours Pediatric Clinic.
- Kensington, MD: The Network supplied allergy and asthma educational materials for a "Healthy Room" at the Silver Creek Middle School (**100** copies each).
- Newark, NJ: The Network participated in a Health Community Event; **125** families attended and each received asthma and allergy educational materials.

## Hispanic Outreach Program

To fill the gap of education and asthma self-management resources among the Hispanic community, the Network developed the Hispanic Outreach Program. The goal is to empower and educate Spanish-speaking individuals, families and communities to achieve better health outcomes and live a more productive life.

This program offers publications, a website ([www.redalergiyasthma.org](http://www.redalergiyasthma.org)) and a toll-free line in Spanish. As part of a CDC cooperative agreement, in 2017 the Network promoted the use of an Asthma Action Plan in Spanish among Spanish-speaking parents. As part of these efforts, **50** organizations working with Hispanic/Latino families were reached, and **1,995** families received an Asthma Action Plan.

Total [www.redalergiyasthma.org](http://www.redalergiyasthma.org) website viewers: **61,500**.



## HealthUnlocked

The Network partnered with HealthUnlocked, a peer-to-peer support network in which patients, caregivers and health advocates connect safely online with guidance from credible organizations and institutions. The Network established

four online communities to allow people with asthma and allergies to engage and support each other while also learning evidence-based information about their disease. With more than 500 patient advocacy organizations on board, HealthUnlocked is the biggest network for advocates in the world.

### Asthma

<http://www.healthunlocked.com/USAsthma>

### Allergies

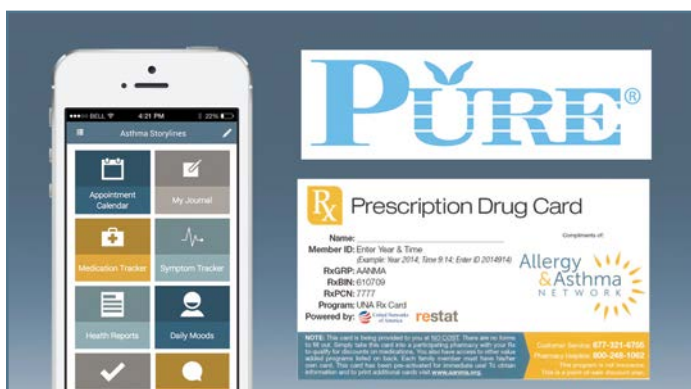
<http://www.healthunlocked.com/USAllergies>

### Anaphylaxis

<http://www.healthunlocked.com/USAnaphylaxis>

### Spanish Language

<https://healthunlocked.com/red-alergia-asma>



## Resources for patients

In 2017, the Network's online resources for patient education included:

- FREE Prescription Assistance Program
- \$0 Copay for Epinephrine Auto-Injectors
- Allergy-Friendly Hotel Rooms from PURE Rooms
- Find an Allergist: ACAAI
- iPhone Apps for Adolescents from the American Academy of Pediatrics
- FREE App: Asthma Storylines – A self-care tool for managing asthma
- Allergy Bedding – 15% discount on Allergy Guardian dust-mite encasings

## HEALTHCARE PROVIDERS OUTREACH

Allergy & Asthma Network reaches out to healthcare providers across the country to identify unmet asthma education needs for their patients and to share educational tools and resources. In 2017, the Network exhibited at 18 professional meetings and distributed more than 7,500 resources.

### 2017 Conferences & Events

- February: Pri Med South (Fort Lauderdale, FL)
- March: AAAAI (Atlanta, GA); World Spina Bifida (San Diego, CA)

- April: Louisiana Respiratory Society (New Orleans, LA); Texas Allergy Society (San Antonio, TX); North Carolina Allergy Society (Concord, NC)
- May: American Thoracic Society (Washington, DC)
- June: Eastern Allergy Society (Palm Beach, FL); California School Health Alliance (Long Beach, CA); NASN (San Diego, CA)
- July: AAE (Milwaukee, WI); AAPA-AAI; (New Orleans, LA July); NMA (Philadelphia, PA)
- September: Vermont/New Hampshire Society for Respiratory Care (Meredith, NH)
- October: AARC (Indianapolis, IN); Chest (Toronto, Canada); ACAAI (Boston, MA)
- November: World Food Championships (Orange Beach, AL)



## 2017 NATIONAL ASTHMA SUMMIT

On October 27, Allergy & Asthma Network – in partnership with the American College of Allergy, Asthma & Immunology – hosted the 2017 USAsthma Summit (Boston, MA). This one-day event brought together 75 healthcare professionals from across the United States (additionally, 139 people watched the Summit via livestream) with a total of 39 states represented.

The goal of this annual event is to bring together representatives from asthma coalitions, state asthma programs, federal agencies, including school nurses, community health workers and other stakeholders, to discuss current trends in asthma care and advocacy issues. Participants brainstormed strategies to advance the implementation of Guidelines-based care throughout the United States, presented findings, shared lessons learned and discussed best practices in allergy and asthma care.

Among the topics:

- Take Action on Asthma: Bringing Communities Together to Create Collective and Sustainable Resources
- Innovations in Asthma Care: Current Pulse on the State of Asthma in the United States
- Advocacy: Steps to Achieve Asthma Care for All (Update on policies affecting asthma care in the US)
- School-based Asthma Interventions Program – Lessons learned from the Student Asthma Research Team

- Federal Collaboration on Sustainable Financing for Asthma in-Home Interventions (panel discussion)
- Health Care Disparities and Asthma: Strategies YOU Can Use to Make a Difference in Underserved Communities
- When Asthma is Not “Just Asthma,” presented by Tonya Winders
- Updates from the National Asthma Control Program, presented by Cathy Bailey, PhD, CDC
- How to Build a Successful Integrated Asthma Care System



## PARTNERSHIPS

In 2017, the Network partnered with the following organizations to raise awareness and understanding of Guidelines-based care for people with allergies, asthma and related conditions:

- American College of Allergy, Asthma & Immunology (ACAAI)
- American College of CHEST Physicians (CHEST)
- American Academy of Allergy, Asthma & Immunology (AAAAI)
- American Thoracic Society (ATS)
- American Academy of Physician Assistants in Allergy, Asthma & Immunology (AAPA-AAI)
- National Association of Pediatric Nurse Practitioners (NAPNAP)
- American Academy of Pediatrics (AAP)
- American Association of Respiratory Care (AARC)
- Association of Asthma Educators (AAE)
- National Association of School Nurses (NASN)
- National Education Association (NEA)
- National Medical Association (NMA)
- Centers for Disease Control and Prevention (CDC)
- Food and Drug Administration (FDA)
- Environmental Protection Agency (EPA)
- Not One More Life
- Severe Asthma Foundation





## MISSION AREA: EDUCATION

In 2017, the Education team provided diverse, evidence-based programs and resources using different channels to empower people with allergies, asthma and related conditions to improve their health outcomes. We do this through a two-pronged approach of providing quality programming and meaningful Guidelines-based resources.



## PROGRAMS

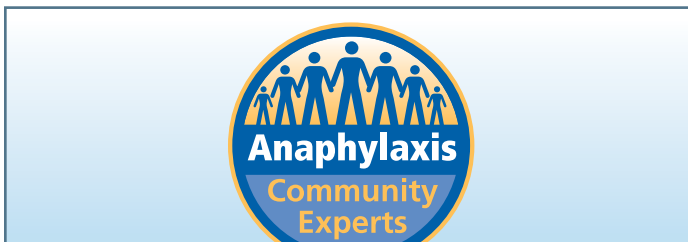
### Advances in Allergy & Asthma Monthly Webinar Series

Our monthly webinar series is designed to bring the latest Guidelines-based information to our wide range of stakeholders, including physicians, specialists, school nurses, respiratory therapists, families and patients. We invite nationally respected speakers to share their experience and expertise on a wide range of subjects.

In 2017, the Network reached a total of **6,831** individuals who listened to the webinars either live or recorded. Since the inception of this Webinar Series in March 2016, we have reached **12,758** healthcare professionals and patients.

- January** – “Allergy & Asthma Student Healthcare Plans – What Providers, School Nurses and Parents Want to Know,” Sally Schoessler, RN  
**1,110** Registrants – **452** Participants – **374** archived views
- February** – “Taking Control of Your Eczema,” Dr. John Lee  
**442** Registrants – **168** Participants – **645** archived views
- March** – “Taking a Pulse of Asthma in a 15-minute Office Visit,” Dr. Stephen Tilles  
**468** Registrants – **210** Participants – **248** archived views
- April** – “The Creation and Implementation of SAMPRO: A School-Based Asthma Management Program,” Dr. Robert Lemanske and Dr. Sujani Kakumanu  
**788** Registrants – **312** Participants – **122** archived views
- May** – “Stinging Insects: Worried?” Dr. James Tracy  
**471** Registrants – **200** Participants – **165** archived views
- June** – “Effective Patient Education,” Tonya Winders  
**338** Registrants – **180** Participants – **128** archived views
- July** – “Allergies & SLIT: Sublingual Immunotherapy,” Dr. Michael Blaiss  
**421** Registrants – **163** Participants – **145** archived views
- August** – “The Evolution of Food Allergy Therapy: Past, Present and Future,” Dr. Matthew Greenhawt  
**675** Registrants – **332** Participants – **109** archived views
- September** – “Asthma Vital Signs,” Dr. William Berger  
**404** Registrants – **186** Participants – **103** archived views
- October** – “Beyond the Gloves: The Latest on Latex Allergy,” Dr. Michael Zacharisen  
**376** Registrants – **148** Participants – **119** archived views

- **October** – “Allergy & Anaphylaxis in School Setting,” Nichole Bobo, RN and Sally Schoessler, RN  
**703** Registrants – **255** Participants – **252** archived views
- **November** – “The Asthma Yardstick: What it Means to Practitioners and Patients,” Dr. Bradley Chipps and Tonya Winders  
**675** Registrants – **308** Participants – **78** archived views
- **December** – “Chronic Urticaria: Antihistamines and Beyond,” Dr. Maeve O’Connor  
**484** Registrants – **211** Participants – **77** archived views



## Anaphylaxis Community Experts

The Anaphylaxis Community Experts (ACE) program is the foremost, comprehensive anaphylaxis education program in the United States. Its goal is to save lives by raising awareness of life-threatening allergies, equipping patients, parents, school staff, emergency responders and others with the skills to recognize and respond immediately to symptoms.

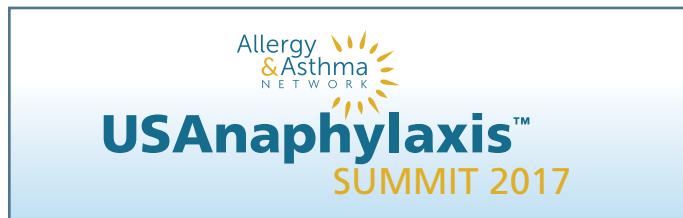
This program is comprised of volunteers, including healthcare providers (board-certified allergists, school nurses, pediatricians, nurse practitioners, respiratory therapists and asthma educators) and lay individuals, such as parents, school staff and marketing professionals.

### ACE achievements:

- The ACE program has **327** teams with **373** volunteers.
- The program spans **46** states.
- Volunteers conduct training and presentations during ACE workshops and community outreach
- Volunteers advocate for epinephrine policy across the U.S.

The Network supports the ACE program with the following:

- Updated website with forms, resources and educational information
- Webinars –
  - o “Stinging Insects – Worried?” with Dr. James Tracy
  - o “You Need 2 Epinephrine Auto-injectors” – with Sally Schoessler and Sue Lockwood
- Infographic – “You Need 2” – The Need for 2 Epinephrine Auto-injectors
- Monthly Newsletters – delivered digitally
- Latex Allergy Resources
  - o Web-based tool kit
  - o Poster
  - o Webinar – “Beyond the Gloves: The Latest on Latex” with Dr. Michael Zacharisen
  - o Social Media posts



## USAnaphylaxis™ Summits 2017

September 15, 2017, at the Gaylord National Resort and Conference Center, National Harbor, MD

For the 5th Annual USAnaphylaxis Summit, the Network invited key opinion leaders to present and discuss important topics related to anaphylaxis and epinephrine. The result of the Summit will be a published journal article in the *Annals of Allergy, Asthma & Immunology*. The article is titled “Current Trends in Anaphylaxis Management in School” and is authored by Matthew Greenhawt, MD.

### Topics:

- Overview & Prevalence of Anaphylaxis
- School Epinephrine Administration Overview
- Epinephrine First, Epinephrine FAST
- Emergency Care of Anaphylaxis
- A Look at Latex
- History and Current State of Legislation
- School Policies
- Epinephrine Administration Date from the EpiPen4Schools Program
- School Issues – Successes & Barriers
- Stock Epinephrine Policies & Protocols
- Developmental & Psychological Concerns for Students
- Positive Outcomes Associated with Stock Epinephrine

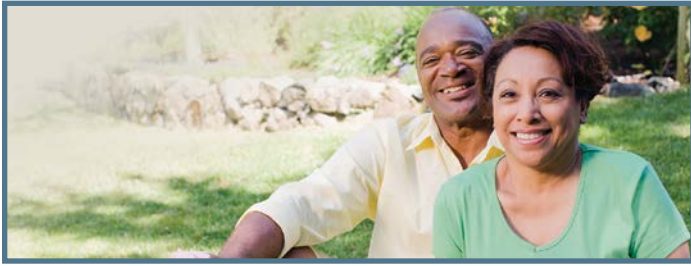
## Latex Allergy Awareness Week

The Network staff led 2017 Latex Allergy Awareness Week. The theme was “Beyond the Gloves – the Latest in Latex Allergy.”

Activities to promote awareness of latex allergy included:

- “Beyond the Gloves” poster
- Webinar with Dr. Michael Zacharisen
- Social media posts (Facebook, Twitter, LinkedIn)
- Support to volunteers seeking governmental proclamations





## Asthma: Take Action, Take Control

A national awareness campaign supported by the Network and CHEST Foundation that involved a multichannel approach based on printed and online publications, social media and PR efforts.

Goal: Provide education to patients, caregivers, families and community members about the most current treatment options for asthma; highlight the importance of referral to specialists; increase awareness and education on the difference between true impairment vs. perceived impairment; and ensure that both patients and providers are working better together to alleviate symptoms and improve health outcomes.

### Achievements:

#### Social Media

- Facebook – More than **20** posts, **30,650** impressions, **198** shares, **290** likes
- Twitter – **35** posts, **24,030** impressions **49** retweets, **72** likes

#### Allergy & Asthma Today

Distribution: **130,000** (including doctor office waiting rooms)

Estimated Readership: **2.1** million

#### Selected content

- “Innovations In Asthma Care: The Emergence of Biologics,” Spring/Summer issue
- “How the Asthma Yardstick Measures Up,” Spring/Summer issue
- “One Deep Breath: A Simple Lesson On Inhaler Technique Helped Save a Girl’s Life,” Fall/Winter issue
- “Breathing Easy On and Off the Court: Richard Jefferson Q&A,” Fall/Winter issue

#### Website

##### Selected Content

- Ask the Allergist: How do Biologics Work? • **502** page views + **1,400** video views on Facebook
- Breathing Easy On and Off the Basketball Court: Richard Jefferson Q&A • **519** page views
- Video Blog: In Case of Asthma Emergency • **92** page views + **1,500** video views on Facebook
- How the New Asthma Yardstick Measures Up • **790** page views
- Ask the Allergist: Managing Stress and Asthma at School • **51** page views, 68 YouTube views + **472** video views on Facebook
- Ask the Allergist: When to Step Down Asthma Medications • **319** page views, **157** YouTube views + **435** video views on Facebook

- Asthma Impacts Quality of Life: Global Data • **363** page views + **455** video views on Facebook

#### E-newsletter

##### Monthly

- **14** total severe asthma posts
- **2,822** total clicks

#### Webinars

##### Severe asthma content

- “Asthma Yardstick: What It Means to Providers and Patients,” Bradley Chipps, MD, November 2017  
**675** Registered, **308** Participated, **78** YouTube views
- “Asthma Vital Signs,” William Berger, MD, September 2017  
**675** Registered, **332** Participated, **109** YouTube views
- “Taking the Pulse of Asthma In a 15-Minute Office Visit,” Stephen Tilles, MD, March 2017  
**468** Registered, **210** Participated, **248** YouTube views

#### PR Placement

##### Press Release

- ‘Still Fighting for Breath’ Global Data Reveals Asthma Significantly Impacts Quality of Life, Sept. 12, 2017



## School Asthma Management Program

Goal: To increase percentage of students with Asthma Action Plans and access to emergency asthma medication at school, and enhance school personnel understanding of NAEPP standards.

### Achievements:

- Supported use of standardized asthma action plan via professional medical societies (AAP, AAAAI, ACAAI, AAFP, others) and raise awareness via PR campaign.
- Crafted strategy to work alongside patient and physician advocates and educate state legislators on the need for stock albuterol.
- Developed Infographic:
  - “Stock Albuterol is Critical for Asthma Emergencies,” **251** views
- Presented a webinar that supported the use of the SAMPRO Asthma Action Plan:
  - “The Creation and Implementation of SAMPRO: A School-based Asthma Management Program,” **788** Registered, **312** Participated, **122** YouTube views
- Collaborated on legislative goals on stock albuterol and standardized asthma action plans.
  - Met with members of the **Congressional Asthma & Allergy Caucus to support HR 4662 (SAMPRO).**
  - **Conducted Allergy & Asthma Day Capitol Hill visits** and briefing on SAMPRO to advance HR 4662.

- Updated educational toolkit and online learning module to enhance understanding of NAEPP guidelines among school personnel:
  - Resources promoted across multichannel platforms and amplified by partnership organizations.



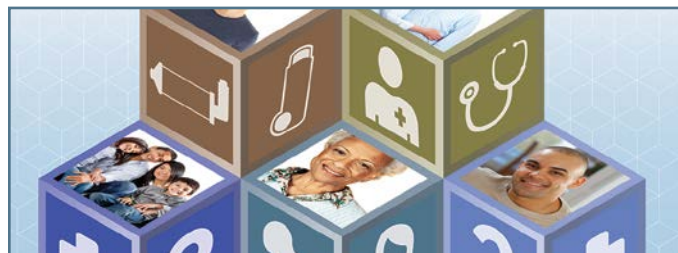
## Chronic Idiopathic Urticaria (CIU) Awareness Campaign

An ongoing campaign designed to raise awareness of this challenging medical condition and to help patients recognize symptoms, know where to turn for help and better understand treatment options.

### Achievements:

Leveraged a multichannel approach via social media, print, traditional media and digital media to raise awareness of CIU:

- Webinar: "Chronic Urticaria: Antihistamines and Beyond" – December 2017  
**484** Registered, **211** Participated, **77** YouTube views
- Ask the Allergist – "Can You Really Be Allergic to the Cold?" – **609** views (posted 12/14/16)
- Ask the Allergist: Pinpointing the Cause of Hives – **164** views **+6109** views on Facebook
- Chronic Urticaria's Impact on Quality of Life – **251** website views
- Ask the Allergist: Hives That Keep Coming Back- **373** website views
- Facebook: **19,133** impressions, Shares: **22**, Likes: **90**
- Twitter: **1034** impressions, Retweets: **8**, Likes: **18**
- Print – AAT article – "Can You Really Be Allergic to Cold?" - reach **2M** readers
- Provide support via HelpLine to patients and caregivers and guide them to credible, reliable sources. More than **1,500** calls.



## Building Blocks for Better Breathing: A Comprehensive Approach to Promote Quality Care for Asthma According to NAEPP Guidelines

A 5-year cooperative agreement with the Centers for Disease Control and Prevention (CDC).

### Goals:

- Lead a national coalition of partners, asthma state programs and other stakeholders to discuss current trends in asthma care and advocacy issues, and brainstorm strategies to advance the implementation of Guidelines-based asthma care throughout the U.S.
- Increase collaboration activities with CDC-funded state asthma programs to support state plan implementation.
- Conduct national communication and education strategies to strengthen the demand for Guidelines-based asthma care and asthma-friendly environments in the U.S. using a multichannel approach
- Eliminate health disparities in asthma management among Hispanic/Latino communities through distribution of educational material in Spanish and promotion of Asthma Action Plan in Spanish.

### Deliverables

- More than **2,500** educational materials distributed for patient education and CHW trainings
- More than **3,000** Respiratory Inhaler posters distributed among states
- Monthly E-newsletter
- Monthly webinar invitations
- More than **1,200** Educational material in Spanish distributed
- Website – [www.redalergiyasma.org](http://www.redalergiyasma.org). Updated with new pages
- Contacted more than **50** organizations working with Hispanic families to secure commitment for distribution of resources
- Distributed **900** hard copies of Asthma Action Plan (English/Spanish) to primary care health centers in CA, NM, FL, TX, CO (high Hispanic asthma populations)
- Distributed material in health fairs (San Francisco Bay Area) – **75** families reached
- Uploaded Asthma Action Plan to [www.redalergiyasma.org](http://www.redalergiyasma.org) and promoted via email
- Promoted SAMPRO toolkit
- **20** Scholarships sent awarded to 2017 USAsthma Summit

## RESOURCES



## EDUCATIONAL PRESENTATIONS

The Network presented at **15** national and statewide conferences to a variety of audiences:

- South Carolina School Nurse Education Day – “Managing Allergies & Anaphylaxis Reactions in the School Setting”
- North Carolina Allergy & Asthma Society – “Update on Advocacy Issues”
- American Academy of Allergy, Asthma & Immunology Poster Presentations – “Decision Mapping” and “The Pharmacist’s Voice in the Collaborative Care of Patients with Asthma”
- Louisiana Society for Respiratory Care – “Shared Decision Making in Respiratory Care”
- Biohealth Capitol Region Summit – Patient Advocacy Panel
- Atlantic Air Summit – “How Climate Impacts Respiratory Patients”
- Texas Allergy, Asthma and Immunology Society – “Patient Education & Advocacy: Making a Difference”
- FDA PRO Consortium – “Patient Engagement in Research & Development”
- American Thoracic Society – “Promoting Access to Guidelines-Based Care for People with Asthma”
- National Association of School Nurses – “Food Allergy Trends in Research & Resources”
- Kentucky School Nurses Conference – “Asthma Management at School”
- Association of Asthma Educators - “Shared Decision Making in Severe Asthma”
- American Academy of Physician Assistants in Allergy, Asthma and Immunology – “Effective Patient Education in Respiratory Care”
- CHEST – “Shared Decision Making in Severe Asthma”
- Vermont/New Hampshire Society for Respiratory Care – “Shared Decision Making in Respiratory Care”
- Texas Respiratory Care Society – “Shared Decision Making in Severe Asthma”

## Allergy & Asthma Today Magazine

The Network’s award-winning magazine is distributed twice a year to patients, families, community health workers, decision makers and health care providers across the country. More than **260,000** copies of the magazine were distributed in 2017, with an estimate of **2.1 million** readers per issue.

Articles span the breadth of allergy and asthma topics. Major stories in 2017:

- *Innovations in Asthma Care*
- *What You Can Do About Climate Change*
- *Power of Deduction: Food Allergy Tax Breaks*
- *Breathing Easy On and Off the Court with NBA Star Richard Jefferson*
- *Oral Food Challenges: What Parents Need to Know*
- *How Access to Healthy Food Impacts Asthma*



## AllergyAsthmaNetwork.org Website

The Network’s website serves as a clearinghouse of news and information for each of the four mission areas. It includes updates on our outreach programs, events and special offers, comprehensive educational pages for asthma, environmental allergies, food allergies, anaphylaxis and related conditions, and detailed information on our advocacy issues and research programs. The website also is an entry point to our Online Store

for orders of posters, magazines and more.

Jan. 1, 2017 – Dec. 31, 2017

Unique Visitors: **106,252**

Total Page Views: **371,723**

Biggest Day of Traffic: January 6, 2018 – **1,633** users and **3,703** page views (peanut allergy guidelines released)

Top Website Landing Page Views:

- Homepage: **47,571**
- Patients: **16,333**
- Professionals: **16,154**
- Store: **13,000**

Top Inside Page Views

- Education: **6,329**
- Education/asthma: **5,623**
- Education/webinars: **4,784**
- School Guide for Allergy and Anaphylaxis: **4,664**

Top 4 News Story Page Views:

- New Peanut Allergy Guidelines Hold Great Promise: **3,098**
- 5 Myths About Spring Allergies: **1,816**
- Can Poinsettia Plants Cause Latex Allergy Reactions? **1,700**
- Power of Deduction: Food Allergy Tax Breaks: **1,608**
- Use Expired Meds? High Risk for Asthma, Severe Allergy Patients: **1,477**

- *Choosing a Preschool*
- *Managing Asthma at School*
- *Eczema: A Struggle to Sleep*
- *A Peanut Allergy Cure?*



## Special Edition Magazines

*Understanding Asthma* (English and Spanish) – **More than 7,500 distributed**

Sections include:

- What is Asthma?
- Treatment and Medications
- Additional Resources
- Diagnosis
- Managing Your Condition

*Understanding Anaphylaxis* (English and Spanish) – **More than 4,500 distributed**

Sections include:

- What is Anaphylaxis?
- Insect Venom Allergy
- Latex Allergy
- Exercise
- Education & Advocacy
- Food Allergy
- Idiopathic
- Medication
- Treatment
- Additional Resources

*Understanding Allergies* (English and Spanish) – **More than 3,500 distributed**

Sections include:

- Allergy Defined
- Treatment & Medications
- Additional Resources
- Symptoms & Diagnosis
- Managing Your Allergies



## eNewsletter

The Network's electronic monthly newsletter includes the latest news in allergy, asthma and related conditions. This platform allows the Network to meet the changing clinical information and address important issues in the media.

**22,000** stakeholders reached per issue with an open rate of over **20%**.

Topics included:

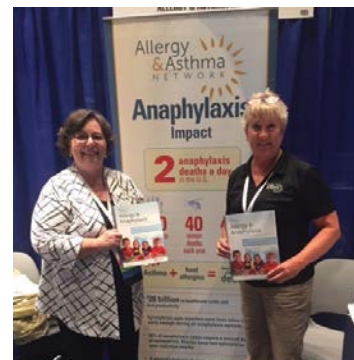
- *Restaurants and Food Allergies*
- *Poinsettias and Latex Allergy*
- *When Traveling Abroad*
- *How Smoking Bans Help*
- *How Do Biologics Work?*
- *Vaccinations and Food Allergies*
- *When to Step Down Asthma Meds*

## Special Interest Guides

*Allergy & Anaphylaxis: A Practical Guide for Schools and Families* – More than **925** distributed with **171**

bonus sections downloaded. Children and youth with severe allergies require a coordinated and collaborative plan to help them avoid anaphylaxis at school. This is an informational and educational guidebook to advise parents, school nurses and staff on how to help at-risk students stay safe at school.

Children and youth with severe allergies require a coordinated and collaborative plan to help them avoid anaphylaxis at school. This is an informational and educational guidebook to advise parents, school nurses and staff on how to help at-risk students stay safe at school.



The guide for schools was highlighted at the National Association of School Nurses conference where it was featured in a presentation for school nurses titled *Food Allergy – Trends in Research and Resources*. Presenters for this breakout session: Michael Pistiner, MD and Sally Schoessler, RN.

*Allergy-Safe Dining* – More than **200** distributed with **13** bonus sections downloaded

Allergy & Asthma Network's *Allergy-Safe Dining: A Guide for the Restaurant and Food Service Industry*, is designed to help restaurant owners, managers, wait staff, hosts, chefs and kitchen staff better understand and address food and latex allergies.

The restaurant guide was distributed as a part of Allergy & Asthma Network's participation in the World Food Championships 2017, the largest food competition among the world's best chefs. A symposium, "Addressing Allergies in Food Service," focused on food allergy awareness, allergen substitutions in recipes and avoiding cross contamination in the kitchen, as well as the psychosocial impact of life-threatening allergies.

The program was moderated by Tonya Winders, President & CEO of the Network, and included presentations from celebrity chef Elizabeth Falkner and Drs. Ruchi Gupta and Michael Pistiner. Falkner is an accomplished chef and cookbook author, and has appeared on numerous TV cooking shows such as "Iron Chef," "Top Chef," and "Food Network Challenge." Dr. Gupta is an associate professor of pediatrics and food allergy researcher at Northwestern Medicine and Ann and Robert H. Lurie Children's Hospital of Chicago. Dr. Pistiner is a pediatric allergist and director of food allergy advocacy, education and prevention of the Food Allergy Center at Mass General Hospital for Children.



## Posters

One of the Network's most unique and requested tools from healthcare providers for patient education:

- **Respiratory Inhalers at a Glance (English and Spanish):** More than **1,500,000** posters distributed. Updated periodically, provides a visual description of inhalers organized by category (short-acting beta2-agonist bronchodilators, long-acting beta2-agonist bronchodilators, inhaled corticosteroids, combination

medications and muscarinic antagonist). Latest version includes Biologics and Bronchial Thermoplasty.

- **Anaphylaxis at a Glance:** More than **2,000** posters distributed. Helps patients and parents identify allergens that can set off a life-threatening allergic reaction, anaphylaxis symptoms, and what to do in case of an emergency. Medically accurate and engaging, this colorful poster is also use at school clinics and emergency rooms for easy reference and patient education.
- **Nasal Sprays:** More than **1,000** posters distributed. Side-by-side guide to antihistamine, anticholinergic and corticosteroid nasal sprays for the treatment of allergic and non-allergic rhinitis, including new non-aqueous aerosols and OTC nasal corticosteroids. Helps patients identify their medications and understand priming and use instructions.
- **Respiratory Inhalers Side by Side:** More than **2,500** distributed. Offers medical professionals factual information at-a-glance for clinical staff reference and patient education, covering active and inactive ingredients, age indication, priming, shaking, cleaning and more.



## Infographics

Graphical depictions of important health issues related to allergies and asthma have an impact on awareness and education. The Network developed several infographics in 2017, including the following:

- Go Generic
- Stock Albuterol is Critical for Asthma Emergencies
- Are You Ready?
- The Effects of Smoking on your Body
- EpiPen4Schools Program Fast Facts
- You Need 2

## Asthma Storylines App

Powered by Health Storylines™, Asthma Storylines is a self-care app for managing asthma. It provides an accurate, shareable record of the asthma experience between physician visits, and helps patients and their care team to collaborate on treatment strategies. More than **2,000** patients are using the app.

The health tool enables the patient:

- TRACK symptoms, vitals, moods, and daily asthma control
- RECORD questions for a healthcare provider
- REMEMBER appointments and to take medications on time
- JOURNAL about asthma and other aspects of daily living
- LEARN more about yourself as you see your health story unfold
- CONNECT with a circle of support, share your health story, and receive messages of encouragement



## Video Blogs

Allergy & Asthma Network is committed to connecting with patients and provider through a multichannel approach that includes video blogs. Each week, we post a video blog (a 1-6 minute video presentation), either produced by the Network and our stakeholders or presented in collaboration with partners. Our top three video blogs for each category are listed below with their reach to our stakeholders:

### A Day in the Life of a Network Family

- Amanda Eisen – Planning a Stress-Free Vacation – **357** page views **240** YouTube views (not posted to FB)
- Stephanie Lowe – Asthma Action Plans – **152** page views **212** YouTube views (not posted to FB)
- Andrea Jensen – What to Do When Your Child is Hospitalized – **92** page views **120** YouTube views, **1,500** Facebook views

### Ask the Allergist

- Dr. Katial – How Do Biologics Work? - **502** page views **259** YouTube views, **1,400** Facebook views
- Dr. Wang – Evaluating the Potential of Oral Immunotherapy, Peanut Patch - **617** page views, **333** YouTube views, **728** Facebook views
- Dr. Dinakar – Pinpointing the Cause of Hives - **424** page views **187** YouTube views, **6,100** Facebook views

### Navigating Healthcare

- Alliance for Patient Access – Understanding Non-Medical Switching – **44** page views, **15,760** YouTube views
- Alliance for Patient Access – Increasing Access to Asthma Medications – **153** page views, **4,335** YouTube views
- Alliance for Patient Access – Prescription Medications & Value-based Contracting – **13** page views, **3,698** YouTube views

## Vivacare Collaboration

Allergy & Asthma Network partnered with Vivacare to provide quality, Guidelines-based resources in an online format for healthcare providers to utilize in patient education. The Allergy & Asthma Education Kit contains a library of 75+ patient education titles from the Network that providers can print, display on their website, and distribute via a mobile app. Currently, more than **500** practices are utilizing these tools.

## Articles to National Publications

The Network provides articles to key publications upon request. Examples from 2017:

### US News and World Report

- A monthly column for publication online, authored by Purvi Parikh, MD.
  - Identifying Eczema: 6 Common Triggers (November 2017)
  - 4 Steps for a Successful Telehealth Appointment (October 2017)
  - Food Allergy Symptoms: Mild vs. Serious (September 2017)
  - These Health Clinics in Zambia Give Children Life-Saving Vaccines
  - Treating the Flu: Answering Frequently Asked Questions (January 2017)

### NASN School Nurse

- To Give Epinephrine or Not to Give Epinephrine – That is (No Longer) the Question! (February 2017)
- Latex Safe at School: A Student-Centered Approach (October 2017)





# MISSION AREA: ADVOCACY

Allergy & Asthma Network raises public awareness and educates policy makers about the importance of smart and effective policies and programs to end the needless death and suffering of the millions of Americans living with asthma, allergies and related conditions. Together with patients, families, healthcare professionals and industry partners, the Network made substantial progress in 2017 toward its advocacy goals by amplifying the patient voice, building capacity and making connections in Washington, D.C. and in communities nationwide.

## AMPLIFY PATIENT VOICE



### Allergy & Asthma Day Capitol Hill (AADCH)

Allergy & Asthma Day Capitol Hill (AADCH) is an annual event in May that brings together patients and their families, along with healthcare professionals, industry partners and stakeholder groups, to raise awareness of asthma and allergies. AADCH gives attendees a chance to meet with their Members of Congress and take part in federal advocacy – a critical component in our work.



The 20th Annual AADCH held May 7, 2017, was a great success with more than **100** participants visiting members of Congress or their legislative staff. AADCH also welcomed the participation of members from the Congressional Asthma & Allergy Caucus, as well as key staff from the U.S. Department of Health and Human Services (HHS) and the Environmental Protection Agency (EPA).

Our 2017 policy priorities focused on ensuring access to care, asthma management in schools, expansion of telehealth services, step therapy, research funding, and the USP Pharmaceutical Compounding Revised Guidelines.

## POLICY AND OUTREACH



### FEDERAL

The Network aggressively worked to achieve its federal advocacy goals and objectives through meetings on the Hill, grassroots campaigns via letter writing/emails/phone calls, social media outreach, delivery of comprehensive information to key decision-makers, and collaborations with other stakeholder groups.

During the first session of the 115th Congress, the Network weighed in on legislative measures and regulatory proposals in the interest of patients and families living with asthma and allergies in line with our key policy priorities, which included:

- Safe, effective and affordable medicines
- Affordable and high-quality healthcare and insurance coverage
- Nurses in all K-12 public schools
- Adequate funding for asthma health and research programs
- Access to innovative therapies and technologies to advance medical treatment
- Mitigate environmental health hazards and address climate change
- End health disparities and move toward greater health equity

Among key legislative measures the Network monitored and weighed in on included:

- *H.R. 2285, the School-Based Respiratory Health Management Act*, which gives grants preference to states that implement comprehensive school-based reversible lower airway disorders (e.g., asthma) and allergy management programs, including student action plans and education and training for school staff to administer asthma- and allergy-related medications in an emergency.
- *H.R. 2550, the Medicare Telehealth Parity Act*, which provides for an incremental expansion of telehealth coverage under Medicare and includes respiratory therapists (RT), among other medical specialists, as qualified telehealth providers. Respiratory care services and remote patient monitoring for patients with certain chronic health conditions including COPD would also be covered. Expansion of telehealth would be an effective way for RTs to provide patients with education and improved management of their condition.
- *H.R. 2077, the Restoring the Patient's Voice Act of 2017*, which provides a clear and transparent process to seek exceptions and approvals for medications subject to step therapy review by health insurance plans, and establishes a reasonable and clear timeframe for override decisions.
- Funding for the U.S. Department of Health and Human Services and the U.S. Environmental Protection Agency programs that support patients with chronic illness (e.g., asthma and severe allergies). Funds are used for data tracking, community outreach and education, and research.
- Funding for the Children's Health Insurance Program (CHIP), which has been an essential source of children's health coverage, ensuring access to high-quality, affordable healthcare for approximately 8.9 million children in working families whose parents earn too much to qualify for Medicaid but too little to purchase private health insurance on their own.

Key federal regulatory matters the Network engaged in included:

## EPA

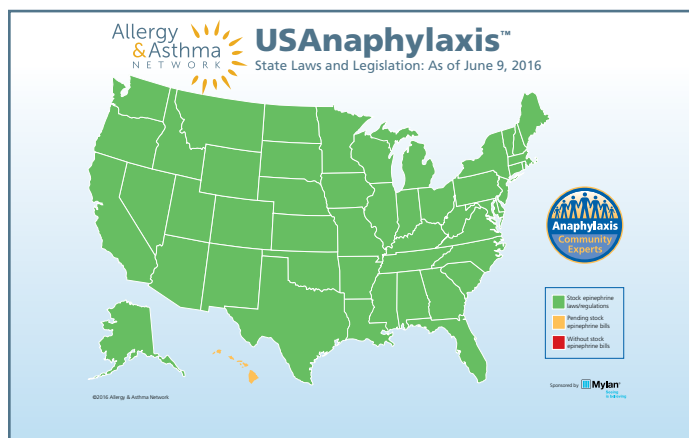
- Implementation for the 2015 National Ambient Air Quality Standards for Ozone: Nonattainment Area Classification and State Implementation Plan Requirements
- Carbon Pollution Emission Guidelines for Existing Stationary Sources: Electric Utility Generating Units
- Emissions Standards for New, Reconstructed, and Modified Sources in the Oil and Natural Gas Sector
- Revision to the Near-Road NO<sub>2</sub> Minimum Monitoring Requirements
- Revisions to the Regional Haze Rule
- Repeal of Emission Requirements for Truck Glider Vehicles, Engines and Kits

## FDA

- Enhancing Patient Engagement Efforts Across the Food and Drug Administration

## USPTF

- USP797 Stakeholder Roundtable: Helping to Ensure Patient Safety and Access through Sterile Compounding Standards for Allergen Immunotherapy Compounded Preparations



## STATES

The Network advocated for policies at the state level that supported people living with allergies and asthma. The Network policy positions are communicated in written and oral testimony and emails and letters to state legislatures. The Network also engaged state and local entities to increase their understanding of policies enacted into law (e.g., school stock epinephrine and albuterol) and ways to implement such policies.

In 2017, the Network continued to advocate for allergy and anaphylaxis policies for school and public entity stock epinephrine auto-injectors. Currently, **49 states** require or

allow for stock epinephrine auto-injectors in schools and **31 states** have public entity laws which permits venues (e.g., recreation camps, youth sports leagues, restaurants, amusement parks, sports arenas and day care facilities) to maintain an epinephrine auto-injector, with the intention of reducing the time it takes to get life-saving epinephrine to a person experiencing a sudden anaphylactic reaction.

The Network also advocated for states to approve school stock albuterol, the medication in quick-relief inhalers that treats asthma flares. There are currently **12 states** with laws or guidelines that permit schools to stock albuterol and administer to a student believed to be in respiratory distress.

Other key issues the Network engaged in at the state level included:

- Telemedicine policies in Texas, Montana and Kansas
- Reimbursement of Respiratory Care under Medicaid in Texas
- Immunity provision changes with respect to asthma & allergic reactions in Nebraska
- Establishment of food allergy plans in schools in Massachusetts
- Step therapy in 12 states

## COMMUNICATIONS

Advocacy messages were carried out by the Network, our members and health stakeholder groups through contact with members of Congress and state legislatures, various media outlets, events, and oral and written comments.

### MEDIA

Key topics addressed in the Network's printed and electronic publications, as well as social media, included the following:

- Allergy & Asthma Day Capitol Hill (Event recap: <http://www.allergyasthmanetwork.org/aadch-patient-stories-highlight-need-for-greater-education-awareness-and-access>)
- Asthma and Allergy Awareness Month in May
- Food Allergy Awareness Week in May
- Latex Allergy Awareness Week in October
- Climate change – What You Can Do: <http://www.allergyasthmanetwork.org/climate-change-what-you-can>
- EPA Plan to Repeal Clean Power Plan: <http://www.allergyasthmanetwork.org/statement-epa-administrators-plan-rescind-clean-power-plan>
- Access to Care
- Children's Health Insurance Program (CHIP) funding
- GOP attempts to overhaul Affordable Care Act

- Stock Albuterol is Critical for Asthma Emergencies infographic: <http://www.allergyasthmanetwork.org/outreach/publications/infographics/stock-albuterol-critical-for-asthma-emergencies>
- 4 Steps to a Successful Telehealth Appointment: <http://www.allergyasthmanetwork.org/steps-successful-telehealth-appointment/>
- Telemedicine in North Dakota: <http://www.allergyasthmanetwork.org/supporting-telemedicine-north-dakota>
- Choosing Health Insurance: Pay Now or Pay Later infographic (addresses high-deductible health plans): <http://www.allergyasthmanetwork.org/pay-now-pay-later>
- Understanding Non-Medical Switching from Alliance for Patient Access: <http://www.allergyasthmanetwork.org/understanding-non-medical-switching-from-afpa>
- Statement on Trump 2018 Budget: <http://www.allergyasthmanetwork.org/statement-trump-administrations-proposed-fy18-budget>
- Lunchbox Installation with Moms Clean Air Force recap: <http://www.allergyasthmanetwork.org/lunchbox-installation-spotlights-children-who-miss-school-due-asthma>

### EVENTS

The Network participated in the following events to raise awareness of allergy, asthma and related conditions and advocate for policies that support patients living with these conditions:

- World Asthma Day – The Network and other children's health advocacy groups came together to highlight missed school days by children with asthma each year. Network President and CEO Tonya Winders was among speakers at a press conference, along with Director of Advocacy Charmayne Anderson who shared her personal story living with asthma and the importance of healthy air quality.
- National Medical Association – The Network exhibited at the annual conference providing educational resources to conference attendees and discussed opportunities to support minority populations living with asthma and allergies.
- USAsthma Summit – An update was provided on Network advocacy efforts at the federal and state level.
- USAnaphylaxis Summit – An update was provided on Network advocacy efforts at the federal and state level and engagement with participants (e.g., health professionals, educators and nonprofits) to develop anaphylaxis awareness, best practices and build state and regional connections.
- U.S. Department of Education – The Network participated at the National Coordinating Committee on School Health

and Safety event to share information and coordinate with other children health stakeholder groups on a healthy school climate.

- Patient Advocacy Leaders United for Lung Health – The Network participated in a roundtable discussion with other public health stakeholders to develop strategies for improving important policy priorities in lung health.

## ADVOCACY TRAINING WEBINAR

The Network's advocacy function is critical to our mission as we raise awareness and educate policy makers about the importance of smart and effective policies and programs to support the millions of Americans living with asthma, allergies and related conditions. As a result, a training webinar was developed to educate our members and volunteers about advocating in their communities and states, and at the federal level. The webinar specifically provides an understanding of what is advocacy, how to be an advocate, and tools and tips to enhance advocacy efforts. To access the webinar:

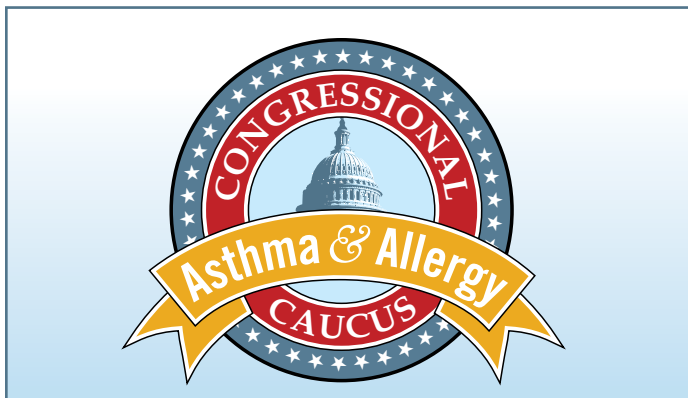
<https://youtu.be/DMdj8q2CUx8>

## COMMENTS

The Network provided oral and written comments to raise awareness of issues impacting patients:

- Washington D.C. City Council's Committee on Health & Human Services hearing "Access to Treatment for Anaphylaxis Amendment Act of 2017."
- U.S. Environmental Protection Agency (EPA) "Proposed Repeal of Emission Requirements for Vehicles, Glider Engines, and Glider Kits Rule."
- EPA's "Proposed Repeal of Carbon Pollution Emission Guidelines for Existing Stationary Sources - Electric Utility Generating Units."
- U.S. Pharmacopeia Convention (USP) Roundtable on current Chapter 797 rules applicable to allergen extracts.
- U.S. Department of Health and Human Services' (HHS) "Strategic Plan FY 2018 – 2022; Strategic Goal 2: Protect the Health of Americans Where They Live, Learn, Work, and Play."
- HHS "Healthy People 2030 Proposed Framework" to achieve full health and well-being for all Americans.

## BUILD CAPACITY



### Congressional Asthma & Allergy Caucus

The Congressional Asthma & Allergy Caucus is a bipartisan group in the House of Representatives that works in partnership with patient advocacy groups, healthcare professionals and industry partners to ensure that public laws, policies, regulations and resources support the achievement of optimal health outcomes for the millions of Americans with allergies and living with asthma.

At the start of 2017, the Network worked with Congressman Eliot Engel (NY) and his staff to recertify the Caucus for the 115th Congress and throughout the year encouraged other lawmakers to join. By yearend, 46 lawmakers had joined.

The work with the Caucus provides an opportunity to engage with members of Congress and their staff to educate and inform on allergy and asthma issues. For example, the Network opposed EPA's proposal to repeal the Clean Power Plan (CPP), which established emission guidelines for states to follow in limiting CO2 emissions from certain fossil fuel-fired power plants. As a result, Caucus Co-Chairs Eliot Engel (NY) and Carol Shea-Porter (NH) delivered floor statements and issued press releases opposing related legislation that would support the CPP repeal and lead to harmful air quality.



- Attended industry events to increase the Network’s visibility and share patient perspective on living with asthma, allergies and related conditions.
- Engaged and participated in advocacy efforts with industry partners on access and treatment options available to support patients living with allergy, asthma and related conditions.
- Partnered with U.S. Department of Health and Human Services’ Office of Minority Health to share asthma resources to broader audiences and engage with other stakeholders in public health.
- Participated in meetings with the U.S Department of Education on environmental health in schools.

**Coalitions**

The Network actively participated in coalitions with stakeholder groups including the American Lung Association (Healthy Air Campaign, Asthma Care Coverage Project), the American Telehealth Association and ACT | The App Association (telehealth and remote patient monitoring), Research!America (medical research and innovation), and Campaign for Tobacco-Free Kids (tobacco control). The Network participated in regular meetings to discuss key issues, shared information through the Network’s social media channels, educated members of Congress and federal agencies on issues, and advocated for sound policies in Congress.



**CORPORATE COUNCIL**

Since 2012, Allergy & Asthma Network has invited industry partners to be part of its Corporate Council. The Council supports the Network’s mission by:

- Collaborating with other groups and leaders in allergy and asthma advocacy and patient care to support initiatives related to education, advocacy and outreach throughout the year.
- Discussing the challenges and barriers that prevent patient access to the services, care and technologies to improve health outcomes and quality of life.
- Exploring important patient education and advocacy issues, learning what already is being done, and considering opportunities for initiatives and collaborations.
- Studying, analyzing and seeking opportunities for education and advocacy programs on behalf of allergy and asthma patients.

The 2017 Corporate Council met to discuss the evolving landscape of the allergy and asthma space. Twelve organizations participated and topics discussed included:

- Online Communities
- Leveraging Telehealth in A&I
- Access to Treatments



**MAKE CONNECTIONS**

The Network engaged with nonprofit, healthcare and governmental partners to maximize our outreach and success to protect and improve the health of people with asthma, allergies and related conditions. Examples include:

- Participated in American Association for Respiratory Care (AARC) Hill Day events to advocate for respiratory care for patients.

- Need to Build Advocacy Among Patients and Healthcare Professionals
- “Value” Definition
- Uncertainty regarding Consolidation in Space
- Opportunities for Education, Advocacy, Outreach and Research
- Challenges that Affect Patients

## 2017 Corporate Council Members

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American College of Allergy, Asthma & Immunology  
AstraZeneca  
Boehringer Ingelheim  
Boston Scientific  
Circassia Pharmaceuticals Inc.  
DVB Technologies  
Genentech Inc.  
GlaxoSmithKline  
Lupin Pharmaceuticals, Inc.  
Mylan Specialty L.P.  
Novartis  
Sanofi US  
TEVA Respiratory



## MISSION AREA: **RESEARCH**

Patient engagement in research and development is critical to innovation and greater understanding of asthma and allergies. Allergy & Asthma Network conducts focus groups and surveys patients and families. Armed with data, the Network serves as the voice of those with allergies, asthma and related conditions, and is able to articulate needs in an influential way with doctors, decision makers and industry professionals.



### **Patient Reported Outcomes Consortium**

Despite a number of safe and effective therapies to treat asthma available, a high proportion of patients remain symptomatic and at risk for exacerbations. No standard PRO measure currently exists for asthma that is fit for measuring important patient-experienced aspects of the disease. Such a measure could be used in addition to measures like spirometry assessment of lung function in the development of drugs for the treatment of persistent asthma. The Network partnered with the Asthma Working Group to develop the Asthma Daily Symptom Diary (ADSD) that will help capture the core symptoms of asthma in adolescents and adults for assessment and treatment benefit.



### **PREPARE PCORI Project**

In 2017 the Network research team started recruiting 1,200 African American and Hispanic/Latino adults, ages 18 to 75, who have asthma, use an ICS inhaler, and have had an asthma attack within the past year. All doctors involved in treating the patients are undergoing training on how to use Asthma-IQ, an online system to help them learn about asthma treatment guidelines and use the guidelines to improve care for patients.

The research team is assigning patients to one of two groups. One group receives usual care from their doctors. The second group receives the usual care and the new asthma treatment approach. With the new treatment approach, patients use an ICS inhaler and a reliever inhaler at the same time when symptoms occur. Patients fill out surveys each month for 15 months. The surveys will report the number of asthma attacks, days missed from work or school, symptoms, and how well patients' asthma is controlled.

Two groups of African American and Hispanic/Latino patients with asthma are meeting regularly with the study team. The groups are giving input about designing and carrying out the study, recruiting patients, analyzing the results of the study and sharing the results. One patient from each of the two groups is on the study's leadership committee.

Allergy & Asthma Network is advising the research team in study design, recruitment and retention strategies.



## What Patients Want

The Network conducted a survey of more than 1,000 asthma patients and published the findings in *Pediatric Respiratory Review* in November 2017. The article, "What Do Patients Want From Their Asthma Doctor," was written by Bruce K. Rubin, MD and Tonya Winders. Most of those who responded wanted convenient access to their doctor, more time spent in office visits with greater attention paid to the patient, help in navigating insurance and prescription costs and paperwork, and a partnership in developing care plans.

Although most patients were well insured for medical coverage (not a given in the United States), half were dissatisfied with their self-reported asthma control, many were concerned about medication side effects, 60% were not cared for by an asthma specialist, and nearly half did not have an Asthma Action Plan. These results are consistent with data from other published studies and suggest we still can do much more to meet the needs of children with asthma.

## Research Partners

### Antidote

Antidote is a digital health company whose mission is to accelerate breakthroughs in potentially life-saving treatments by bridging the gap between medical research and the people who need it. In a world where 80% of clinical trials are delayed or closed due to lack of awareness, Antidote has partnered with Allergy & Asthma Network with their Connect Network cutting-edge technology to match the right patients with the

right trials. This helps medical researchers make progress, faster – and offering new treatment options to patients in need.

The Connect Network is a community of health portals, non-profit organizations, patient advocates, and influencers who believe there can be no breakthroughs, no new treatments or cures, without people taking part in research. Connect members embed the Antidote Match search engine on their websites, empowering their website visitors to discover research options and connect to the medical teams that can make those options reality.

There are currently hundreds of Connect partners, reaching millions of patients per month.

As a member of Antidote's Connect Network, Allergy & Asthma Network builds a world of clarity, accessibility, and better health for all including:

- Clinical trials content — How to join, why to join, benefits/risks (Novartis, GSK)
- Patient video or written interviews — Every Day Heroes Campaign
- Expert interviews — Interview experts on relevant topics.
- Research round-ups — Highlighting research that's particularly interesting

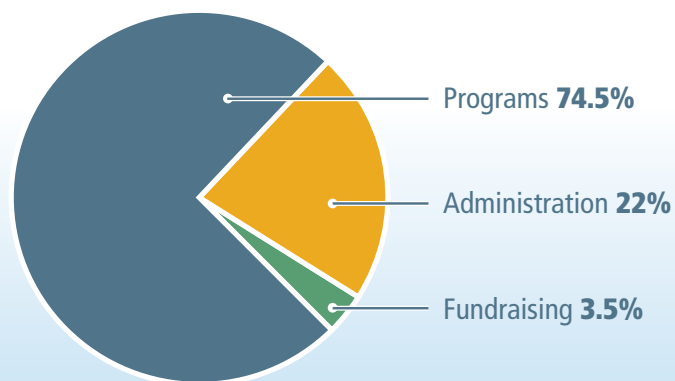
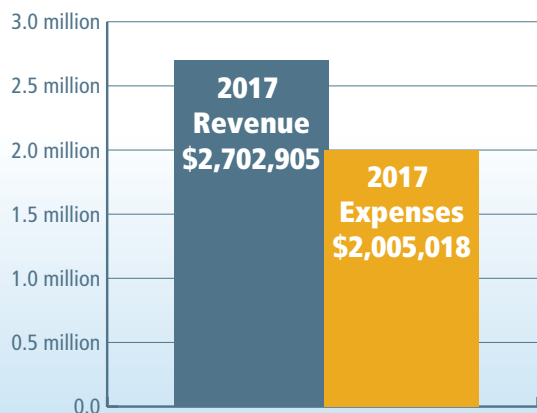
### PRO Consortium

The Patient-Reported Outcome (PRO) Consortium was formed in late 2008 by the Critical Path Institute (C-Path) in cooperation with the U.S. Food and Drug Administration's (FDA) Center for Drug Evaluation and Research and the pharmaceutical industry, and formally launched in March 2009. The mission of the PRO Consortium is to establish and maintain a collaborative framework with appropriate stakeholders for the qualification of PRO measures and other clinical outcome assessment (COA) tools that will be publicly available for use in clinical trials where COA-based endpoints are used to support product labeling claims. The PRO Consortium's membership is comprised of pharmaceutical companies along with C-Path as the managing member. Patients, clinicians, measurement consultants and representatives from the FDA and National Institutes of Health (NIH) provide critical advice and assistance to the PRO Consortium's Coordinating Committee and working groups.

### Patient-Reported Outcome Measures Study

The PRO Measures Study assesses one or more aspects of a patient's health status based on information gathered directly from the patient, without interpretation by clinicians or others. Patients provide information concerning the impact of an intervention from their perspective. PRO measures offer a means for capturing treatment benefit in terms of how a patient feels or functions as a result of a therapeutic intervention. Allergy & Asthma Network partnered with PRO/C-Path and GSK for a pediatric home diary study. This is an important project due to the inconsistencies well-documented in pediatric diaries compared to pediatric caregiver reports. Network President/CEO Tonya Winders presented at the 2017 C-PATH conference in Washington, D.C.





# FINANCIAL STANDING

Allergy & Asthma Network is a 501(c)(3) charitable organization. The organization conducts its mission-driven work due to individual donations, corporate contributions, resource sales and government grant funds.

2017 sponsors included: American College of Allergy, Asthma and Immunology (ACAAI); Aimmune Therapeutics; Alk Abello; AstraZeneca; Boehringer Ingelheim; Boston Scientific; Centers for Disease Control and Prevention (CDC); CHEST Foundation; Circassia; DBV Technologies; Genentech Inc.; GlaxoSmithKline; HomeLab; Kaleo; Lupin Pharmaceuticals, Inc.; Mylan Specialty L.P.; Novartis; Sanofi Genzyme US; and TEVA Pharmaceuticals.

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Allergy & Asthma Network is governed by a multidisciplinary Board of Directors. The Network also receives guidance from its medical advisory board, which reviews and approves all content and provides insight into the latest research in allergy and asthma care.

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