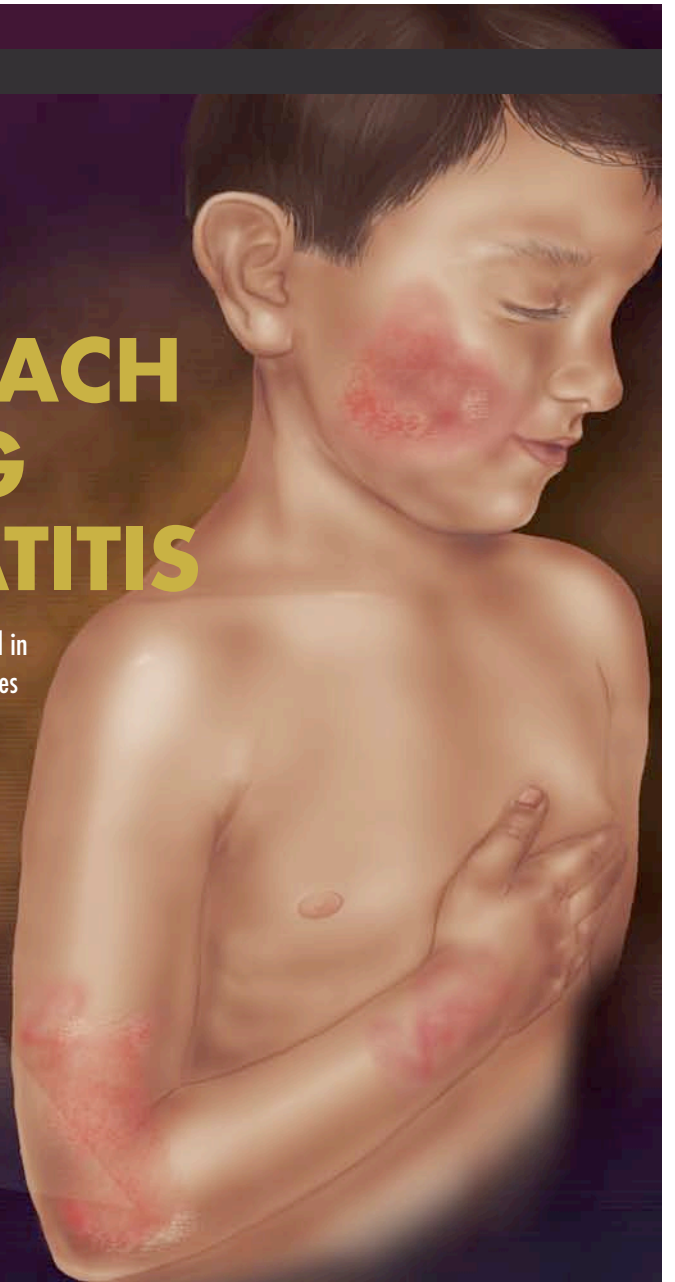
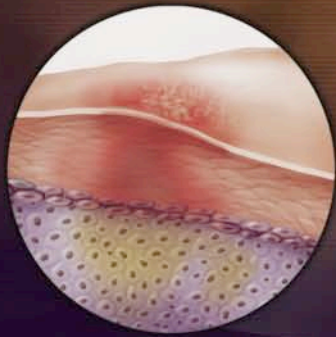


A NEW APPROACH TO MANAGING ATOPIC DERMATITIS

Despite some bumps, The Eczema Center at Rady Children's Hospital in San Diego is making headway toward showing that dedicated services can improve care.

BONNIE DARVES, CONTRIBUTING EDITOR



The good thing about being the first to attempt a new concept that finds success is the recognition that eventually ensues. The downside is that treading unfamiliar turf inevitably involves mis-steps, tough learning lessons, and in the context of a large organization, dealing with politics and unreasonable expectations.

That just about sums up the state of things at the recently opened pediatric eczema center at Rady Children's Hospital at University of California-San Diego, the first center of its kind. Co-director Lawrence Eichenfield, MD, admits that developing the center, a standalone facility

adjacent to the hospital that provides comprehensive, multidisciplinary clinical care and extensive family education, and also operating a dedicated research program has proved a gratifying, if exhausting, undertaking.

"It takes a lot of effort to change models of care and how you interact with patients — and to develop the support network you will need to accomplish new ways of doing things," Dr. Eichenfield says. "We assumed it would take considerable time and energy, but honestly, it sometimes took far more than we expected."

As it turned out, the disease's known morbidity and its prevalence — now

estimated at 20% worldwide, up from 7% a few decades ago — was not sufficient rationale for some naysayers, at least initially. Then, the 1-year timeline between finalizing the concept and opening the dedicated space in January 2009 was entirely too ambitious, Dr. Eichenfield acknowledges; and the center's founders encountered a couple of roadblocks, in the form of institutional concerns and resistance to the concept from some quarters.

"If I did this again, I'd first make sure the timeline was reasonable, and I would ensure that the disciplines and institutions involved are supportive and agree to contribute to nurtur-



A Profile of The Eczema Center

WHAT: The Eczema Center at Rady Children's Hospital, University of California-San Diego, the first standalone dedicated pediatric eczema care and research center of its kind, began services in April 2007 and opened in a dedicated facility in 2009. To date, more than 30 trials and studies have been conducted.

WHO: Staffed by five dermatologists, including specialists with expertise in such areas as atopy syndrome, chemical sensitivities in the skin, and use of systemic therapies in severe eczema. A nurse care coordinator and RN clinical research coordinator, as well as a foundation liaison, help manage day-to-day operations and outreach activities.

PATIENT POPULATION: Infants to adolescents with moderate to severe atopic dermatitis, whose condition requires frequent aggressive treatment and might improve with intensive education. The center does not treat adults, but several adults with eczema are involved in center activities.

GROWTH: According to dermatologists at the center, the center has greatly increased the number of referrals for eczema, as well as self-referrals. The center regularly receives calls from all over the United States. The center typically tries to refer these families to dermatology colleagues closer to their homes, but many patients from out of the region and out of the state are treated at the center.

WEB SITE: www.EczemaCenter.org. ■

ing something new that will benefit the community," he says, admitting that political tensions ran high at times and that securing funding, now solidly in place, was difficult.

The center's funding comes from multiple sources: the community, families, the hospital and the pharmaceutical industry, and industry has provided much of the funding for the intensive educational programs. "Frankly, we would not be able to operate without this support," Dr. Eichenfield says, adding that the learning curve ahead is substantial. "We're conscious of the fact that we wouldn't necessarily advise others to

do things the way we have. We're doing a lot of testing to move the field forward, and we're not sure yet what works best."

Although there's no data yet to confirm Dr. Eichenfield's sense that the intensive education and single-site model are improving care, a 3-year study is in the works and encouraging anecdotal evidence is in abundance. "We get a lot more hugs in our patient care visits than we used to," he explains, "which likely reflects the severe impact of eczema on families. Having the center has certainly made us all more sensitive to the challenges these patients and families experience."

The traffic on the center's Web site is likely indicative of families' need for disease-specific information and services, notes Andrew Krakowski, MD, a pediatric dermatologist who has been involved in the center since its startup. "We saw the number of hits to our Web site increase from about 12,000 in 2007 to more than 45,000 in 2008," he says, adding that current projections suggest 2009 numbers will greatly exceed 2008 totals.

EDUCATION INTERVENTIONS EVOLVING

Since start-up, in fact, one of the biggest challenges for center staff has been deciding which educational meth-



Figure 1. The Rady Children's Hospital at University of California-San Diego is home to The Eczema Center, a standalone facility adjacent to the hospital that provides comprehensive, multidisciplinary clinical care and extensive family education, and also operates a dedicated research program.

ods to pursue and which to abandon, and how best to meet families' needs outside the clinic setting. Because the center has committed to providing intensive education as a differentiating factor and some of its funding is contingent on that mission, experimentation has been the order of the day. Center staff members have discovered that supplying parents with a video, developed by the American Academy of Dermatology, that shows a family performing a wet wrap with corticosteroids, is far more effective than simply offering a one-time teaching session in the office, according to Therese Cosan, RN, the center's care coordinator.

"We're not sure which interventions will be the most effective, but what we do know now is that patients and families can't be taught how to manage eczema in a 5-minute office visit, and that education must be intensive and ongoing to be effective." — Dr. Eichenfield

"That allows the parents to review the process on their own time," explains Ms. Cosan, noting that the visual "refresher course" is especially valuable to new parents of infants with moderate disease, who may be understandably flustered and worried during those early visits. "It's a tough

way for a new mom to start out with a new baby."

The center has also been trying out group education venues and resources. The 90-minute school sessions have been effective, Dr. Eichenfield says, but the staff is still trying to figure out the best venue for those sessions. "Some people like to get together in groups, but other parents might prefer to log on to a Web conference, for example, so we're looking into that. The educational support aspect is probably what's changed the most since we opened — and will continue to change — because that's the area that's been least well studied," explains Dr. Eichenfield, who also is chief

of pediatric and adolescent dermatology at Rady Children's.

The center has just begun to look at the epidemiology and demographics of the patients and families it serves, for example, to determine what percentage of those individuals have Internet access and would be interested in more extensive online education offerings. The center already offers a virtual curriculum on its Web site, which provides instruction, in visual format, on such topics as how to do wet wraps and

bleach baths, and how to interpret and understand medication dosing. Other additions include a 40-page eczema primer, instructions on how to request a specialist consult for a patient with poorly managed eczema, and an eczema "action plan" for parents.

"We're not sure which interventions will be the most effective, but what we do know now is that patients and families can't be taught how to manage eczema in a 5-minute office visit, and that education must be intensive and ongoing to be effective," Dr. Eichenfield says. He mentions the recent randomized trial, conducted at Rady, which found that patients with atopic dermatitis whose parents received 6 weeks of intensive education fared far better, in terms of flares and overall disease control, than patients whose parents didn't receive the education.¹

A MULTI-DISCIPLINARY APPROACH

Dr. Krakowski thinks that the center's dedicated facility and its expanded multi-disciplinary approach to care have both paid dividends. Everyone involved, he explains, agreed early on that a "bricks and mortar" specialty-care facility was the best way to consolidate resources and offer patients comprehensive care in a single setting. "Likewise, our healthcare providers longed

for a way to carve out the 45 to 60 minutes they needed per new eczema patient to explain the disease process and get everyone on board with the treatment plan,” Dr. Krakowski recalls. “Creating the center was a natural approach to satisfying those objectives.”

“From a clinical perspective, we learned early on that in successful eczema management there is simply no substitute for a knowledgeable patient and a coordinated team.”

— Dr. Krakowski

The center operates as its own entity but is closely aligned and physically proximal to UCSD’s other dermatology clinics and services. “From a practical perspective, that means that we can diagnose an eczema patient in our regular clinic and have them smoothly transition, if need be, to the eczema center next door,” Dr. Krakowski explains.

The center’s approach to multi-disciplinary care, which Dr. Krakowski describes as “from-bench-to-bedside,” combines the clinical expertise and disease education in a concerted manner whose objective is to equip families to better manage the eczema and thereby improve patients’ quality of life and avoid hospital visits. “From a clinical perspective, we learned early on that in successful eczema management there is simply no substitute for a knowledgeable patient and a coordinated team,” he says.

For example, the center’s clinical director, Magdalene Dohil, MD, has established a care “network” in which the pediatric dermatologists work in concert with allergists, infectious disease experts, gastroenterologists, psychologists and behavioral therapists. The goal, Dr. Krakowski explains, is that by the time patients and caregivers leave the center, “everyone is on the same page,” that is, patients (and caregivers) understand the science behind the condition and the treatments available. “Consequently, the patients themselves are more comfortable having a hand in managing their own disease — ready to

address their eczema more from the perspective of running a marathon rather than a 50-yard dash. That can make all the difference.”

On the outreach end of the spectrum, The Eczema Center operates an active phone and e-mail advice line for

parents, and caregivers of current patients are encouraged to call as often as needed. To that end, Ms. Cosan spends about 60% of any given week answering phone calls and helping parents get through acute exacerbations, and several hours answering e-mails from families and care-givers throughout the country. “I give parents the liberty to call me at any time during the week, especially if there’s a crisis — so that they don’t just react,” she says. “When you empower them, and they know they’ll be able to reach you for advice, they often discover that they can manage the flare without coming in, if they learn how to better manage the disease.”

At the same time, Ms. Cosan acknowledges that providing care in a dedicated center raises parents’ expectations, sometimes unrealistically. “We see a lot of patients and parents who’ve been through the regular system for years, with poor results — and they come in thinking you can just ‘fix things.’ But of course, that’s not necessarily the case,” Ms. Cosan explains. The center’s clinical staff must iterate, she adds, that they will provide “the best, most current standard of care,” but can’t perform miracles. “That’s a tough situation sometimes,” she allows.

BENEFITS FOR PARENTS AND PATIENTS

The center’s clinical staff, which includes five dermatologists, a nurse care coordinator and clinical research coordinator (see sidebar on page

29), is still struggling to get the center off the ground and to fine-tune operations and resources. But for the patients and families who’ve landed there after years of fragmented or sub-optimal care — many pediatricians and GPs aren’t well trained in treating eczema — the place is a godsend.

Some parents, so frustrated by their inability to access specialists, travel considerable distances to have their children treated at the center. “We have one family that flies here once a month for care,” says Ms. Cosan, referring to the parents of a young girl who has both severe atopic dermatitis and molluscum contagiosum, and was attempting to remove the lesions herself.

For Marceme Neilson, a San Diego mother of three boys — two, ages 7 and 10, of whom have moderate eczema that surfaced in infancy — the center’s resources have made a significant difference in her boys’ conditions as well as her confidence in managing exacerbations.

“Before, I just kept going to the pediatrician every time there was a flare,” Ms. Neilson recalls, “but there really wasn’t any improvement. It got to the point that my [then] 9-year-old would go to bed at night asking me to pray for him, he was so uncomfort-

“Consequently, the patients themselves are more comfortable having a hand in managing their own disease — ready to address their eczema more from the perspective of running a marathon rather than a 50-yard dash. That can make all the difference.” — Dr. Krakowski

able. Now we’re on a completely different regimen, and in the past year, the flares have become much more manageable. The education is amazing.” In fact, Ms. Neilson has become such a believer in the aggressive approach to care that she has agreed to co-chair the center’s nascent support group. “I think that a lot of parents are in the situation I was in before, and I would like to help,” she says.

Forerunners Share Tips, Lessons Learned

It's no small feat to launch a disease-specific care center in dermatology, but it's do-able, and since Rady Children's Hospital launched its eczema center, a handful of other hospitals and academic centers have followed suit, Drs. Eichenfield and Krakowski note, and more continue to call to ask for advice on opening a disease-focused facility. To that end, they offer the following tips and cautions:

—Start by identifying the players, from selecting specific staff to connecting with eczema families in the community. It is important to have the right people involved from the start. These are the people who will add vitality, personality and sustainability to your new program. Also consider adding a dedicated Web site to your practice's existing one. It's fairly easy and inexpensive to do, and this allows you to create an online headquarters from which your programs can be publicized and coordinated. — *Dr. Krakowski*

—Understand that delivering educational interventions is a costly endeavor, and that trial and error will be the order of the day. There's actually a substantial cost in figuring out what works and what doesn't, and the center or program has to be prepared, financially, to absorb that cost. — *Dr. Eichenfield*

—Gauge the potential local interest in a disease-focused center first. Remember why and for whom you might do add an eczema-specific service, and then take the time to ask your patients if they will actually utilize it. Then allow your patients to guide the scope of your local program. There is no stronger voice than that of patients and their families. At its heart, our eczema center truly is a grassroots effort, and we would not want it any other way. — *Dr. Krakowski* ■

A LEARNING EXPERIENCE FOR DERMATOLOGISTS

Parents aren't the only ones who've been educated as the center has evolved. The dermatologists, by virtue of slowing down and intensifying the education process, have discovered more about what's been lacking in their own approach to care — and how to improve that care. For instance, though it's long been known that pa-

tients (or caregivers) often don't comply with physicians' recommendations regarding medications and dosing, it's not often clear why that occurs.

In the case of pediatric eczema, fear of overdosing corticosteroids is a major concern, the center's staff have found out, and they've taken steps to address that. Dermatologists and nurses not only state that a dosing regimen is "safe," they make the

point of telling parents about the science behind their statement, Dr. Eichenfield explains, and they discuss particular dosing nuances.

"Families are more comfortable knowing that medications can be used safely within certain parameters when we tell them what those are, by saying, 'you can use 60 mg of this topical corticosteroid in next 10 days and I want you to use at least 40 mg,'" Dr. Eichenfield explains. Dermatologists explain that the center's own staff have used the recommended quantity of a certain medication on infants 3 months of age and under for a certain period, that other centers have done the same, and that studies have shown that [amount] to be safe. "Giving a prescription is different than giving parents detailed use instructions, we have learned. We have always had handouts, but it's the more detailed education that makes the parents less fearful. This is very helpful for families."

The next step in the center's evolution is the creation of a support network, which is just getting off the ground now, and plans are underway to broaden the center's leadership to include individuals from the community, Dr. Eichenfield notes. "We want interested people in the community involved in planning the center's evolution and its activities, so that we can ensure the center is actually helping the community and helping families of these patients," he explains.

The ultimate hope, of course, is that reimbursement will follow innovation. At present, The Eczema Center's educational interventions are self-funded, but the dermatologists hope ultimately to be able make an outcomes and economic case for the value of those efforts. "If we can do that, we might be able to receive reimbursement beyond what we receive for the normal office visits," Dr. Eichenfield says. "That's one goal, anyway." ■

Reference

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