



2019 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.

As an innovator in encouraging family participation in treatment plans, Allergy & Asthma Network specializes in making accurate medical information relevant and understandable to all while promoting standards of care that are proven to work. We believe that integrating prevention with treatment helps reduce emergency healthcare visits, keeps children in school and adults at work, and allows participation in sports and other activities of daily life.

The organization's patient-centered philosophy makes an empowering difference for individuals seeking disease management advice in consumer- friendly language. From newsletters, magazines, special publications in English and Spanish, and a bilingual support toll-free helpline, the Network speaks to patients' needs in a way that achieves quantitative and qualitative results.

This report highlights the Network's 2019 programs, initiatives, partnerships and resources.

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Looking Back, Looking Ahead

As we enter 2020, Allergy & Asthma Network is poised to lead our community forward with confidence and unwavering commitment built over the past 35 years. 2019 proved to be another key year of success in advancing the mission to end needless death and suffering due to allergy, asthma and related conditions through outreach, education, advocacy and research.

In this annual report, you will see our members, volunteers, board, staff and leadership hard at work – from community health fairs to international medical congresses; from our award-winning publications to training community health workers; from Capitol Hill to state legislatures; from the research bench to the bedside.

Each of the programs and resources outlined herein are evidence of the work we dedicate ourselves to daily. You will hear from many Network stakeholders firsthand.

In 2019, we saw dozens of lives saved by stock epinephrine and albuterol school policies. We witnessed hundreds of underserved children learning more about how to manage their chronic conditions. We launched an international awareness campaign to address steroid stewardship. We shaped clinical trials and published peer review articles in atopic dermatitis, asthma, nasal polyposis and more.

We could not have this impact without your support .Thank you for your continued commitment to the mission of Allergy & Asthma Network. We still have work to do as we learn how to "Breathe Better Together"!

Anya A. Winden

Tonya Winders, President & CEO



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John Tucker, Chair, Board of Directors



EDUCATION



At Allergy & Asthma Network we often say an **ENGAGED** patient who is **EDUCATED** with guidelines-based tools becomes a person who is **EMPOWERED** to create a healthier life for themselves and their family. We believe in education for each patient at their individual health-literacy level and every day we work hard to "walk our talk."

In 2019, our Education Team goal has been to provide diverse, evidence-based programs and resources using multichannels to better equip people with allergies, asthma and related conditions to improve their health outcomes.

From our signature magazine, *Allergy & Asthma Today*, to our webinar series to our award-winning *Understanding Guides*, to infographics, website updates and monthly e-newsletters, we strive to make a difference in the lives of patients.

We're proud to showcase our publications, programs and resources as we move the mission forward each day!

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Sally Schoessler Director of Education

2019 AT A GLANCE

Advances in Allergy and Asthma Webinar Series

– Montlhy webinars supported by the American College of Allergy, Asthma and Immunology (ACAAI) to provide the latest trends in topics related to asthma, allergies and related conditions to physicians, nurses, respiratory therapists, asthma educators, patients and more. Most viewed in 2019:

-Vaping: What We Need to Know

-The Next Steps in Peanut Allergy and Anaphylaxis for the Infant: Special Considerations for this Growing Population

https://allergyasthmanetwork.org/category/ webinars-updates/



"For several years, the American College of Allergy, Asthma and Immunology has partnered with Allergy & Asthma Network to offer webinars for providers and patients. With over **34,000** listeners, we have collaborated to identify topics that are timely and provide vital information that makes a difference in the lives of patients. In August of 2019, I spoke about vaping – a subject that has been a high impact topic on the minds of patients.



We had close to 1000 people register and over 1100 people listened between the live presentation and the recorded, archived webinar. The feedback that we received was overwhelmingly positive and helps both organizations make a difference in the lives of patients."

Todd Mahr, MD LaCrosse, WI 2019 President American College of Allergy, Asthma & Immunology

Online Learning HQ – Sixteen modules on allergy, asthma and related conditions provide continuing education credit to nurses and respiratory therapists. *https://allergyasthmahqlms.com/*

Ask the Allergist – A video-based series in which an expert on the field answers a frequently asked question. Total of **43** on demand. **12** made in 2019 https://allergyasthmanetwork.org/ask-the-allergist-

nttps://allergyasthmanetwork.org/ask-the-allergistpodcasts-and-videos/

Monthly eNewsletters – Timely news, resources and information for patients and health care providers. Reaches over **47,000** per issue. Open rate **25%**

Asthma Medication Assistance online tool –Graphical depiction of most inhaled medications with phone numbers and website links to direct patients to prescription assistant program. *https://allergyasthmanetwork.org/what-is-asthma/what-if-i-cant-afford-my-asthma-medication/*

Practical Tips for Daily Living with Allergies & Asthma – 25 short – casual videos created by Network partners to provide patients with tips to help them live with allergies and asthma.

Infographics –How to Avoid the September Asthma Peak; What Patients Want; What's the Best Treatment for my Atopic Dermatitis?





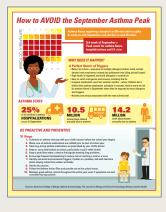


Use the list below to contact the manufacturer to find out about its patient assistance program.

If you are still unable to afford the prescribed medication, talk with your doctor. It's very important to use your medication as prescribed. Be sure to ask your doctor for help you so you dont go without taking your asthma medication or other respiratory medication.

Short-acting beta2-agonist bronchodilators





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	Corticosteroids	Calcineurin inhibitors	Crisaborole 2%
	Controls redness and itching; apply 1-2X per day; approved for children, including infants as young as 3 months	For use on eyelids, ampits, mouth area, groin; apply 1-2X per day; approved for children ages 2 or older	For use on eyelids, armpits, mouth area, groin; apply 1-2X per day; approved for children ages 2 or older
	Redness, stretch marks, skin thinning, spider veins, face rash	Stinging or burning may occur upon first use; very slight risk of	Stinging or burning sensation may occur
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Allergy & Asthma Today magazine– Articles and personal stories distributed for free to patients and health care providers offices. **Reach is over 2,000,000**.

Understanding Overlap Conditions –Addresses 25 rare or related conditions that mimic asthma or allergy, making them more difficult to diagnosis. **5500** copies distributed.

Posters (updated)

Respiratory Treatment Poster (English & Spanish) –More than **1 million** distributed.

Respiratory Treatment Side by Side. More than **8000** distributed.

Epinephrine Treatment. More than 7000 distributed

Conference for Asthma Research and Education

(CARE) Conference – A one-day conference at Ann & Robert H. Lurie Children's Hospital of Chicago (Illinois) to address asthma issues in underserved communities. Over **125** families and health professionals on site. A collaboration with the American Thoracic Society Public Advisory Roundtable and Science and Outcomes of Allergy & Asthma Research.

Presentations – We presented to local and national groups including the American Thoracic Society, School Based Health Alliance, Texas Children's Hospital, National Association of School Nurses, Association of Asthma Educators and CHEST International.

"Producing videos for the Network was a great learning tool for me, and great teaching tool for school nurses. Showing how to make using inhalers fun, makes medication administration an educational moment! Keeping a few items (pinwheels, small bubblers, and straws) assists students in a light way (no lectures), how to exhale and inhale properly, getting the medication



into the lungs. This is an important tool and I hope helps students and school nurses."

Sandra Moritz, Med, BS, RN, NCSN School Nurse Consultant





Epinephrine Treatments-



OUTREACH



More than 25 million Americans have asthma, but not all have equal access to highquality healthcare. The disease is more common among African-American, Hispanic/ Latino and Native American populations, particularly those in poor, urban areas. For this reason our focus in 2019 was to work towards eliminate health disparities in care using a multichannel approach to reach communities of color. We did that by participating in health fairs and local events in targeted areas; expanding our volunteer program; continuing to offer a bilingual toll-free help line; developing and disseminating cultural competent educational materials in English and Spanish; training community health workers to conduct environmental home visits; partnering with National Hispanic Medical Association, National Medical Association and the CDC to increase patient engagement; and bringing together asthma partners from all 50 states (including Puerto Rico) to a national meeting to discuss ways to advance guidelines-based care for all.

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Marcela Gieminiani Director of Outreach

2019 AT A GLANCE

The Network & the Media

To expand awareness of the Network and the conditions we had the honor to work alongside board certified allergist Purvi Parikh, MD, as our national media spokesperson

Media impresions in 2019: > 1.3 billion.

Social media: Expanded users visits 60%

Visit:

www.facebook.com/AllergyAsthmaHQ; www.twitter.com/AllergyAsthmaHQ and www.instagram.com/AllergyAsthmaHQ

Toll-Free Help line (800.878.4403)

Direct line of communication for patients and families (English & Spanish). **>300** calls.

Membership: The Network offers free and paid membership to provide access to all its educational material, resources and support. **4,300** new members .

https://members.allergyasthmanetwork.org/general/
register_member_type.asp?



"Being the national media spokesperson for Allergy & Asthma Network has been life changing for me. As a board-certified allergist and immunologist, I give my patients advice on a daily basis on how to stay healthy, control their illness, and how to avoid life threatening circumstances. Through being a media spokesperson, I have been blessed to give this same advice to millions of patients and their families

whom I may never meet. If that helps prevent even one exacerbation, a life-threatening ER visit, or hospital admission, or death I feel I have succeeded. I am eternally grateful to this organization and the great work they are doing to prevent these bad outcomes for all patients and families near and far."

Purvi Parikh, MD

Outreach Service Coordinators (OSCs). Expanded volunteers to all 50 states

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"In 2019 we expanded the program all across the United States and participated in health fairs and community events in 32 cities were we offered asthma and allergies education and distributed free educational material to more than 9000 families. We are grateful to have so many amazing people as part of our mission



to continue helping others breathe better."

Tracy Bush, Outreach and Volunteer Coordinator

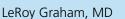
Asthma Screenings

In partnership with Not One More Life, conducted asthma screenings and asthma education events for African American families in Atlanta, Chicago an Omaha. **150** families reached.



Allergy

"Partnering with local churches is a great way to reach at-risk populations and build trust with patients in need of better quality care.."



Professional Partners

We partner with local and national medical-professional associations to conduct programs and to provide educational tools and resources for their practices and their patients. AAAAI; NHMA, NMA, Texas Allergy (TAAIS), Chest, ATS, AAE, NASN, AAP, ACAAI, AARC. "I'm so privileged to be part of Allergy & Asthma Network. I have severe asthma and the Network provides great support, education and research. Getting the information out and sharing it with others is very important to me. The materials they provide are amazing."

Brenda Young, patient

National Asthma Control Program

Awareness and education for Hispanic/Latino communities. With the support of the U.S. Centers for Control Disease and Prevention (CDC) **2,350** Hispanic families were reached.

OCS Overexposed - Oral Corticoesteroid Stewardship Campaign

A national education campaign to raise awareness of appropriate oral corticosteroid use and reveal OCS overuse for what it often is – a treatment plan failure. This campaign is led by the Network and is comprised of more than 10 partnering groups including patient advocacy organizations, medical societies and industry stakeholders.

https://allergyasthmanetwork.org/about-us/



Community Health Worker Trainings

In partnership with state asthma programs, we trained more than **100** community health workers in Ohio and Texas on in-home visits and interventions for indoor asthma management in low-income communities.



"Community health workers are the kingpin of the medical home and so important for families with asthma. They are the liaison between the family and the medical team. They help the family understand what is going on and what is needed on their (the family's) end. I spent a week traveling

thru the state of Ohio providing CHW training to people from all paths in life and they walked away knowing that they would be able to make a change in a family's life."

Gayle Higgins, AE, CHW training facilitator

Telehealth Coach Program

Developed a telehealth platform and recruited more than **40** healthcare professionals to begin offering services in 2020. Includes asthma & food allergy coach visits to develop better self-management skills.

https://allergyasthmanetwork.org/telehealth-for-asthmaallergies/



2019 USAsthma Summit

Hosted in Houston, TX, we brought together over **900** people live and remotely (via livestream) from all 50 states and Puerto Rico to advance guidelines-based care and eliminate health disparities among communities of color in the United States.

"The USAsthma Summit was an excellent event and I learned new information about asthma data in the United States. It also helped me to connect with other asthma program managers and hear what they are doing in their communities for asthma patients and their families."

Ibis Montalvo Félix- MPHE, Ed.Dc, Asthma Program Manager, Puerto Rico Department of Health, San Juan, Puerto Rico





ADVOCACY



Health advocacy is essential to protect patient health and safety. Advocates play a crucial role in raising awareness, educating policymakers and the general public, removing barriers and making issues widely known to make medical care and treatment more accessible and effective. Healthcare challenges need thoughtful solutions to support patients, their families and communities. Engaging stakeholders and key constituencies are also important in this effort. Each year, the Network actively engages in advocacy at the federal and state levels of government to raise visibility and influence policy to improve care and promote lifesaving research for the millions of people affected by asthma, allergies and related conditions.

In 2019, our advocacy efforts aligned with our policy priorities which included: Access to Care, Affordable Medications and Treatments, Asthma and Allergy Federal Funding, Health Equity, and updates to Food Package Labels to include sesame and allergen cross-contact.

harmayne Anderson

Charmayne Anderson Director of Advocacy

2019 AT A GLANCE

Advocated for federal policies, programs and regulations that support patients and their families

Federal funding for fiscal year (FY) 2020 was provided for the National Institutes of Health (NIH); the Centers for Disease Control and Prevention (CDC) - which includes the National Asthma Control Program; the Health Resources and Services Administration (HRSA) to support the medical workforce; the Environmental Protection Agency, which includes environmental oversight activities and asthma programming; and the U.S. Department of Housing and Urban Development's (HUD) Healthy Homes Initiative that addresses health and safety hazards in the home.

Engaged with other groups to add "Food Allergies" to the list of conditions eligible to be studied under the U.S. Department of Defense's (DOD) Peer-Reviewed Medical Research Program, which includes medical research projects relevant to military health. This effort also led to further investment in the Consortium of Food Allergy Research (CoFAR) established by the National Institute of Allergy and Infectious Diseases (NIAID) to support clinical research on food allergies.



"It is hard for me to articulate my experience with Allergy & Asthma Network. To say it has been a blessing would be an understatement!! My relationship started with the Network a little over a year ago. I feel the Network has become like family. The Network has had a huge impact on our small foundation,



The Brendon McLarty Memorial Foundation, in so many ways. We had a goal to get legislation passed in our state. Yet, we were not even sure where to begin. With the guidance and encouragement of the Network, we were able to advocate and successfully see SB 381 signed into law in April of 2019. The Network coached me through conference calls, provided us with written material to advocate, and so much more. We are incredibly grateful I am so passionate about. I am honored to join the Board of Directors. It is truly an incredible opportunity!"

> Jennifer Blair, Executive Director, Brendon McClarty Memorial Foundation

Worked with members in Congress to have bills reintroduced in the 116th Congress, including the *School-Based Allergies and Asthma Management Program Act* that incentivizes states to implement comprehensive asthma and allergy management programs in schools, and the Safe Step Act which requires health plans to provide exceptions for medications subject to step therapy protocol. Network comments and testimony were also shared with federal agencies on matters, including the U.S. Environmental Protection Agency's (EPA) regulations over air and water quality and the approval of new treatment therapies for children and teens with peanut allergies at the U.S Food and Drug Administration (FDA).

"Since joining the board of Allergy & Asthma Network and as a member of the Advocacy Committee, I have truly enjoyed being involved with the Network's advocacy efforts. The best part is our engagement during Allergy & Asthma Day Capitol Hill (AADCH). Each year the Hill visits are wellorganized, more productive



and result in greater engagement with members of Congress on key issue areas and successful policy changes that benefit patients and their families."

Anthony Cook, Patient and Network Board Member

"Allergy & Asthma Network is a powerful force for change that approaches each challenge with a deep understanding of the voice of the patient. When looking for an advocacy partner, I always feel confident working alongside the Network. Together, we have presented strong cases to the federal government, set an achievable



roadmap for change, and thoughtfully pursued protections for millions of patients living with food allergies in the United States. Although advocating for change is challenging work, the Network has made the process educational and effective."

Erin Malawer, Executive Director, AllergyStrong

Advocated for policies at the state level to support individuals living with chronic and life-threatening conditions. Our grassroots efforts included patient testimonies, thousands of letters of support and stakeholder engagements which resulted in laws in over **20** states covering areas such as school stock of albuterol, step therapy and prior authorization, food allergy guidelines, public entity stock of epinephrine, latex allergies, and telehealth.





Allergy & Asthma Day Capitol Hill (AADCH)

In its 22nd year, 2019 brought together members of Congress, staffers, patients, families, caregivers, advocates, healthcare professionals, industry leaders and other stakeholders to discuss critical legislative and regulatory issues facing patients living with asthma, allergies and related conditions. We had record attendance with over 150 participants advocating on Capitol Hill.

In all, patients, families, healthcare providers and patient advocates tallied 125 visits with members of Congress in a single day.

Our virtual advocacy day event ensure that federal policies, regulations and resources are in place to support optimal health outcomes for people with chronic and life-threatening conditions.

More on Advocacy: https://allergyasthmanetwork.org/advocacy/

"The Network has been irreplaceable partner as we at ACAAI work together to help our patients. The biggest victories have been the preservation of allergy shots and allowing students to carry injectable epinephrine and rescue inhalers. These treatments might not be available today without the continued advocacy efforts of Allergy & Asthma Network and the bringing together of many stakeholders to raise awareness and advocate for allergy and asthma policies during the annual Allergy & Asthma Day Capitol Hill in Washington, D.C."

> Allen Meadows, MD, President, American College of Allergy, Asthma and Immunology (ACAAI)









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.

As Allergy & Asthma Network moves into its 35th year, we look back and are proud of the advancements we contributed to in treatment for allergies, asthma and other related conditions. Research for the Network has evolved over the past few years and now plays a more significant role in our overall mission by including the patient voice in both clinical trials, investigator research initiatives, and patient and family focus groups. In the past year, we completed more surveys, added patient advisory boards, and developed an asthma patient registry.

Mary Hart Director of Research

2019 AT A GLANCE

PREPARE PCORI Project (Person Empowered Asthma Relieve)

To recruit **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 to ensure patient voice is heard and incorporated into all aspects of the study. www.preparestudy.net

Patient Activation Measurement Study (PAM)

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

HealthUnlocked – Living with Asthma Community

This online community provides a space for people to share advice, receive support and meet others who truly understand what you're going through. The Network administers this community and can pose questions to gain global insight from patients on specific health related issues. **513** members

"I am a Network Patient Advisor and have participated in many patient focus groups discussing asthma treatments that include various medications and how they effect me. The most recent group will change the future of core asthma outcomes measured for clinical trials. I believe my voice matters and the patient focus groups conducted by the



Network will have an impact on future development of asthma treatment and clinical practice."

Charnette Darrington Zaskoda, severe asthma patient



coreAsthma – Core Outcomes in Moderate to Severe Asthma

To reach agreement on a "core set" of 10-12 patient-reported outcomes to be used in clinical trials of therapies for moderate to severe asthma. Includes patients, caregivers, patient advocates, health care providers, payers, and other stakeholders. The Network served as coreAsthma Advisory Board Members.

Antidote

To survey **4,000** patients with a variety of conditions and uncover how people think about clinical trials, and why they may participate – or not. Results will provide valuable insight that can enable deeper engagement with patients and physicians in more significant ways.

More on Research Projects

https://allergyasthmanetwork.org/research/research-projects/

"As a board-certified physician in asthma and immunology, pediatrics and a clinical research investigator, I work each day with my patients and their families diagnosed with asthma, allergies, eczema and related



conditions to improve their health and find better ways to treat and prevent diseases. Clinical Research is so important! Allergy & Asthma Network plays an important role in clinical research by conducting physician surveys and patient focus groups to gain better understanding of real-world physician practice and their use of shared-decision making tools."

Margaret A. Adair

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.

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