



# 2018 ANNUAL MEETING REPORT





# INTRODUCTION

Dermatological conditions are more than skin deep, as any of the participants at the Derma Care Access Network’s 2018 Annual Meeting could tell you. Hosted by the Royal Danish Embassy in Washington, D.C., the meeting allowed patients, parents of patients and health care professionals to weigh in on dermatological conditions and the treatment barriers that patients face.

His Excellency Lars Lose, Ambassador of Denmark, opened the event by describing his own history with dermatological disease. “Like many in my country,” Ambassador Lose explained, “I planned to study forestry at university. Then I discovered that I was allergic to dirt.”

The audience chuckled, but Ambassador Lose’s recollection underscored one of the event’s major themes: **Dermatological conditions can change the lives of patients and their families.** Panelists and speakers brought this theme to life by sharing their stories.

# CARA'S STORY

## ECZEMA

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Cara Ellis knows the impact of dermatological conditions all too well.

Her five-year-old son, Walker, has battled eczema “from day one,” Cara explained, his condition exacerbated because he was born in winter. Watching her infant struggle in discomfort, unable to sleep, was “gut wrenching,” Cara recalled. She and her husband scrambled for solutions. “You name it, I tried it,” Cara explained.

When the family finally sought dermatological care and were prescribed a topical cream for Walker, Cara hoped their struggle was over. She was wrong.

Her insurance company directed her to first try wet wraps and wet pajamas. The approaches did nothing to improve Walker’s eczema – or the sleepless nights the family already endured. In a process known as step therapy, or “fail first,” Cara was then directed by her insurer to use three different hydrocortisone creams, none distinguishable from the other. When these also failed to help Walker, Cara’s family finally got insurance coverage for the cream prescribed by Walker’s dermatologist.

But coverage did not shield Cara and her family from the treatment’s cost burden.

Cara recalls paying \$225 out of pocket for a single tube of Walker’s ointment – a challenge for a single-income family living on a budget. The ointment did improve Walker’s eczema. It also steered Cara on a crusade to understand more about the ingredients in everyday personal care products, cosmetics and cleaning solutions.





# EILEEN'S STORY

## EPIDERMOLYSIS BULLOSA

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Some people view dermatological conditions as purely cosmetic. Eileen Attar knows better.

On the day that Eileen's son Brady was born, patches of his skin were missing. "His feet were raw," Eileen recalled. Hospital staff whisked Brady to the NICU. He was later diagnosed with epidermolysis bullosa, a disease Eileen had never heard of.

The rare genetic condition causes near-constant abrasions, scabs and sores across the body. The external symptoms are exacerbated by other complications. Brady has metabolic needs that require a G-tube for feeding. The condition also affects his eyes, "pretty much everything in his whole body," Eileen acknowledged.

Brady needed round-the-clock care, including hours a day spent wrapping and re-wrapping the specialized bandages that protect his wounds. Bath time was a battle, Eileen recollected.

Exhausted and deeply concerned for their son, Eileen and her husband still had to rally to meet the next challenge: getting Brady the care he needed.

The family's health insurer balked at the prospect of getting Brady a home health nurse. The insurer also repeatedly denied coverage for Brady's bandages, leaving Eileen's family to pay \$6,000 out of pocket for a single month's supply. Medical expenses mounted as Eileen's insurance appeals got denied again and again.

In a desperate attempt to convince insurers how severe Brady's disease is, Eileen consented to something she avoids: sharing photos that reveal Brady's struggle. Even then, Eileen's insurer wanted more – a tally of Brady's wounds, measurements of their size.

The family continues to battle with their insurer for appropriate coverage, but Brady did qualify for a Medicaid waiver that provides his home health care. The Attar family plans to move from Texas to Colorado this year for a climate that's better for Brady. "I've seen my son standing with his face pressed to the window, watching his brother play outside," Eileen explained, "No more."

# CAROLYN'S STORY

## BULLOUS PEMPHIGOID

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A simple surgery turned into a nightmare when Carolyn Fota unexpectedly developed bullous pemphigoid, causing hives and watery blisters to develop across her body.

It took a “small army” of clinicians from Stafford Hospital, Fort Belvoir Community Hospital, Walter Reed National Medical Center and New York’s Mayo Clinic to arrive at her diagnosis.

Carolyn suffered severe pain, unbearable itching and utter disbelief. “Oh, no,” Carolyn recalled telling her physician, “Am I the poor [so-and-so] who has pemphigus?” Treatment consisted of oral medications, while Carolyn’s arms and legs were wrapped in sterile dressings after topical steroids.

In addition to the physical symptoms, Carolyn found herself feeling scared, depressed – and very isolated. “I said to my husband, ‘We’re going to survive this,’” Carolyn recalled.

Her 27-year marriage wasn’t the only thing to help Carolyn through her ordeal. The International Pemphigus Pemphigoid Foundation also provided critical support, including peer health coaching. The group saw Carolyn through her treatment and her transition back to everyday life.

Today, Carolyn carries the organization’s mission forward, advocating for treatment and access on Capitol Hill, writing articles, and assisting the International Pemphigus Pemphigoid Foundation in its outreach.



# THE HEALTH PROFESSIONALS' STORY

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Dermatologists don't need to be told that the conditions they treat impact all aspects of patients' lives. "People think dermatology is about wrinkles, injections, cosmetic enhancements," explained Derma Care Access Network Medical Director Adam Friedman, MD, adding "It's much, much more than that."



Dr. Friedman emphasized how dermatological conditions can impact patients' ability to be present and productive at work. They can also undercut patients' time with family and their ability to contribute to their communities, Dr. Friedman explained.

Despite these facts, health care providers and staff spend a lot of time – too much, in their own words – rationalizing dermatological care to health insurers.

"I went into medicine to treat patients," explained Dillon Nussbaum, a medical assistant at Rockville, Maryland's Washington Dermatology Center. "I didn't go into medicine to do paperwork." Dillon described health plans' prior authorizations as time-consuming exercises that take providers away from patient care – and put the health insurer between a patient and his or her physician.

Fellow medical assistant Courtney Clayton echoed her colleague's frustrations. "I'll have health insurance representatives tell me, 'The patient needs to take this other drug first,'" Courtney said, "And I tell them, 'That drug doesn't even treat this condition!'"

While treatments for dermatological conditions continue to advance, health plan designs impose a significant hurdle for patients and clinicians.





## MOVING FORWARD

The event concluded with a group discussion of advocacy, led by Alliance for Patient Access Executive Director Brian Kennedy. Fellow advocates in attendance shared their own experiences and best practices.

The group expressed interest in coordinating to improve dermatological patients' access to appropriate health care. In particular, the prospect of better educating employers about the need for robust health coverage elicited interest from the group.

The Derma Care Access Network now plans to coordinate with the AIMED Alliance to conduct a series of webinars educating large employers about access barriers.



The Derma Care Access Network sponsors educational initiatives and advocacy programs designed to encourage informed policymaking about the benefits of access to approved therapies and appropriate clinical care.

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