

**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 50 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.

Allergy & Asthma Network (The Network) takes a proactive and collaborative approach to developing quality asthma and allergy education, advocacy and community outreach programs, providing patients and families complete access to practical, timely, accurate, relevant, emotionally supportive and actionable publications, materials and services.

The organization's patient-centered philosophy makes an empowering difference for individuals desiring 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. The Network aligns all programs and activity based on four mission areas: education, advocacy, outreach and research.

#### **STAFF**

President and CEO: Tonya Winders

Director of Advocacy: Charmayne Anderson Director of Education: Sally Schoessler

Director of Outreach and Multicultural Affairs: Marcela Gieminiani

Creative Director: Paul Tury Managing Editor: Gary Fitzgerald

Outreach Service Coordinator: Sue Lockwood

Accountant: Jitasa

Treasurer: Randolph Taylor, CPA

### **BOARD OF DIRECTORS**

John Scott Tucker, Chair Michael Amato

Randall W. Brown, MD, MPH

Cristin Buckley

Michael Corjulo, APRN, CPNP, AE-C

Brooke Curran

A.L. "Tony" DeWitt, RRT, CRT, JD, FAARC

Gayle N. Higgins, FNP Tom Kallstrom, MBA, RRT Prem K. Menon, MD

Natalie Napolitano, MPH, RRT-NPS

Bruce Kalman Rubin, MD

Jodie Stabinski, RN, MSN, CPNP, AE-C

Randolph Taylor, CPA

Dennis Williams, PharmD, BCPS, AE-C

Tonya Winders, MBA

### **ADDRESS**

8229 Boone Blvd. Suite 260 Vienna, VA 22182 703.641.9595

800.878.4403

AllergyAsthmaNetwork.org

facebook.com/AllergyAsthmaHQ

twitter.com/AllergyAsthmaHQ



Allergy & Asthma Network reaches out to patients, families, caregivers, healthcare providers and industry professionals across the country to educate and expand awareness about allergies, asthma and related conditions. During 2016, the Network participated in 30 outreach activities for patient education, attended 18 medical meetings and recruited more than 7,000 new members.



# **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. In 2016, more than 7,000 new members joined the organization.



# **PUBLIC RELATIONS**

Allergy & Asthma Network works with 5W, a PR company located in New York, to raise awareness of the Network and the diseases. To accomplish this goal, 5W uses media platforms including national and regional broadcast, print (long and short leads) 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 2016, the Network was featured in **275** media placements, reaching **1,410,281,464** impressions. The complete report is available per request.

The Network's communications team writes and sends press releases every month to inform patients and families about disease prevention policies and access, outreach and screening events, food and latex allergy safety tips and new mobile apps and digital tools to help improve asthma management, among others. The Network uses PR Newswire services and also posts on <a href="https://www.allergyasthmanetwork.org/category/press-page/">https://www.allergyasthmanetwork.org/category/press-page/</a>

In 2016 the Network produced and disseminated **13 press releases**.

# PATIENT OUTREACH



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

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



## Social Media

The Network uses social media (Facebook and Twitter) to increase outreach and engagement, informing patients, families and

caregivers on the latest asthma and allergy news, 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.

In 2016, the Network increased **>4,000** Facebook followers and **>2000** Twitter followers



## **Contact Us & Helpline**

The Network offers a direct line of communication for patients and families. This service has two components: toll-free line and online contact us form. Both are managed by Network staff providing answers and assistance to anyone with nonemergency questions about asthma, allergies, COPD, anaphylaxis, medications, tests and treatments. In 2016 the Network received more than **2,800 calls** and more than **400 e-mails**.



## **Outreach Activities**

In 2016, the Network participated in more than **30 outreach** activities. Examples include:

- Eshelman School of Pharmacy rural outreach program (Asthma 101 and educational materials to 80 families).
- WVU Medicine Kid's Health Fair (asthma 101 and educational material to **75** families)
- Partnered with Breathe DC to provide material for their 2016 Asthma Camp Breathe Happy (Upper Marlboro, MD).
   Reached 60 children from ages 8 to 12
- MCPHS University in Worcester, Girls Inc. program (Asthma and Allergies 101 and educational materials for 50 students)

- Live, Laugh, Breathe. The Asthma Action Fair. Asthma Educational seminar, free spacers, peak flow meters, giveaways, asthma screenings, medical professionals on site. Reached out to 310 families
- 3 health fairs and 2 community events in Denver, CO. Reached **350** people
- Health fair organized by the Center for Multicultural Wellness. Reached 220 patients, including Hispanic/Latino families
- Jerome Alston Memorial Foundation in Norfolk family event. Reached 150 families.
- Boice-Willis Clinic (NC) outreach event. Reached **150** families
- Morton East High School health fair (IL). Reached 203 families
- The Seed Chapter Public School (WDC). Asthma and allergies 101 and educational material. Reached **80** students
- Support the New Mexico Department of Health with educational material for their community health workers's pilot program targeting tribes and Hispanic/latino communities. Reached 155 families, including Native Americans and Hispanics/Latinos
- Health fair and asthma screenings, Florida Allergy Clinic, Dr. Sami Nallamshetty. Reached 75 families
- Embarcadero Street Festival (CA) Health fair and outreach event. Provided asthma screenings and educational material to 60 families.
- Luther Machen Elementary School (Hampton, VA) Asthma Month celebration. Asthma 101, educational material to 55 families. Donation of 25 spacers for low-income families



"The parents and the children are so very grateful for your support. We just cannot express how wonderful it is to have a helping hand in the Allergy & Asthma Network."

– Lesia Sylcott, President, Luther W. Machen PTA

"Thank you so much for these materials. I felt that it was Christmas when the package came, I have so much excitement about sharing the information. The population of children I work with are very low income and sometimes low literacy so adapting education style to what they can relate to is necessary. The materials that you provided will go a long way and be much appreciated by the patient as well. "If you ever have extra's please send them to me, I do not have a budget for various education materials for the families to go home with so I am always looking for things. I appreciate all of your hard work and perseverance in fighting for asthma and awareness. I can feel that this is a passion of yours just like myself, I always say my paycheck is a bonus!"

— Annmarie Thomas, RRT, AE-C, Asthma Coordinator, Eskenazi Health, Indianapolis, IN



## 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**

During 2016, 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
- Doctor On Demand free telehealth visits for allergy and asthma patients



# HEALTHCARE PROVIDERS OUTREACH

Allergy & Asthma Network reaches out to health care providers across the country to identified unmet asthma education needs for their patients and to make available educational tools and resources. In 2016, the Network exhibited at **18 professional meetings**. More than **7,500 resources** were distributed.

- March AAAAI Annual Meeting (Los Angeles, CA); NAPNAP (Atlanta, GA); APHA (Baltimore, MD)
- April Virginia Head Start (Fredericksburg, VA); Texas Allergy Society (San Antonio, TX)
- May Nationwide Children Hospital (Columbus, OH); ATS (San Francisco, CA)
- June AANP (San Antonio, TX)
- July Spina Bifida Association (Minneapolis, MN); School Based Health Alliance (Arlington, VA); National Association of School Nurses (Indianapolis, IN); Convenient Health Care (Orlando, FL)
- August AAE (Jacksonville, FL); AAPA-AAI (San Antonio, TX)
- September European Respiratory Society (London, UK);
   Emergency Nursing (Los Angeles, CA)
- October AARC (San Antonio, TX); AAP (San Francisco, CA); CHEST (Los Angeles, CA)
- November ACAAI Annual Scientific Meeting (San Francisco, CA)



# 2016 NATIONAL ASTHMA SUMMIT

On November 11, 2016, Allergy & Asthma Network and the American College of Allergy, Asthma & Immunology (ACAAI) successfully hosted the 2016 National Asthma Summit (San Francisco, CA). This one-day event brought together 100 people (representatives of local asthma programs, asthma coalitions, federal agencies) from 27 states. Participants heard from nationally recognized experts about current trends in asthma care and advocacy issues, and brainstormed strategies to advance the implementation of Guidelines-based asthma care throughout the U.S.

This meeting was hosted with partial support from the Centers for Disease Control and Prevention (CDC) National Asthma Control Program.

### Among the topics:

- Disparities in asthma care: Where you live matters
- State legislative and Medicaid policy changes accelerate asthma improvement
- Albuterol for all: Advancing stock albuterol in schools
- Innovative approaches to funding comprehensive asthma management: Leveraging technology in asthma care
- School-based asthma management: Standardized care for children with asthma.





























# **PARTNERSHIPS**

In 2016, the Network partnered with the following organizations to raise awareness and understanding of guideline-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)
- Centers for Disease Control and Prevention (CDC)
- Food and Drug Administration (FDA)
- Environmental Protection Agency (EPA)



During 2016, 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-prong approach of providing quality programming and meaningful Guidelines-based resources.

## **PROGRAMS**



## Advances in Allergy & Asthma Monthly Webinar Series

Monthly webinar series designed to bring the latest Guidelinesbased 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.

March – "Inhaler Confusion" by Dr. Randall Brown 769 Registrants – 113 Participants – 659 archived views

April – "Yellow Zone Strategies: Home Management of Asthma Exacerbations" by Dr. Chitra Dinakar 674 Registrants – 318 Participants – 170 archived views May – "Why is This the Worst Season Ever for Seasonal Allergies?" by Dr. Maeve O'Connor

## 438 Registrants – 153 Participants – 107 archived views

June – "Patient Centered Care at its Best: Shared Decision Making" by Tonya Winders

### 332 Registrants – 141 Participants – 89 archived views

July – "Insect Sting Allergy: To Worry or Not to Worry and What to Do About It" – Dr. David B.K. Golden

## 458 Registrants – 171 Participants – 224 archived views

August – "The September Asthma Peak: Clinical Trends and Practical Strategies" by Dr. Bryan Martin

### 605 Registrants - 249 Participants - 183 archived views

September – "Webside vs. Bedside Manner: Telehealth for Allergies & Asthma" by Dr. Tania Elliott

## 404 Registrants – 186 Participants – 103 archived views

October – "Latex Allergy - Addressing Barriers to Emergency Anaphylaxis Care" by Dr. Wes Sublett

## 168 Registrants - 50 Participants - 58 archived views

October – "Overcoming Barriers in the Real World – A Look at Clinical Issues, School Concerns and Living with Latex Allergy" by Dr. Sandra Gawchik, Dr. Patricia Beierwaltes & Sally Schoessler, RN

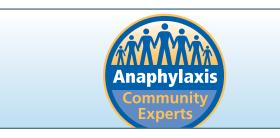
## 130 Registrants – 38 Participants – 41 archived views

November – "Severe Asthma: Evaluation, Management and New Advances" by Dr. Bradley Chipps

## 813 Registrants - 409 Participants - 86 archived views

December – "Smoking and Asthma" by Dr. Michael Blaiss

537 Registrants – 243 Participants – 50 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.

The 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:

- 372 teams across 46 states.
- Volunteers conducted 13,538 training and presentations during ACE workshops and community outreach
- The Network distributed 22,473 copies of Allergy & Asthma Network's award-winning and medically reviewed resources
- 3 national press releases, 1,134 total pickup
- **1,512** media interviews
- 938.400 families and communities reached



## **USAnaphylaxis™ Summits**

The USAnaphylaxis Summits bring together nationally and internationally known experts in the field of allergy and anaphylaxis with stakeholders, including allergists, pediatricians, school nurses, patients, patient advocacy organizations and more. Experts present on high level topics, which provide the foundation for discussion. The summits were held: September 23 in St. Louis, MO; September 30 in Orlando, FL; and October 7 in Henderson, NV.

147 participants from 20 states and Toronto, Canada, including board-certified allergists and pediatricians; allergy-related patient advocate organizations; school nurses; food allergy bloggers; support group leaders; parents of food-allergic children; psychologists and social workers; asthma educators; nurse practitioners and school teachers.

## **Topics:**

- Develop anaphylaxis awareness best practices to share with everyone after the conference
- Help participants build stronger connections within their state or region
- Preventive Drug Lists: Counteracting Unintentional Consequences of High–Deductible Health Plans Anaphylaxis Legislation and Forecast
- Anaphylaxis Research Update
- Implementing Strategies for Emergency Anaphylaxis Care
- Anaphylaxis Roundtable Expert Panel on Addressing Barriers to Emergency Anaphylaxis Care
- Implementing a National Food Allergy Management & Education (FAME) Program
- School Food Allergy and Anaphylaxis Management for the Pediatrician: Extending the Medical Home with Critical Collaboration
- Farm to Table: Food and Latex Allergies



## **American Academy of Pediatrics Champions** Program in Allergy, Asthma and Anaphylaxis

This program was developed and implemented with the support of the American Academy of Pediatrics. The Medical Home Chapter Champions Program on Asthma, Allergy and Anaphylaxis serves to meet an identified need for the development of a high-impact, national initiative focused on improved quality care of pediatric patients with asthma, allergy and/or anaphylaxis issues within medical homes. The goal is to promote the delivery of high-quality asthma, allergy and anaphylaxis care through team-based, family-centered care coordination and co-management among patients and their families, primary care pediatricians, and pediatric asthma and allergy specialists, while improving health outcomes for all children.

## **Achievements:**

- Increased from 40.2% to 78.4% use of asthma action
- Increased from 56.6% to 95.7% confirmation of diagnosis using appropriate testing
- Increased from **47.4% to 88.0%** appropriate epinephrine prescription
- Increased from 23.4% to 57.0% of food allergy/ anaphylaxis action plans
- Increased from 14.3% to 53.0% self-injectable epinephrine technique

### Also, this program presented a webinar series as follows:

- Food Allergy: Epidemiology, Diagnosis and Management in the Medical Home

- Yellow Zone Practice Parameters for Management of Acute Loss of Asthma Control
- Effective Engagement: How Motivational Interviewing can be used to Improve Asthma Management with Patients and their Families
- Groundbreaking Asthma and Allergy Articles from 2015:
   Implications for Care and Practice in the Medical Home
- Preparing Adolescents with Asthma and Allergies for Transition to Independent Living



## **Severe Asthma Campaign**

National awareness campaign with 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, highlighting the importance of referral to specialists to improve patient outcomes; and increase awareness and education on the difference between true impairment vs. perceived impairment, ensuring that both patients and providers are working better together to alleviate symptoms and improve health outcomes.

## **Achievements:**

- 233 placements resulting in 739,503,464 media impressions via print, digital, online, TV, and radio.
- 5 pitches each month to raise awareness of severe asthma
- 18 articles in Allergy & Asthma today magazine in the three issues between July-December 2016 with an estimated readership is 2.1M per article for a total reach of >37M.
- 30 E-news articles on asthma between July-December 2016 with 2,662 click thrus on these stories and an estimated readership of 120,000 per article for a total reach of 4.2M.



## **Tobacco Campaign**

The Network supported the CDC TIPS initiative with campaign resources aimed at spreading the message that smoking is harmful to people with asthma.

#### **Achievements:**

- 2 articles on e-newsletter (>18,000 subscribers)
- 1 dedicated web page
- 1 dedicated email blast
- 1 webinar "Smoking and Asthma" by Michael Blaiss, MD.
- 1 infographic
- Facebook and Twitter posts



## **PURE Rooms Travel Tips**

The program is designed to provide patients and providers access to travel tips and resources designed for allergy and asthma sufferers.

Achievements: Developed and published the following articles on website:

- Spring Break Allergy and Asthma Travel Tips
- Sending Kids to Camp with Asthma or Allergies
- Portable Nebulizers can Help Make Travel Easier
- Best Travel Apps for People with Allergies and Asthma
- Considering a Homestay? Here are Some Allergy-Friendly Tips

More information: www.allergyasthmanetwork.org/category/travel-tips/



## **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:**

- Introduce standardized asthma action plan via professional medical societies (AAP, AAAAI, ACAAI, AAFP, others) and raise awareness via PR campaign.
- Craft strategy to work alongside patient and physician advocates and educate state legislators on the need for stock albuterol.
  - Introduction of HR 4662 in March 2016 to create incentive for states to stock albuterol and standardize asthma action plans.
  - Met with members of the Allergy & Asthma 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.

- Craft educational toolkit and online learning module to enhance understanding of NAEPP guidelines among school personnel
  - Developed School Nurse Toolkit that was disseminated at NASN National meeting in June 2016 and distributed to all school nurses in August. Reached more than 16,000 school nurses and more than **2,000** participants through webinars
  - Resources promoted across multichannel platform and amplified by partnering organizations.



## **Chronic Idiopathic Urticaria (CIU) Awareness Campaign**

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. This campaign includes a multichannel approach via social media, print, traditional and social media.

#### **Achievements:**

- Leverage a multichannel approach via social media, print, traditional media and digital media to raise awareness of
  - Social Media: 2,543 clicks; 366 shares; organic reach 83.712
  - Print AAT 2 articles reach 4M readers
  - Traditional Media 1,275,000
  - Digital Media **8,660,000**
- Provide support via HelpLine to patients and caregivers and guide them to credible, reliable sources. More than **2,500**
- Satellite Media Tour to drive awareness: 42,207,500 reached



# Patient Engagement in Asthma Research

National education initiative based on quarterly webinars, traditional media and social media to address common myths and misperceptions regarding participation in clinical trials.

#### **Activities include:**

- Enhance understanding of the clinical trial R&D process
- Address common myths and misperceptions regarding participation in research

- Increase awareness of clinical trials among people diagnosed with allergies, asthma and CIU
- Launch "Everyday Heroes" campaign to recognize contribution of those who choose to participate in clinical trials

#### **Achievements:**

- Webinars: 3.841 attendees
- Print: 10M reached in **4** issues of Allergy & Asthma Today
- Traditional Media: 28 placements with over 1,400,000 media impressions
- Social Media: 136 posts; 59 shares; 52,963 organic reach
- Actual number of patients served by the program, as part of the total (estimated reach x A&I prevalence of 20% = patients reached):
  - Webinars: **3,841 attendees** x 20% (prevalence of A&I) = 768
  - Print: **10M reached in 4** issues of *Allergy & Asthma* Today magazine x 20% = 2M
  - Traditional Media: 28 placements with over **1,400,000** media impressions x 20% = **280,000**
  - Social Media: 136 posts; 59 shares; 52,963 organic reach x 20% = 10,592



## **Asthma Camps Awareness**

To increase awareness of asthma camps via a multichannel approach (print, digital, monthly email blast, e-newsletter)

#### **Achievements**

- Asthma Camp Tool Kit (Al Keith's "Asthma Blues CDC, 60-page guide with sections for songs, lessons and activities, demo holding chambers and stress balls for campers at asthma camp)
- 66 asthma camps with a reach of 3,980 campers.
- 239 page views and download of the toolkit on our website.

## **Get Smart About Asthma**

To promote access to quality of care according to NAEPP guidelines and to increase awareness of asthma camps, its benefits to improve the overall well-being, quality of life, school achievements and life opportunities for children with asthma by improving their skills in asthma management and control.



## **Back to School Campaign**

To deliver Guidelines-based resources to the hands of practicing school nurses to promote the use of evidence in every day practice. Pediatric patients affected with asthma and allergies spend the majority of their weekday waking hours at school and their chronic health needs must be addressed in the school setting. School nurses historically work with minimal resources and by providing them with up-to-date, meaningful posters and information, the children and youth across the country will be more likely to not just survive, but thrive and experience better health outcomes.

#### **Achievements:**

 More than 500 kits with information and educational tools for asthma management delivered to schools nurses across the country.



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

This is a 5-year cooperative agreement with the Centers for Disease Control and Prevention (CDC) with the goal of implementing national communication and education strategies to strengthen the demand for Guidelines-based asthma care and asthma-friendly environments in the United States and among children with asthma, their parents and caregivers including the Hispanic/Latino community. The focus is expanding the use of asthma action plans among the Hispanic community.

In September 2016, we entered Y02 of this program with the goal to expand our network of partners and organizations working with Hispanic/Latino families to promote the use of an asthma action plan among Spanish speaking parents so they can better support their child in their native language.



# **EDUCATIONAL PRESENTATIONS**

The Network presented at 16 national and statewide conferences to a variety of audiences:

- Centers for Disease Control and Prevention –
   Environmental Hazards and Health Effects Conference
   "Asthma and Air Quality: Clean Air @ Home, School & Work"
- North Carolina Allergy & Asthma Society "Effective Patient Education"
- Virginia Head Start "Creating a Culture of Health in Partnership with Families"
- Pennsylvania Association of School Nurses & Practitioners – "Bullying and Food Allergies – What Can the School Nurse Do?"
- Kentucky Asthma Symposium "Effective Patient Education"
- School Based Health Alliance "Shared Decision Making in Allergy & Anaphylaxis Care"
- National Association of School Nurses "Asthma Care Coordination: Developing Collaborative Care Teams"
- American Association for Respiratory Care Pulmonary Disease Educators Course – "Effective Patient Education"
- Southeastern Allergy Society "Effective Patient Education"
- American Association for Respiratory Care "What Patients Want and Need from their Asthma Provider"
- American Academy of Allergy, Asthma and Immunology Practice Management Symposium— "Asthma Education Reimbursement"
- Association of Asthma Educators "Shared Decision Making and Asthma Education Reimbursement
- Patient-Centered Outcomes Research Institute
   PREPARE "What Patients Want and Need from their Asthma Provider"
- Kentucky Asthma Coalitions "Taking Asthma to School - Evidence-Based Care & Resources"
- World Congress for Patient Advocacy "Increasing Patient Advocacy through the Use of Volunteers in a Community-Based Program"
- New York State Association of School Nurses –
   "Advancing Your Practice with a Professional &
   Personal Approach" and "Epinephrine Policies and
   Protocols"

# **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. More than **500,000** copies of the magazine were distributed in 2016, with an estimated 1.2 million readers per issue. Our articles span the breadth of allergy and asthma topics. Our cover stories in 2016 were:

- Does Where You Live Matter? How Environment Impacts Asthma and Allergy Health
- Making Healthcare Work for You: How to Manage Asthma and Allergies on a Budget and Maximize Your
- Sarah Jessica Parker: How the Popular TV and Film Actress and Producer Taught Her Son To Self-Manage Food Allergies
- The Allergic March: Is it Possible to Prevent Allergies and Asthma?



#### **eNewsletter**

The Network's monthly electronic newsletter delivers to members the latest news, research and perspectives in the field of asthma and allergies. It also includes an Ask the Allergist feature. The format allows the Network to update members on changing clinical information and important issues in the media.

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



## **Special Edition Magazines**

Understanding Asthma (English and Spanish) – More than 20,000 distributed

#### Sections include:

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

Understanding Anaphylaxis (English and Spanish) – More than 40.000 distributed

#### Sections include:

- What is Anaphylaxis? Food Allergy Insect Venom Allergy - Idiopathic - Latex Allergy - Medication - Treatment Exercise

 Additional Resources Education & Advocacy

Understanding Allergies (English and Spanish)- More than

## 6,000 distributed

## Sections include:

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



## **Infographics**

Graphical depictions of important health issues related to allergies and asthma have an impact on awareness and education. The Network developed several Infographics during 2016, including the following:

- Asthma and Smoking
- Allergic Asthma and What You Can Do About It
- Asthma an Economic Burden
- **OPEN Asthma Survey**



#### **Posters**

One of our most unique and requested tools from healthcare providers for patient education:

- Respiratory Inhalers at a Glance (English and Spanish): More than 385,000 English version posters and more than 16,000 Spanish version posters distributed. Updated periodically, provides a visual description of inhalers organized by category (short-acting beta2agonist bronchodilators, long-acting beta2-agonist bronchodilators, inhaled corticosteroids, combination medications and muscarinic antagonist)
- Anaphylaxis at a Glance: More than 5,000 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: More than 5,000 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 corticosteroids. Helps patients identify their medications and understand priming and use instructions.
- Respiratory Inhalers Side by Side: More than 20,000 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.



# Telehealth and Mobile Applications (Collaboration with Doctors on Demand)

In 2016, the Network partnered with Doctor On Demand to expand access to allergy and asthma care providing video visits with board-certified physicians. For people with allergies and

asthma, this service offers immediate access to board-certified allergists via video visits and other services, such as allergy home inspections that help patients identify and remove allergens and asthma triggers from their homes. Patients download the Doctor On Demand app or visit www.doctorondemand.com, answer questions about why they are seeing a doctor, and get connected for a video visit.



## **Asthma Storylines App**

Powered by Health Storylines<sup>™</sup>, 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.

Take control of asthma with a powerful health tool that enables 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 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**

We value our partnerships and provide articles to key publications upon request. Two examples:

## **US News and World Report**

The Network provided a monthly column for publication online, authored Purvi Parikh, MD. Topics for 2016 were:

- Smart Sinus Care
- Pregnancy and Asthma
- Top 10 Things You Need to Know About Asthma
- Summer Travel Tips for Asthma/Food Allergies
- Olympic and NFL Athletes and Asthma
- What Should be in an Asthma Action Plan and the September Asthma Peak
- What to Expect on your First Allergist Visit
- Halloween and the Importance of Carrying Epinephrine vs. Benadryl
- Latex Allergy
- When Experts and Patients Come Together: **USAnaphylaxis Summit Recap**
- Kittens for Christmas? Pet Allergy: It's Not About the Fur

#### **NASN School Nurse**

- Enhancing Asthma Medication Delivery: Spacers and Valved Holding Chambers
- School Nurse Alert: New Epinephrine Auto-Injector Instructions
- Asthma and Vocal Chord Dysfunction: Can You Tell the Difference?
- To Give Epinephrine or Not to Give Epinephrine THAT is (No Longer) the Question!



## **Resources Targeted to Conference Attendees**

In 2016, the Network provided resources to partners and stakeholders, including:

- American College of Allergy, Asthma and Immunology: **3,939** resource packets distributed with a full complement of Network resources
- National Association of School Nurses: **420** resource packets distributed to school nurses with targeted resources. Included new resources developed for school nurses: Signs & Symptoms of Asthma & Anaphylaxis for School Staff and Credible, Trusted Resources for School Nurses
- American Association of Respiratory Care: **400** resource packets distributed to respiratory therapists with targeted resources Included new resources developed for respiratory therapists: Asthma Education: An Outline for a Model Patient Education Program, Parent Information for Managing Asthma at Daycare or School and Credible, Trusted Resources for **Respiratory Therapists**



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 other related conditions. Together with patients, families, healthcare professionals and industry partners, the Network made substantial progress in 2016 toward our advocacy goals by amplifying the patient voice, building capacity and making connections in Washington, D.C. and in communities around the country.

# **AMPLIFY PATIENT VOICE**



## Allergy & Asthma Day Capitol Hill (AADCH)

AADCH is an annual event in the month of 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 our attendees a chance to meet with their members of Congress to take part in federal advocacy – a critical component in our work to end needless suffering and death due to allergies and asthma.

AADCH 2016 was a great success with over **80** participants visiting with more than **100** members of Congress or their legislative staff. Also in attendance were singer-songwriter Natalie Grant and her daughter Gracie – who has asthma – and former NFL player Ickey Woods whose son Jovante died from asthma. Our AADCH event 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). Legislative priorities focused the year's advocacy efforts on access to high quality and affordable healthcare, safe and effective medicines, mitigating environmental health hazards, and innovative therapies and technologies.

# **POLICY AND OUTREACH**



#### **FEDERAL**

The Network aggressively worked to achieve its federal advocacy goals and objectives through 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. During the 114<sup>th</sup> Congress, the Network weighed in on legislative measures and regulatory proposals in the interest of patients and families living with asthma and allergies, including:

 Medicare Telehealth Parity Act (H.R. 2948) – Provided for an incremental expansion of telehealth coverage under the Medicare program that includes respiratory therapists (RT) among other medical specialists, as qualified telehealth providers. Respiratory care services would also be covered and remote patient monitoring for patients with certain chronic conditions that include COPD.

- School-Based Asthma Management Program Act (H.R. 4662) – Added provisions to the criteria for the federal asthma grant preference such that states would be incentivized to ensure that schools stock asthma-related quick-relief medications, asthma-related devices and educational materials; implemented an asthma action plan for students with asthma diagnosis; and provided asthma education for school staff.
- School Asthma Management Plan Act (S. 1065) Helped schools and families afford the new inhalers they need by providing over \$100 million in funding to schools in low-income, high-incidence areas to purchase inhalers and holding chambers so children with asthma will have access to the treatment they need. Schools were also required to develop and implement asthma management plans. The bill provided for additional funding for asthma research and improved collaboration among federal agencies for better asthma surveillance and data collection.
- Creating Opportunities Now for Necessary and Effective Care Technologies (CONNECT) for Health Act (H.R. 4442/S. 2484) – Promoted cost savings and quality care under the Medicare program through the use of telehealth and remote patient monitoring services. It also would allow new originating sites – dialysis facilities, telestroke evaluation and management sites and Native American health service facilities – and permit further telehealth and remote patient monitoring in community health centers and rural health clinics.
- Federal Aviation Administration (FAA) Reauthorization Act (H.R. 636) – The Senate FAA Reauthorization bill, H.R. 636, authorized funds for the FAA through September 30, 2017. The bill included provisions directing the FAA to: 1) evaluate the medical equipment and supplies required on airline flights, and 2) ensure that the required items meet the emergency medical needs of children. The Senate bill specifically mentioned epinephrine auto-injectors. The House bill, H.R. 4441, did not include this language.
- Airline Access to Emergency Epinephrine Act (S. 1972) - Required airlines to 1) clarify that 1:1,000 epinephrine ampules included in emergency medical kits carried on airport are intended to be used for the treatment of anaphylaxis; and 2) carry not fewer than 2 packs of epinephrine auto-injectors (one for individuals weighing less than 66 pounds and one for use on individuals weighing more than 66 pounds) as an initial treatment for anaphylaxis. Air carriers are also required to provide crewmember training based on the advice of experts and to know how to recognize an acute allergic reaction and how to administer the auto-injectable epinephrine.

- Nurses for Under-Resourced Schools Everywhere (NURSE) Act (S. 2572) - Provided grants to increase the number of school nurses in public elementary schools and secondary schools.
- Federal Asthma Program Funding. Continued funding for federal programs that support asthma education, outreach and research at the Centers for Disease Control and Prevention, Environmental Protection Agency and the National Institutes of Health.

While legislation we supported continued to gain increased bipartisan support and committee engagement in 2016, the measures were not finalized prior to the end of the 114th Congress. However, we are optimistic measures will be reintroduced in the 115<sup>th</sup> Congress.

In the 114<sup>th</sup> Congress, the Network continued to be positioned as a key expert on asthma and allergy issues, resulting in more direct interaction with members of Congress and staff and advance notice of new initiatives. The Network was often called upon to provide guidance to lawmakers in their efforts to draft legislation and solidify support. For example, the Network engaged with Congressman Don Beyer (VA) in his efforts to draft a federal public entity bill that would authorize the possession of epinephrine autoinjectors for use by a trained employee, volunteer or agent for emergency treatment of a person experiencing anaphylactic symptoms; Congressman Gregg Harper (MS) on proposed telehealth policies for respiratory care services under Medicare; and Congressman Eliot Engel (NY) on a legislative proposal regarding food establishments displaying information on the major food allergens.

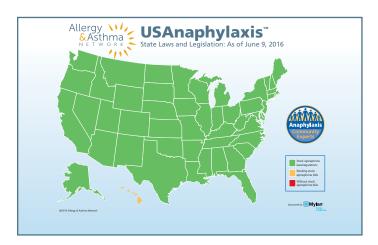


## REGULATORY

The Network actively engaged on regulatory matters at the federal level, including:

• Written comments submitted to the Food and Drug Administration (FDA) on a proposal to ban powdered surgeon's gloves, powdered patient examination gloves, and absorbable powder for lubricating a surgeon's glove.

- Oral comments delivered at the Office of Management and Budget (OMB) on EPA's proposed rule to implement the greenhouse gas emission guidelines for existing fossil fuel-fired electric generating units under the Clean Air Act.
- Oral comments delivered at FDA on proposed changes to U.S. Pharmacopeia's (USP) Pharmaceutical Compounding: Sterile Preparation Guidelines – Chapter 797.
- Written comments submitted to the Centers for Medicare & Medicaid Services (CMS) on a proposal to implement a nationwide demonstration impacting all Medicare Part B medicines.
- Participated in the development and dissemination of Peanut Prevention Guidelines in coordination with NIH/ NIAID



### **STATES**

The Network advocated for policies at the state level that supported individuals living with allergies and asthma. We communicated Network policy positions via emails and letters to state legislatures, and mobilized Network members and Anaphylaxis Community Experts (ACE) volunteers through our emailed Action Alerts to contact their state representatives. We also engaged state and local entities to increase their understanding of policies enacted into law (e.g., school stock epinephrine and public access) and ways to implement such policies.

In 2016, we advocated for allergy-anaphylaxis policies in California, Illinois, New Hampshire, New York and Ohio, each of which became law. Currently, 49 states allow for stock epinephrine auto-injectors in schools and 30 states have public entity laws that permit venues (e.g., recreation camps, youth sports leagues, restaurants, amusement parks, sports arenas and daycare facilities) to maintain an epinephrine auto-injector on site, with the intention of reducing the time it takes to get life-saving epinephrine to a person having a sudden anaphylactic reaction.

The Network continued to advocate for states to approve school stock emergency supplies of albuterol, the medication in guick-relief inhalers that treats asthma flares. There are currently 10 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.



# **COMMUNICATIONS**

Network staff and members carried out advocacy messages through contact with members of Congress and state legislatures and various media outlets. The Network provided both oral and written testimony.

#### FEDERAL AND STATE

Network members and volunteers across the country connect with their federal and state representatives on key policy issues.

For example, prior to a vote in the House of Representatives on a funding bill (H.R. 5538, fiscal year 2017 Interior and Environment Appropriations) that contained provisions to block, weaken, and delay critical clean air protections, Network members and volunteers contacted their House members to vote NO in order to protect public health from air pollution. The bill did not pass in its current form and Congress approved a Continuing Resolution (CR; H.R. 2028) to continue policy and funding provisions of fiscal year 2016 Appropriations legislation until April 2017. The CR did not include controversial riders, or major changes in existing federal policy.

In the state of Louisiana, the Network reached out to all members of the Health and Welfare Committee and the full House of Representatives to support a telemedicine policy proposal (HB 570) that would enable Louisiana residents to secure high-quality care through the use of modern technologies. The bill passed the House and the Senate and was signed into law (No. 630) on June 17, 2016.



## **SOCIAL MEDIA**

The Network's growing presence on Twitter (twitter. com/AllergyAsthmaHQ) and Facebook (facebook.com/ AllergyAsthmaHQ) extended our policy outreach. In 2016, the Network's social media advocacy campaigns included:

- Allergy & Asthma Day Capitol Hill 2016 used hashtag #AADCH2016 on Facebook and Twitter to raise awareness of key policy priorities, engage participants, and connect with members of Congress.
- Climate Change and the Clean Air Act

www.facebook.com/AllergyAsthmaHQ/ posts/10154235301982419

www.facebook.com/AllergyAsthmaHQ/ posts/10154222860392419

www.facebook.com/AllergyAsthmaHQ/ posts/10154217397257419

www.facebook.com/AllergyAsthmaHQ/ posts/10154162670442419



## PRINT MEDIA

"Stock Albuterol in Schools is Critical For Asthma Emergencies" written by Director of Advocacy Charmayne Anderson about the need for immediate access to emergency medications in schools for children with asthma. (Distributed on PR Newswire, a national newswire, it was picked up by 182 media outlets for a total potential audience of 12+ million).



## **EVENTS**

In 2016, the Network participated in the following events:

- ecoAmerica's American Climate Leadership Summit - Collaborated with a diverse group of more than 200 leaders from business, health, faith, higher education, communities, government, culture, philanthropy and climate on climate solutions by sharing information, exchanging ideas and best practices, and planning to build capacity for effective action.
- Children's Environmental Health Network -Collaborated with children environmental health advocates (e.g., nonprofit, government, industry) to raise awareness and understanding on critical issues regarding children's health and the environment; and mobilize action.

#### • World Congress Summit on Patient Advocacy

Presented on panel "Increasing Patient Advocacy
 Through the Use of Volunteers in A Community-Based
 Program" to share information on Network's ACE
 volunteer program and advocacy participation.



#### INTERVIEWS/TESTIMONY

- Live television broadcast interview by Network Director
  of Advocacy with Moms Clean Air Force on Climate
  Change and Asthma during the health segment
  on Voice of America TV (a radio and television
  broadcaster with an estimated global audience of 236.6
  million people).
- Testimony before the Washington D.C. City Council's Committee on Health & Human Services on bill B21-883, "Access to Treatment for Anaphylaxis Amendment Act of 2016".
- Research America Congressional Briefing, Patient Voice in R&D

# **BUILD CAPACITY**



## **Congressional Asthma & Allergy Caucus**

The Congressional Asthma & Allergy Caucus (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.

The Network encourages lawmakers to join the Caucus and communicates with our members/volunteers through emailed Action Alerts and at AADCH to urge them to contact their representatives to join the Caucus. The Caucus membership continued to grow in 2016 and by year's end, **41 lawmakers** had joined. To further engage members of Congress and their staff on allergy and asthma issues, the Network will partner with the Caucus in 2017 to conduct congressional briefings and other public health events.



## **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), and **Research!America** (medical research and innovation). 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.



## MAKE CONNECTIONS

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

- Participated in American Association for Respiratory Care Hill Day events to advocate for respiratory care for patients.
- Attended Novartis Pharmaceuticals' "Power of Partnering Summit" increasing the Network's visibility and learned best practices for public interest communications and advocacy.
- Engaged and participated in advocacy efforts
  with industry partners Mylan (epinephrine and
  anaphylaxis) and GlaxoSmithKline, AstraZeneca and
  TEVA (asthma and other chronic respiratory diseases).
- 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 the area of public health.
- Participated in meetings with the Environmental Protection Agency on children's environmental health issues.
- Participated in **Alliance for Patient Access Respiratory Workgroup** which produced a white paper on Access to Respiratory Care and Immunotherapy



# **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 group members 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 that improve their 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 2016 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
- Need to Build Advocacy Among Patients & HCP's
- "Value" Definition
- Uncertainty re Consolidation in Space
- Pharma
- Payers
- ACO's
- Oportunities for Education, Advocacy, Outreach and Research
- Challenges that May Affect Patients



The 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.



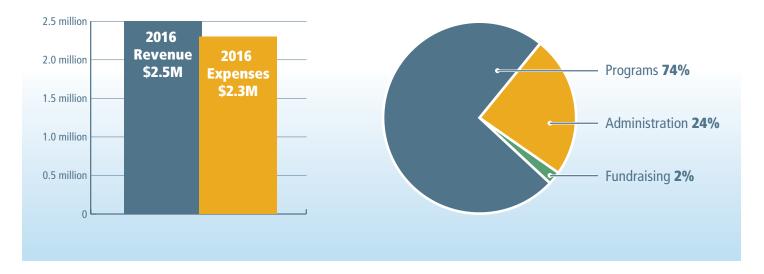
## **OPEN Asthma Survey:**

The Observations of Patient Experience in the Nation (OPEN) Asthma Survey was commissioned by Allergy & Asthma Network to explore current attitudes of patients and healthcare providers about asthma control with the goal of identifying gaps in perception of the patient's condition. The Network surveyed **2,900** people living with asthma who were treated with daily prescription medicine, as well as **850** healthcare providers who treat patients with asthma. More: allergyasthmanetwork.org/research/open-asthma-survey.



## **Decision Mapping:**

Since 1985, Allergy & Asthma Network has surveyed countless individuals, families and healthcare professionals about allergy and asthma care – how they make daily decisions about all types of allergy and asthma related conditions — and how policies benefit or sometimes create barriers to care. In 2016, the Network worked to analyze this data. The goal is to paint a picture of beliefs, behaviors and trends. We'll publish what we've learned, share the knowledge with decision makers and hopefully leave the world breathing a lot easier in the process.



# 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.

2016 sponsors include: American College of Allergy, Asthma and Immunology (ACAAI), AstraZeneca, Boehringer Ingelheim, Boston Scientific, Centers for Disease Control and Prevention (CDC), CHEST Foundation, Circassia, Genentech Inc., GlaxoSmithKline, Homelab, InspiRX, Lupin Pharmaceuticals, Inc., MEDA, Mylan Specialty L.P., Novartis, Pure Room, Sanofi US, Reid, McNally & Savage and TEVA Respiratory.

# LEADERSHIP

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

