



2018 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 education, advocacy and community outreach programs.

The organization's patient-centered philosophy makes an empowering difference for individuals seeking disease 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 2018 programs, initiatives, partnerships, resources and other activities.

STAFF

President and CEO:
Tonya Winders

Director of Advocacy:
Charmayne Anderson

Director of Development
Mary Hart

Director of Education:
Sally Schoessler

Director of Outreach and Operations:
Marcela Gieminiani

Director of Research:
Cara Kraft

Creative Director:
Paul Tury

Senior Editor/Communications Strategist:
Gary Fitzgerald

Outreach Service Coordinator:
Sue Lockwood

Global Outreach and Education Coordinator:
Allison Bahn

Project Manager:
Lisa Jordan

Accountant:
Jitasa

Treasurer:
Randolph Taylor, CPA

ADDRESS

8229 Boone Blvd. Suite 260
Vienna, VA 22182
703.641.9595
800.878.4403

AllergyAsthmaNetwork.org
facebook.com/AllergyAsthmaHQ
twitter.com/AllergyAsthmaHQ
instagram.com/AllergyAsthmaHQ
youtube.com/Breatherville

A Note from the President

2018 proved to be yet another successful year for Allergy & Asthma Network!

In this annual report, you will hear directly from patients, caregivers and healthcare professionals who have benefited from your generosity. From conducting health fair screenings at Lung Health Experience events to disseminating over one million educational posters and magazines. From advocating on Capitol Hill to supporting state policy to increase access to care. From co-developing four shared decision-making tools to ensuring the patient voice is heard in research and development. Each of these initiatives have served one key purpose: to end the needless death and suffering due to asthma, allergies and related conditions.



Our four key mission areas (outreach, education, advocacy and research) are detailed in this report. The level of engagement and volume of activity is impressive and I am proud to lead such a dedicated team at the Network. The truth is, however, the Network is not just the team that is based in northern Virginia; the Network is also your family and families

like yours who are living with these conditions. It is by our collective efforts that we have been able to reduce the burden of disease while also saving lives.

Thank you for your continued commitment to the mission of Allergy & Asthma Network. We hope you find this annual report both informative and inspirational. While we are proud of our 2018 accomplishments, we still have work to do. Together we believe there will come a day when we say, "There once was this thing called asthma...allergies...anaphylaxis...atopic dermatitis."

A handwritten signature in black ink that reads "Tonya A. Winders". The signature is written in a cursive, flowing style.

Tonya Winders
President/CEO
Allergy & Asthma Network

MISSION AREA: OUTREACH

Our Director of Outreach has a direct connection to communities and people we serve. In her own words:

I always enjoy representing Allergy & Asthma Network at health fairs and community events. Meeting and talking with patients and families, providing educational materials, sharing tips to remove allergens from home, or simply listening to their stories – it's gratifying to know we are making a real difference.



When the event targets Hispanic/Latino families, the experience takes on a more personal meaning for me. I was born and raised in Chile and Spanish is my native language. Whenever I get the chance to interact with Spanish-speaking families and talk to them about allergies and asthma in their own language, I feel I'm giving them the necessary tools and guidance to feel empowered to better understand and manage their condition – and achieve better health outcomes.

Reaching out to this population is part of the Network's Hispanic Outreach Program. Launched in 2003, the goal is to improve access to care and eliminate health disparities in asthma. We do this through a multichannel approach, but with one consistent message: asthma is a chronic disease, and with the right care it can be manageable.

As part of our program, we have developed and translated more than 30 publications and brochures in Spanish, addressing asthma and allergy diagnosis, treatment and prevention – from environmental allergies and how to properly use medications to the importance of having an Asthma Action Plan. The Network distributes these publications and brochures for free to hospitals, schools, healthcare centers and free clinics, among others.

We partner with community health workers – called promotoras de salud in the Hispanic community – to educate patients and families in their own neighborhoods and language; we work with volunteers across the country to conduct allergy and asthma screenings at local health fairs, churches and community events; and we have a toll-free helpline in Spanish that receives hundreds of calls every month. Our Spanish website is www.redalergiyasma.org.

The Network is always looking for partners to expand our Hispanic Outreach Program.

In addition, we offer free Network memberships, which includes access to our patient resources and prescription assistance.

A handwritten signature in black ink, appearing to read 'Marcela Gieminiani'.

Marcela Gieminiani
Director of Outreach



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 2018, the Network participated in over **50** outreach activities, attended **19** medical professional meetings and recruited more than **7,000** new members. The Network's public relations efforts achieved more than **900M** impressions in traditional and social media.

"All asthma is NOT the same – it's a multifaceted disease and it's important that patients with chronic, recurring symptoms consult with their asthma specialist ... I view my severe asthma as a part of my life that I control. I refuse to let it define who I am. I encourage patients with severe asthma to do the same."

– **Donna Matlach**, severe asthma patient and Allergy & Asthma Network Board Member



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 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. 5W uses media platforms including national and regional broadcasts, print and top online outlets on topics such as May's World Asthma Day, Asthma Awareness Month 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 2018, the Network was featured in **180** outlets totaling **929,616,422**. "Allergies" was the topic with most impressions, followed by "asthma" and "food allergies."

OUTREACH SERVICE COORDINATOR PROGRAM

Allergy & Asthma Network's national headquarters is in Vienna, Virginia, but its local presence depends on community volunteers we call Outreach Service Coordinators (OSCs). 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 2018, the Network had **volunteers in 39 states and participated in 65 outreach events across the country.**

PATIENT OUTREACH

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

- Engages in social media activities
- Offers toll-free helpline (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, Twitter, Instagram and LinkedIn) 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, 2018 - Dec. 31, 2018

Twitter

New followers: **1,259**
 Impressions: **731,300**
 Profile visits: **20,000**

Facebook

People reached: **>850,000**
 Page views: **11,800**
 Total video views: **35,378**

Instagram:

Followers: **1000**
 Posts: **1300**

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 2018, the Network received **1,400** calls and more than **190** e-mails; **285** of those communications were followed up with free informational resources.



"My son Elijah did not die in vain. My family and I will be his voice by creating an echo for him, by raising awareness ... More than 15 million people suffer from food allergies, including 5.9 million children. We all need to come together and collaborate on a platform to make change, and even find a cure. Now how do we do that? It starts with you, me, we. Now is the time we can make a difference."

– Thomas Silvera, food allergy dad

Outreach Activities

In 2018, the Network participated in more than 50 outreach activities, including health fairs, community events and asthma camps, and provided educational material for free distribution to school nurses, respiratory therapists, state and local asthma programs, asthma coalitions and community health workers, among others.

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) and a toll-free line in Spanish. As part of a CDC cooperative agreement, in 2018, the Network promoted the use of an Asthma Action Plan in Spanish among Spanish-speaking

parents. As part of these efforts, **60** organizations working with Hispanic/Latino families were reached, and **2,200** families received an Asthma Action Plan.

Total www.redalergiyasthma.org website viewers: **63,200**.

Resources for patients

In 2018, 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 download: Asthma Storylines – a self-care tool for managing asthma

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 2018, the Network exhibited at 19 professional meetings and distributed more than 8,100 resources.



"We had a great event for our community at the 2019 Asthma Action Fair on Saturday, May 18th. Thank you very much for the support and donation of Allergy & Asthma Network materials! We counted 275 people attending the event. It was a huge success! The picture below is of our volunteer team members working the event. The two ladies in the front, pink shirts: (left) Mary Benjamin, our Pediatric Asthma Educator & (right – me!) Holly Lawing, Manager Pediatric Asthma Program of Cape Fear Valley Health.

Best Regards,

*Holly Lawing, RCP, RRT, AE-C
Manager, Pediatric Asthma Program*

2018 USASTHMA SUMMIT

On November 16, 2018, Allergy & Asthma Network – in partnership with the American College of Allergy, Asthma & Immunology – hosted the 2018 USAsthma Summit (Seattle, WA). This one-day event brought together 95 healthcare providers from across the United States (including nurses, community health workers, pediatricians, asthma program managers) and additionally, 780 people watched the Summit via livestream) with all 50 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.

PARTNERSHIPS

In 2018, 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 Hispanic Medical Association (NMA)
- National Medical Association (NMA)
- Centers for Disease Control and Prevention (CDC)
- Food and Drug Administration (FDA)
- Environmental Protection Agency (EPA)
- Not One More Life (officially joined Allergy & Asthma Network)
- Severe Asthma Foundation (officially joined Allergy & Asthma Network)
- Hispanic Federation

MISSION AREA: EDUCATION

We are known as the “Poster People”!

It doesn't matter where you go or who you talk to in the world of “lung health providers,” most everybody has seen or used our Respiratory Treatments poster. The poster has been used for years in practice and is constantly updated to keep up with the growing number of inhalers and medications on the market.



One respiratory therapist from the Baylor Scott & White Lung Center in Dallas, Texas says, “We have the poster on all our exam room walls and use it with every patient encounter. Many people may not know the name of the medication they are using but they can pick out a picture of it on the poster. It is the most valuable tool available for us to use educating our patients about their medications and the different delivery devices.”

Posters are just a small portion of what we offer in providing education to patients, families, healthcare providers, policy makers and industry.

Our educational resources make a difference in the lives of professionals and patients. Thanks to having stock epinephrine available as well as non-nurse personnel trained to administer the medication, a life was saved in an Indiana school district this past fall. The student had no action plan in place and had just learned of a food allergy. Through great leadership by the school nurse, school personnel were made aware of the allergy and were quickly able to identify signs of anaphylaxis after an accidental exposure.

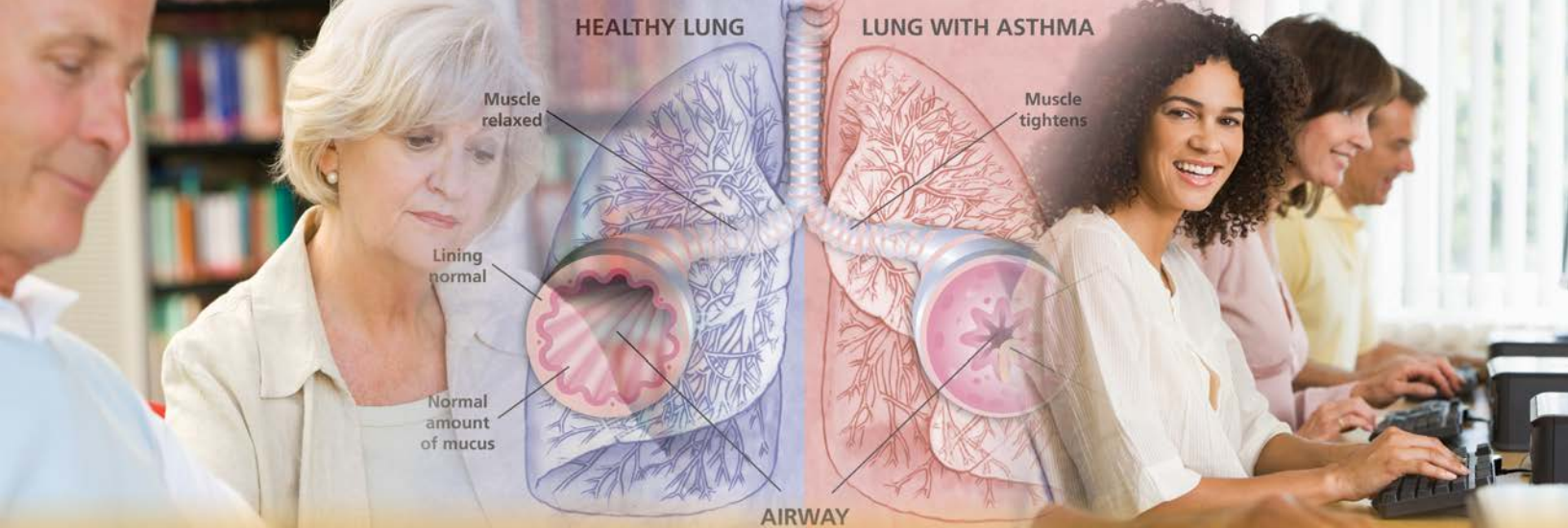
Stock epinephrine has been a critical component of ensuring student safety across the nation during a time when not all families have had affordable access to life-saving medication.

In New York State, our resource, *Allergy & Anaphylaxis: A Practical Guide for Schools & Families*, was the basis for school allergy management training of new school nurses at the state's School Nurse Orientation.

Take a look at some of the outstanding events and education we provided in 2018.

A handwritten signature in black ink that reads "Sally Schoessler". The signature is fluid and cursive.

Sally Schoessler
Director of Education



MISSION AREA: EDUCATION

During 2018, the Education Team’s goal of providing diverse, evidence-based programs and resources using multiple channels to empower people with allergies, asthma and related conditions to improve their health outcomes was successfully met. The team developed digital educational tools and resources tailored to meet audience unmet needs.

PROGRAMS

Advances in Allergy & Asthma Monthly Webinar Series

Monthly webinar series 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 2018, we reached a total of 8,968 individuals who listened to our webinars either live or recorded. Since the inception of our Webinar Series in March of 2016, we have reached a total of 25,549 professionals and patients.

- **January** – “Emergency Action Planning for Children with Anaphylaxis”
Dr. Todd Mahr
803 Registrants – **405** Participants – **265** archived views
- **February** – “Love is in the Air – Don’t Let Aspirin-Exacerbated Respiratory Disease (AERD) Take Your Breath Away”
Dr. Tanya Laidlaw
323 Registrants – **138** Participants – **1,294** archived views
- **March** – “Vital Partnerships for Patients, Caregivers & Physicians: Shared Decision Making in Immunotherapy”
Dr. Don Bukstein
298 Registrants – **109** Participants – **69** archived views
- **April** – “School Food Allergy Issues: Plans, Policies, Peers & Pizza Parties”
Dr. Ruchi Gupta
750 Registrants – **294** Participants – **189** archived views
- **May** – “Steroid Overreliance in Severe Asthma”
Dr. Gary Steven
631 Registrants – **245** Participants – **269** archived views
- **June** – “The Itchy and Scratchy Show: Handling Atopic Dermatitis”
Dr. Weily Soong
386 Registrants – **162** Participants – **219** archived views
- **July** – “When Histamine Meets Skin: The Trials & Tribulations of Atopic Dermatitis”
Dr. David Khan
256 Registrants – **86** Participants – **43** archived views
- **August** – “Improving Care: Asthma Tools”
Dr. Don Bukstein and Tonya Winders
439 Registrants – **189** Participants
- **September** – “Pediatric Asthma Yardstick”
Dr. Bradley Chipps
575 Registrants – **292** Participants – **116** archived views
- **October** – “Latex Allergy: Myths & Truths: What the Evidence Reveals”
Dr. Kevin J. Kelley
327 Registrants – **128** Participants – **77** archived views
- **November** – “What You Need to Know About Asthma Adherence”
Dr. Andrew Weinstein
517 Registrants – **213** Participants – **72** archived views
- **December** – “Modern Living: Taking Your Breath Away - A Look at Asthma Disparities”
Dr. Anne Maitland
467 Registrants – **193** Participants – **28** archived views

Online Learning HQ

- Launched in 2018, Allergy & Asthma Network offers Continuing Education (CE) to Allied Health Professionals to support their professional learning. We offer CRCE, ACPE, CME, CNE as well as casual “Coffee Talks” with Dr. Don Bukstein.
- Webinars from our series are provided for the educational programming with 38 programs available from the Network in the growing library.
- Additional programs are available in the Online Learning HQ provided by Altus Learn.
- Features include an All-Access Pass for subscribers and a CE wallet to track completed CE for reporting purposes.

“Unless you are a parent living with this situation every day, you don’t realize how difficult it is to avoid peanuts in foods, as even the slightest risk of cross-contact can lead to life-threatening reactions. Normal activities – such as going to school, playdates, eating out at restaurants, or leaving a child with a sitter for date night – present added complications and anxiety for families with a child with peanut allergy. I am proud to share my story so that parents of children with peanut allergy realize they are not alone, and to create a community where people can inspire, educate and support each other.”

– Tia Mowry, food allergy mom, actress and author



- Total numbers of users in 2018: **259**
- Total number of All Access Pass Subscribers in our first year: **6**

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 ACEs program has **327 teams** with **373 volunteers**.
- The program spans **46 states**.
- Volunteers conduct training and presentations during ACE workshops and community outreach

USAnaphylaxis™ Summit Conference

April 20, 2018 at Gaylord Opryland Resort and Conference Center, Nashville, Tennessee

For our 6th Annual Summit, we invited nationally respected speakers to present on important topics related to anaphylaxis and epinephrine.

Resources developed for the Summit:

- Stock Epinephrine Implementation Tool Kit
- Steps to Stock Epinephrine Infographic

Topics and speakers:

- **Anaphylaxis in the School Setting**
 - o Overview of Anaphylaxis, Dr. Ruchi Gupta
 - o Legislative History of Stock Epinephrine, Charmayne Anderson
 - o Panel Presentation: Stock Epinephrine at School: Prevalence & Practice
 - o Sally Schoessler
 - o Eric Edwards
 - o Dr. Martha White
 - o Nina Fekaris, NASN President
 - o Lunch and Learn Panel: Stock Epinephrine in Action
- **Implementation of Stock Epinephrine – How to Do It Well**
 - o Implementation Strategies: From Doctor’s Orders to Medication Delivery, Tia Campbell
 - o Policies, Protocols and Practical Implementation Tools, Sandra Moritz
 - o Moving Forward: Where Do We Go From Here? Tonya Winders

Severe Asthma Campaign

Our national awareness campaign with a multichannel approach based on printed and online publications, social media and PR efforts was continued in 2018. Goal: Provides education to patients, caregivers, families and community members about the most current treatment options for asthma, highlights the importance of referral to specialists to improve patient outcomes. It is also increase awareness and education on the difference between true impairment vs perceived impairment and increases patients' understanding of their conditions through education, and thereby ensures that both patients and providers are working better together to alleviate symptoms.

Achievements in 2018:

- Launch of Severe Asthma Shared Decision Making Tools with ACAAI and CHEST Foundation
- Published severe asthma article in USA Today's Lung Health supplement – "When Asthma Is Not Just Asthma" addressing Type 2 Inflammation
- Severe Asthma and Oral Corticosteroids Workgroup participation, with launch of press release, statement, infographic, webinar, etc.

Latex Allergy Awareness Week

Our theme for Latex Allergy Awareness Week 2018 was "Latex Allergy: Myths & Truths: What the Evidence Reveals." Activities to promote awareness of latex allergy included:

- Poster development
- Webinar with Dr. Kevin J. Kelley
- Social media posts
- Facebook
- Twitter
- LinkedIn
- Support to volunteers seeking governmental proclamations
- Infographic titled, "Latex Allergy = Allergy, Anaphylaxis, Asthma, Food Allergy"

School Asthma Management Program

Goal: 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:

1. Introduce standardized asthma action plan via professional medical societies (AAP, AAAAI, ACAAI, AAFP, others). and raise awareness via PR campaign
2. Employed strategy to work alongside patient and physician advocates educating state legislators on the need for stock albuterol
 - **Reintroduction of HR 4662 in December 2017** to create incentive for states to stock albuterol and standardize asthma action plans.
 - Met with members of the **Asthma & Allergy Caucus to support HR 4662** (SAMPRO).
 - **Conducted Allergy & Asthma Day Capitol Hill**

visits and briefing on this topic and encouraged support of HR 4662. **Reached over 200 federal decision makers** and over 2M families with key messages regarding the importance of asthma action plans.

3. Promoted educational toolkit and online learning module to enhance understanding of NAEPP guidelines among school personnel
 - **16,000** school nurses reached and over **2,000** participants through webinars
 - SAMPRO webinar viewed 69 times on YouTube in 2018 bringing total to 503 views.
4. Resources in English and Spanish languages promoted across multichannel platform and amplified by partnering organizations.

"I want to help people to be able to talk about atopic dermatitis – so that it becomes less of a secretive disease, so that patients don't feel there's a stigma attached to it, and they don't feel socially isolated because of it. The more people talk about it, the better the chance of achieving that goal."

– Peter Moffat, atopic dermatitis patient, TV and film writer and producer



A couple of school nurses commented on the use of *Allergy & Anaphylaxis: A Practical Guide for Schools & Families* in their school:

Hi Sally,

I hope all is well with you. I wanted to reach out to you and tell you that I have used *Allergy & Anaphylaxis: A Practical Guide for Schools & Families* repeatedly in my practice at the high school level. Most recently I carried it into a meeting with school staff and a very anxious parent of a new student with severe food allergies. I referred to the information contained in the resource and the parent visibly relaxed. They were relieved when they saw that we had the resources and training to deal with severe food allergies. It opened the door for a very productive planning session and a smooth transition for the student into a new school.

Thanks for all the help you give us in NYSASN!

Carol Bumbolow MSN,BA,RN,NCSN
School Nurse Orientation Coordinator

Dear Sally,

I am on the faculty at SNO (School Nurse Orientation) and taught allergy and anaphylaxis last summer. After reaching out to Allergy & Asthma Network, I received 85 copies of *Allergy & Anaphylaxis: A Practical Guide for Schools and Families*. We had 112 SNO participants so every nurse was not able to receive a copy. The nurses that did not receive a copy expressed disappointment, however, they were given a web address to download a version.

I used the booklet for my presentation and referred to the *Anaphylaxis at a Glance* poster. I informed the nurses that I use this resource when instructing school personnel how to recognize and manage anaphylaxis. I also referred to the articles on latex and bee stings. School nurses are always on the alert for bullying, and the article initiated some discussion. I also apprised them of resources for staff training, which are very helpful.

I appreciate getting the resource and feel it facilitated me in getting favorable feedback on the presentation.

Sincerely,

Mary Fitzpatrick, BSN, RN, NCSN

EDUCATIONAL PRESENTATIONS

National and statewide presentations to a variety of audiences

- Diagnosis of Pediatric Severe Asthma – American Thoracic Society
- Allergies and Anaphylaxis in the School Setting – School Based Health Alliance
- Inhaler Confusion – National Association of School Nurses
- Shared Decision Making in Severe Pediatric Asthma – Association of PAs in Allergy, Asthma & Immunology
- Severe Asthma Tools & Shared Decision Making – American Association of Respiratory Care
- National Advocacy Initiatives – Association of Asthma Educators

RESOURCES

Allergy & Asthma Today Magazine

The Network's award-winning magazine is distributed quarterly to patients, families, community health workers, decision makers and healthcare providers across the country. Over 500,000 copies of the magazine were distributed in 2017, with an estimate of 2.1 million readers per issue.

Our articles span the breadth of allergy and asthma topics, with our major stories in 2018:

Spring/Summer Edition

- *After the ER: Ensuring a Safe Transition of Care*
- *Come Together – Shared Decision Making between doctor and patient is transforming healthcare*
- *After the Storm: Flood cleanup is essential to keep mold at bay – especially after hurricanes*
- *Don't Keep It a Secret - Peter Moffat, executive producer of HBO's "The Night Of," discusses his atopic dermatitis*
- *Living with Animal Allergies – And Learning to Trust Immunotherapy*
- *Why Lupin Allergy Is Becoming More Common*
- *Going Places: Plan ahead so that your asthma and allergies don't ruin your summer vacation.*

Fall/Winter Edition

- *The Asthma Gender Gap - Why adult asthma is more common – and often more severe – among women*
- *Choosing Relief: From "active ingredients" to "dosing instructions, here's a step-by-step guide on how to read a medication label*
- *Sharing Is Caring - A new Shared Decision Making tool for severe asthma helps doctors and patients determine the best treatment*
- *'We Called Him Itty' - Izaiah Fiedler was outgoing, kind-hearted and had big dreams. When he died in May 2017, nothing about it made sense, his mom says*
- *Elijah's Echo - After his 3-year-old son died from an anaphylactic reaction, Thomas Silvera is stressing the need*

for improved food allergy education in childcare settings

- *Your Ragweed Pollen Primer*

What is ragweed and why is it so bothersome every fall? Can you still go outside and enjoy nature? Here's what you need to know.

Regular Features

- *Tell All*
- *Ask the Allergist*
- *News & Views*
- *Asthma Education*
- *Infographic*
- *Well + Good*
- *Advocates in Action*
- *Anaphylaxis Education*
- *ACE Spotlight*
- *All in Good Taste*
- *Breatherville*

eNewsletter

The Network's electronic monthly newsletter has the latest news in the allergy and asthma world. This format allows us to be flexible to meet the changing clinical information and important issues in the media.

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

eNewsletter Lead Stories and metrics for 2018:

- *January – How to Stay Ahead of Severe Asthma*
Open rate: **21.3%**, Click Through Rate: **21.4%**
- *February – Ask the Allergist: When Pollen is a Problem*
Open rate: **20.7%**, Click Through Rate: **25.0%**
- *March – Ask the Allergist: Addressing Mold After Major Flooding*
Open rate: **19.1%**, Click Through Rate: **23.7%**
- *April - Benefits of Bronchial Thermoplasty: 'My Quality of Life Improved'*
Open rate: **20.8%**, Click Through Rate: **15.6%**
- *May – Advancing High-Quality Care. Health Equity at #AADCH2018*
Open rate: **21.0%**, Click Through Rate: **19.2%**
- *June – New Asthma Tool Determines Best Treatment for Severe Asthma Patients*
Open rate: **21.2%**, Click Through Rate: **18.8%**
- *July – Ask the Allergist: Severe Asthma Know-How*
Open rate: **20.6%**, Click Through Rate: **18.7%**
- *August – Ask the Allergist: When Allergies Keep You Awake*
Open rate: **21.3%**, Click Through Rate: **21.5%**
- *September – New "Balancing Act" Video: Severe Asthma and Oral Corticosteroids*
Open rate: **20.5%**, Click Through Rate: **18.6%**
- *October – Examining the Asthma Gender Gap*
Open rate: **21.8%**, Click Through Rate: **16.5%**
- *November – Asthma and Oral Corticosteroids*
Open rate: **18.0%**, Click Through Rate: **29.8%**
- *December – 2018 USAsthma Summit Now Available Online*
Open rate: **19.5%**, Click Through Rate: **18.0%**

Special Edition Magazines

Updated in 2018 - **Understanding Asthma** (English and Spanish) – Over 8,000 distributed

Sections include:

- What is Asthma?

- Diagnosis
- Treatment and Medications
- Severe Asthma
- Managing Your Condition
- Additional Resources

Updated in 2018 - **Understanding Anaphylaxis** (English and Spanish) – Over 2,000 distributed

Sections include:

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

Updated in 2018 - **Understanding Allergies** (English and Spanish)– Over 3,000 distributed

Sections include:

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

Developed in 2018 - **Understanding Atopic Dermatitis** – Over 200 distributed

Sections include:

- Atopic Dermatitis Defined
- Symptoms
- Treatments & Medications
- Managing Your Condition
- Additional Resources

Graphical depictions of important health issues related to allergies and asthma have an impact on awareness and education. The Network developed several Infographics during 2018, including the following:

- Type 2 Inflammation
- Asthma and Oral Corticosteroids
- Latex Allergy = Allergy, Anaphylaxis, Asthma, Food Allergy
- Shared Decision Making: Benefits to Patients
- 6 Steps to Shared Decision Making
- Go Generic
- Asthma Rates by Gender
- Asthma Health Disparities
- 'Still Fighting For Breath' Global Data
- Atopic Dermatitis Fast Facts

Special Interest Guides

Our special interest guides address allergies at school and in food service.

- *Allergy Safe Dining* – Designed to help restaurant owners, wait staff, hosts, chefs and kitchen staff better understand

and address food and latex allergies.

- *Allergy and Anaphylaxis: A Practical Guide for Schools and Families* - 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.
 - **400** copies were distributed at the National Association of School Nurses conference through a sponsorship with School Health Corporation.
 - **647** copies were downloaded from our website.

Posters

One of the most unique and requested tools from healthcare providers for patient education.

- Respiratory Treatments (English and Spanish): Over **110,000** English version posters and more than **2,000** Spanish version posters distributed. Updated in 2018, 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)
- Anaphylaxis at a Glance: Over **1,000** 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 great for school clinics and emergency rooms for easy reference and patient education.
- Nasal Sprays: Over **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 non-aqueous aerosols and OTC corticosteroids. Helps patients identify their medications and understand priming and use instructions.
- Respiratory Inhalers Side by Side: Over **2,000** distributed. Offers medical professionals factual information for clinical staff reference and patient education, covering active and inactive ingredients, age indication, priming, shaking, cleaning and more.

Shared Decision Making Support Documents

- Web-based resources were developed to assist patients when using the various Shared Decision Making tools that have been developed in collaboration with ACAAI and CHEST.
- Resources include:
 - Essential Steps to Shared Decision Making
 - Come Together
 - Severe Asthma Shared Decision Making
 - How Does Shared Decision Making Work?
 - Webinars
 - 4 interactive tools developed in 2018. Asthma, Allergy immunotherapy, Atopic Dermatitis and Pediatric Asthma

Video Blogs

We posted weekly video blogs in 2018 to our website and social media channels.

- Our popular “Ask the Allergist” segments included the following topics:
 - Anaphylaxis or Asthma Flare?
 - Teens and Medication Adherence
 - Outgrowing a Food Allergy
- Patient Testimonials:
 - Jeff and Cristin Buckley
 - Amanda Eisen
 - Stephanie and Nate Lowe
- Other Topics:
 - Frequently Asked Questions about AERD
 - Student Videos

Asthma Storylines App

Powered by Health Storylines™, this is a self-care tool for managing asthma. It gives you an accurate, shareable record of the asthma experience between physician visits, and helps you and your care team collaborate on treatment strategies.

Take control of asthma with health tools that enable you to:

- TRACK symptoms, vitals, moods, and daily asthma control
- RECORD questions you have for your 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 your circle of support, share with them your health story, and receive messages of encouragement from them

Vivacare Collaboration

Allergy & Asthma Network partnered with Vivacare to provide quality, guidelines-based resources in an online format to healthcare providers to use 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, over 500 practices are utilizing these tools.

Articles to National Publications

We value our partnerships and provide articles to key publications and websites upon request.

Two examples include:

- *US News and World Report*
The Network provided submissions for publication Topics for 2018 were:
 - January: *How to Read an OTC Medication Label*
 - April: *How to Treat Spring Allergies – Understanding the Newly Updated Allergic Rhinitis Guidelines*
 - May: *Oral Corticosteroids – How to Use Them Widely*
 - June: *Managing Eczema – To Bathe or Not to Bathe*

- November: *Is Dust Mite Immunotherapy Right For You?*
- NASN School Nurse
 - *Steps to Stock – Keeping Students Safe with Fully Implemented Stock Epinephrine*
 - *Caring for the Student with Asthma at School – What's Out There to Help the School Nurse?*

- National Association of School Nurses
 - **400** copies of *Allergy & Anaphylaxis, A Practical Guide for Schools & Families* were distributed in collaboration with School Health Corporation.

School nurses regularly use Allergy & Asthma Network resources to engage, educate and empower other nurses, educators, school staff, students and families. Hear what an impact evidence-based yet easy-to-follow educational materials can have in diffusing anxiety and even prevent a death at a school due to food allergies.

Resources Targeted to Conference Attendees

In 2018, The Network provided meaningful resources to partners and stakeholders:

I have gradually awakened back to the world that was stolen from me due to my severe asthma. I received bronchial thermoplasty and my health improved so much I am able to start gardening again. I can now sit outside and engage with my family. I can cook a meal without going into an asthma attack. I still have days when my asthma flares, but it is easily managed with inhalers. When I was really sick with my asthma I took lots of prednisone. It affected my bones and I had to have foot surgery. That's when I realized Prednisone affects more than just the lungs!

When I needed more treatment for my lungs, Allergy & Asthma Network fought to keep me alive. I will always be forever grateful to Tonya. I have met some great new friends – Mary and Cara - from the Network who are true warriors searching for a cure for asthma and assuring patient voices are being heard. Thank you!!

— Charnette Darrington Zaskoda



MISSION AREA: ADVOCACY

Asthma has always been a part of my life. As a young child in the 1970s, I experienced repeat emergency room visits because I struggled to breathe. The treatment I received was “a shot” – inhalers were not a treatment option at that time. I am sure this is why I fear needles to this day.



Looking back through the years, I often wonder: Could I have prevented my frequent asthma flares? My family lived in an apartment with our pet dog, amid wall-to-wall carpeting, window seal air leaks, and cockroaches. This was our home – our normal. There were no conversations about allergen triggers or what changes in our apartment would create an allergen-free home. My mother even smoked when I was young, but she quit due to my asthma.

For years I believed I could not participate in strenuous physical activity because of my asthma. I struggled in gym and dance classes – I ended up observing more than participating. I envied those who could enjoy sports without worry about asthma. I wanted their sense of freedom.

I finally reached a point where I was determined to not let the disease control me. I wanted to participate in life – not watch it from the sidelines.

I worked with my doctor to get a better understanding of my asthma, recognize my triggers and learn to manage it effectively. I gained a greater sense of confidence in myself and became a dancer, gymnast, a professional NFL cheerleader with the Washington Redskins, and now a runner.

Which brings me to today. As an advocate for asthma patients on the national stage, including the halls of Congress during our annual Allergy & Asthma Day Capitol Hill, I want to use this platform to increase awareness of the disease, especially in underserved communities where the disease affects so many who have limited resources.

And I want to encourage patients to participate fully in life, to pursue their passions – to not let asthma hold them back. You can live a healthy and productive life with asthma, one breath at a time.

A handwritten signature in cursive script that reads "Charmayne Anderson".

Charmayne Anderson
Director of Advocacy



The Network's Charmayne Anderson does not let asthma slow her down.



MISSION AREA: ADVOCACY

Allergy & Asthma Network (“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 other related conditions. Together with patients, families, healthcare professionals and industry partners, the Network made substantial progress in 2018 toward our advocacy goals by amplifying the patient’s voice, building capacity and making connections in Washington, D.C., and in communities nationwide.

Our signature event to further our mission is Allergy & Asthma Day Capitol Hill (AADCH). This annual event in the month of May brings together patients and their families along with healthcare professionals, industry partners and stakeholder groups to raise awareness of asthma and allergy issues with members of Congress.

Among the participants were Francine and her son, Luca, who suffered his first allergic reaction after eating nuts while traveling on an airplane that did not carry epinephrine auto-injectors, the life-saving medication for anaphylaxis emergencies. Both Francine and Luca traveled to D.C. to make their voice heard on the importance of airlines carrying epinephrine auto-injectors on airplanes, as well as training for crewmembers to recognize anaphylaxis symptoms and administer the medication. “We need to protect passengers on airline carriers and make sure everyone is safe. You cannot serve food and not be able to protect your passengers. In the skies there are no options, no ambulances and no guarantee that anyone can save you,” Francine says.

“No matter who you are or where you live, everyone with asthma deserves equal access to quality healthcare and patient education.”

– Drushane Teehee, asthma mom



AMPLIFY PATIENT VOICE

The Network fosters relationships at the federal and state levels of government to educate on policies that impact patients. We further engage our members and volunteers across the country to connect with their federal and state representatives to bring a personal connection to the issues. Over the past year, our work included meetings on Capitol 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. 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.
- Access to innovative therapies and technologies to advance medical treatment.
- Affordable and high-quality healthcare and insurance coverage.
- Adequate funding for asthma health and research programs.
- Mitigate environmental health hazards and address climate change.
- End health disparities and move toward greater health equity.

“About 84,000 children have asthma in New York City, and African-Americans and Latinos are disproportionately affected. These populations are often not able to afford their medications. As co-chair of the Congressional Asthma & Allergy Caucus, I’m grateful to all who have taken the time to learn about asthma and allergies and raise awareness about living with the condition.”

– Rep. Eliot Engel (D-NY)



In addition to our work at the federal level, the Network advocated for policies at the state level (e.g., school stock albuterol, step therapy, public entity stock epinephrine and telehealth) to support individuals living with allergies and asthma.

In 2018, we continued to advocate for allergy-anaphylaxis policies for school and public entity stock for epinephrine auto-injectors. Currently, 49 states allow for stock epinephrine auto-injectors in schools and 34 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 having a sudden anaphylactic reaction.

The Network also advocated for states to approve school stock emergency supplies of albuterol, the medication in quick-relief inhalers that treats asthma flares. There are currently 13 states with laws or guidelines that permit schools to stock albuterol with a prescription and administer to a student believed to be in respiratory distress.

BUILD CAPACITY

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), Food Allergy Research and Education (FARE), Research!America (medical research and innovation), MAPRx (Medicare), Children’s Asthma Leadership Coalition, I Am Essential (affordable healthcare), and Campaign for Tobacco-Free Kids. 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.

The Congressional Asthma & Allergy Caucus is a bipartisan group in the U.S. 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. Our work with the Caucus provided the Network with an opportunity to engage with members of Congress and their staff to educate and inform on allergy and asthma issues.

MAKE CONNECTIONS

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

- Participated in American Association for Respiratory Care (AARC) Hill Day events to advocate for patients.
- 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 on access and treatment options available to support patients.
- 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 “Housing Is Summit” sponsored by the Council of Large Public Housing Authorities to develop solutions to improve education and health outcomes to better serve low-income people.

"[Legislation requiring epinephrine auto-injectors on all airlines] is important so that something like what happened to me – a severe allergic reaction to cashews on a flight from Aruba to Long Island – never happens again. If a 10-year-old knows the risks, all airlines should, too."

– Luca Ingrassia, 10



- Panelist at the Customer Centric Medical Information Conference, Boston, to provide patient perspective in medical information development and delivery.
- Exhibitor at the National Medical Association Conference, Orlando, Florida.
- Addressed the USAnaphylaxis Summit, Nashville, Tennessee, to update on federal and state policies concerning severe allergy.



I feel so blessed and honored that I was asked to speak at the American Thoracic Society's International conference on behalf of Allergy & Asthma Network. Having severe asthma can be a very tough and lonely journey at times. Being surrounded by thousands of pulmonologists who are fighting the severe asthma fight with me and giving so much support and guidance was a surreal feeling for me. I walked away from the conference not feeling so alone in this journey and with hope in my heart.

– Melody Papazis severe asthma Patient

MISSION AREA: RESEARCH

Speaking recently at a research conference on asthma, I made a point to mention an asthma medication frequently used in the early 1980s but now off the market. When I asked the audience if they had used it or even heard of it, no one raised their hand, nodded, or said "Yes."



A smile crossed my face.

How far we have come, I thought, in developing new and innovative medicines for asthma.

Since I was a young girl, I knew I wanted to be a respiratory therapist. I wanted to help people with asthma breathe better, starting with myself. I lost my grandfather and a dear childhood friend to asthma – and I didn't want to lose anyone else.

In my 35 years – and still counting – as a respiratory therapist, asthma and allergy care has continued to progress in terms of diagnosis, management and treatment, thanks in part to medical advances and clinical research.

As a result, we are now beyond the basics of how we treat lung disease. We are better able to diagnose asthma and allergies and treat specific traits of these chronic diseases to help patients live their best life possible, with the best treatment plans.

We still have a long way to go on this journey. More than 22 million people in the United States live with asthma today. You can have a role as we research ways to end health disparities, activate patients and seek funding for asthma and allergy clinical trials. You can even participate in developing new treatments and therapies.

Check out AllergyAsthmaNetwork.org/Research to learn more about our research work and how to participate in a clinical trial. Join our free online forum, HealthUnlocked.com/LivingWithAsthma, to chat with fellow patients and share experiences.

I am so grateful to not only be a part of these remarkable advances, but also see it happen in my lifetime. I continue to smile knowing that the clinical research conducted today – and in the future – will bring us closer to fulfilling our mission to end the needless death and suffering due to asthma, allergies and related conditions.

Remember: You control your asthma; it does not control you!

A handwritten signature in black ink that reads "Cara Kraft".

Cara Kraft, RRT, AE-C
Director of Research





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.

PROJECT AND STUDY HIGHLIGHTS

PREPARE PCORI Project PREPARE – Person Empowered Asthma Relief www.preparestudy.net

In 2018, Allergy & Asthma Network's research team continued efforts in 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. As Patient Advocacy Stakeholders, we ensure that the patient voice is heard and incorporated into all aspects of the PREPARE study including study design, study implementation, analysis, interpretation and development of understandable messages for dissemination. Allergy & Asthma Network is advising the research team in study design, materials, recruitment and retention strategies.

HealthUnlocked - Living with Asthma Community

Can just talking to others improve your health?

It's no secret that receiving emotional support and communicating with people who really understand what you're going through can help improve your well-being. Recent research has also shown that connecting with people in online communities can improve your health.

One of
the community
members recently
shared,
**"I am so lucky to
have found this site,
I think it has saved
my life."**

"Native American children need greater access to quality healthcare, provided by healthcare professionals who are knowledgeable about both evidence-based treatments and the culture of their patients ... More research is needed to increase understanding of factors that cause asthma in Native American communities, as well as to find more effective ways to offer healthcare services to children."

– Bruce Bender, PhD, National Jewish Health



Online communities, such as our Living with Asthma community on HealthUnlocked, provide a space for people to share advice, receive support and meet others who truly understand what you're going through. Sharing experiences can help people make informed health decisions, improve interactions with healthcare professionals and empower them when managing their health.

Patient Activation Measurement Study (PAM)

In this study, Allergy & Asthma Network partnered with HealthUnlocked to evaluate the impact of online peer support offered by the 'Living with Asthma' community on its newly registered members using validated outcomes measures and

"Even with all of our asthma medicines, we can do better. Our response to asthma from a national public health standpoint is that we have 'lifted boats,' but we still have left some behind ... The answer is to be more targeted with our therapeutic approaches, determine what's best for our communities, and involve those most at risk."

– **Randall Brown, MD, AE-C**, director of asthma programs at the Center for Managing Chronic Disease for the University of Michigan School of Public Health, AAN Board Member



by analyzing self-reported information from users before and after joining the community relating to their attitude towards managing their condition.

Antidote

Antidote is a digital health company whose mission is to accelerate breakthroughs in potentially life-saving

antidote

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 offer new treatment options to patients in need.

The Connect Network is a community of health portals, nonprofit organizations, patient advocates and influencers who believe there can be no breakthroughs, 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
- Patient video or written interviews — Everyday Heroes campaign
- Expert interviews — Interview experts on relevant topics.
- Research roundups — Highlighting research that's particularly compelling

Antidote/AAN Survey - Patient Perspective on Clinical Research 2018

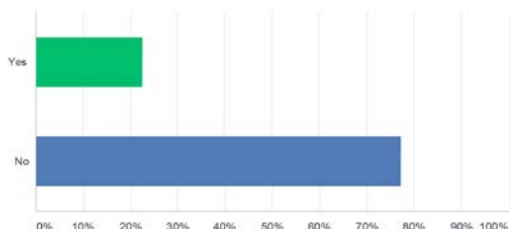
Despite the clinical research industry's continual search for solutions to the challenges posed by inadequate clinical trial recruitment and retention, an easy path to finding qualified study participants in a timely fashion continues to elude the industry.

Considering that improvements in medicines and treatments cannot happen without clinical research, it is startling how few people know much about it, much less have ever really considered participating. This report is meant to shed more light into the reasons behind the low participation by reporting on the motivators of some of the people we would expect to know the most about clinical research – patients with asthma, allergies or other conditions. The information they provided

about why they joined a clinical trial or about what would motivate them to participate in the future provides valuable insight that can enable deeper engagement with patients and physicians in more significant ways.

This study also reaffirms the influence physicians and other health care practitioners have. The importance of their roles cannot be overstated: Patients want to hear about clinical trials primarily from medical professionals. Furthermore, talking with the doctors or clinical researchers involved in a trial would make these patients feel more like a partner in the research.

Has your doctor ever shared information with you about clinical trials?



We are always looking for opportunities to partner with industry in the development of clinical research. It is important they hear from the patient from the very beginning of an idea and we provide the patient voice.

Below is a step by step process from start to finish of how we operate and fit into research and development with our partners.

RESEARCH & DEVELOPMENT SUPPORT SERVICES

Prediscovery

- Convene stakeholders to share ideas and research collaborations across disciplines, institutions, countries and sectors
- Employ the patients' voice to help investigators identify unmet needs
- Fund basic science and provide translational tools
- Educate and motivate patients to participate and advocate for research
- Advise National Institutes of Health (NIH)
- Develop natural history database

Preclinical

- Help define highest impact approaches for development
- Engage in a knowledge-exchange with KOL's
- Facilitate matchmaking among industry partners and researchers
- Facilitate sponsor interviews with patients and KOL's for study design and research protocol
- Collaborate with FDA regarding guidance, risk-benefit evaluation, participation in meetings

Phase I

- Provide information on unmet needs and disease burden
- Recruit participants promptly and effectively
- Continue to educate and motivate patients and families
- Support patient costs for the trial

Phase II & III

- Continue support in Phase I
- Assist sponsor in determining best trial design including identification of barriers
- Conduct patient-preference studies or risk-benefit assessments

Everyday Heroes Awareness Campaign

Everyday heroes are everywhere. They give their voice, their time and their effort for the causes they love – to make a difference and impact in the lives of people with asthma, allergies and related conditions.



This campaign recognises individuals who have participated in clinical trials.

Allergy & Asthma Network conducted market research and aided in patient focus groups to support research and development in 2018

- Aid in patient focus groups for protocol design
- Aid in recruitment for IRB-approved clinical trials
- Conduct market research to support the research and development process
- Conduct market research to trend beliefs, behaviors and trends in asthma and allergy care



Severe asthma patient Melody Papazis and Allergy & Asthma Network's Mary Hart

- Provide input into patient-reported outcomes and quality of life instruments to be used
- Review patient-related materials (informed consent forms, educational materials)
- Assist with recruitment and retention
- Evaluate data and advise on relevancy
- Assist in development of patient communication at conclusion of trial

FDA Review & Approval

- Accompany sponsor to any FDA meetings
- Provide patient representative to serve on FDA advisory committee
- Provide testimony at FDA advisory committee or hearing

During Post-Approval

- Work with sponsor and payers to obtain reimbursement
- Advise sponsor of any gaps to address with post-marketing studies
- Assist in post-marketing surveillance
- Provide communications support and feedback from the patient community via social media, website, email and blogs

This is a long and drawn-out process but it works! It's essential to ensure the patient voice is in all research and development activities.

LEADERSHIP

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.

BOARD OF DIRECTORS

John Tucker, Chair
 Randy Taylor, Treasurer
 Marla Adair, Esq.
 William Berger, MD
 Randy Brown, AE-C, MD
 Cristin Buckley
 Tony Cook
 Gayle Higgins, FND, AE-C
 Donna Matlach
 Prem Menon, MD, Secretary
 Sandra Moritz, MEd, RN
 Jodie Stabinski, FNP, AE-C
 Dennis Williams, PharmD, Vice Chair

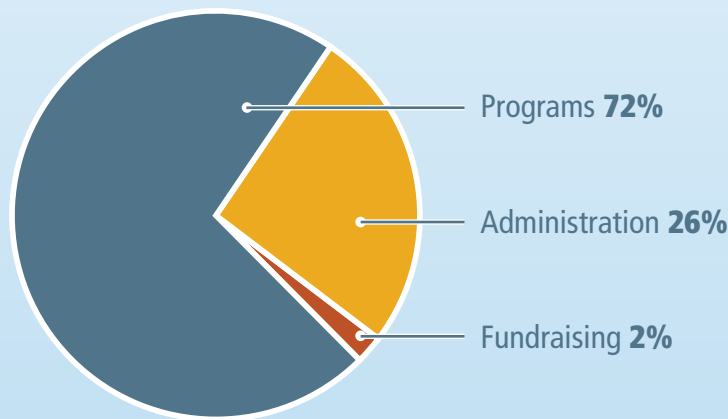
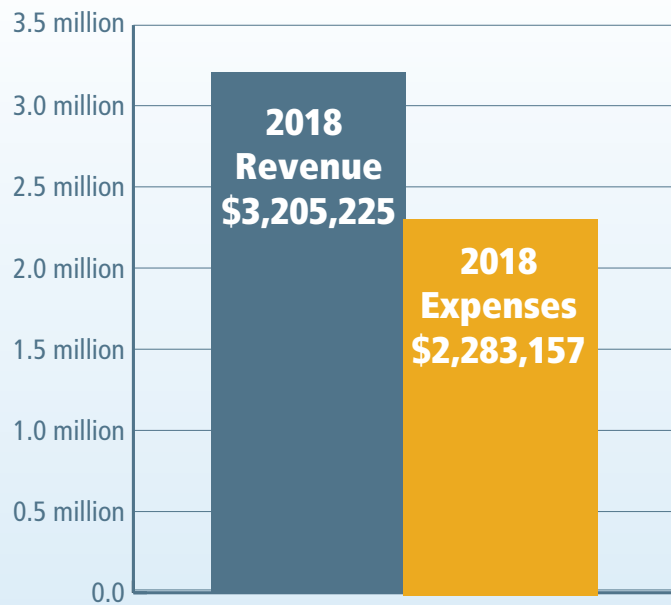
MEDICAL ADVISORY BOARD

William E. Berger, MD
 Antonio Castillo, MD
 Mary Cataletto, MD, AE-C
 Eileen Censullo, MBA, FAARC, RRT
 Bradley E. Chipps, MD
 Peyton A. Eggleston, MD
 Andrea Holka, AE-C
 Andrea Jensen, CHES, AE-C
 Neil R. MacIntyre Jr., MD
 Erin Malawer
 Michael H. Mellon, MD
 Prem Menon, MD
 Purvi Parikh, MD
 Dennis Williams, PharmD

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.

2018 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; Kaleo; Mylan Specialty L.P.; Novartis; Sanofi Genzyme US; and TEVA Pharmaceuticals.



A Note from the Chairman of the Allergy & Asthma Network Board of Directors

Friends,

On May 8th, I was seated in the Rayburn House Office Building – surrounded by a remarkable group of friends, allies, supporters, members, and advocates – listening to House Majority Leader Steny Hoyer describe his personal experience with life-threatening asthma, and how it altered the course of his life. On that day, this team of extraordinary advocates shared their personal stories of passion, pain, and grief in a thundering message to our Nation’s law makers: allergies and asthma impact all of us. From access to care and affordability of medication to health equity and food safety, Allergy & Asthma Network is leading the charge.

This was another year of exceptional progress for the Network. We continued to celebrate a long-fought victory over United Allergy Services, in defiance of the odds and as a testament to our perseverance and commitment to our members. The fearlessness and dedication of the Network’s leader, Tonya Winders, and her incredible team has positioned the Network to tackle new challenges as we engage a community beyond our nation’s borders and begin to influence broader conversations about allergy and asthma care globally.

The path ahead is not without its challenges: the Network is in a continuous battle as we look to build a sustainable future. The ever-changing map of nonprofit funders, against a broader trend of consolidation and tax policy changes, means that our team will need to work harder than ever to foster the resources necessary to accomplish our mission.

The Network is positioned as a leader in the allergy and asthma community, guiding others as it seeks to grow core mission area work in education, outreach, advocacy, and research. I’m exceptionally honored and humbled to be small part of Allergy & Asthma Network; an organization that lives its mission in every sense. We fight together to end the needless death and suffering due to asthma, allergies, and related conditions – and we won’t stop until that fight is won!

Join the fight by donating your time, expertise and financial resources to ensure we maximize our efforts, strengthen our voice and impact more patients and healthcare professionals. We are all up to the challenge.

My Best,



John S. Tucker
Allergy & Asthma Network
Board Chair