AFFECTING ACCESS TO QUALITY CARE BEYOND OUR CLINIC WALLS

If you are like most patients, you may think that the quality of care is focused solely on your office visit(s). The truth is, to impact excellence in care many of our dermatologists are involved beyond our clinic walls to ensure that people everywhere receive the best dermatologic care by:

- Providing quality care to vulnerable patient populations
- Advocating on Capitol Hill to increase access to treatments
- Working with the World Health Organization to train healthcare workers in developing countries on how to diagnose and treat life-threatening skin diseases
- Mentoring the next generation of dermatologic leaders
- Creating opportunities for advancement of underrepresented doctors

“I must share my deepest gratitude and admiration for this wonderful work. Providing the best care to the underserved through volunteerism is one of the noblest missions we can strive for – these men and women are heroes in my book.”

David Fisher, MD, PhD,
Chief of the Department of Dermatology

ADVOCATING FOR OUR PATIENTS RIGHTS: ACCESS TO CARE AND TREATMENTS

Do the high out-of-pocket costs of some specialty medicines prevent you from being able to access medically necessary medications? Has Medicare Advantage ever changed your provider network mid-year before open enrollment?

Arianne Shadi Kourosh, MD and Daniel Sugai, MD, represented Massachusetts at the American Academy of Dermatology’s Association (AADA) Legislative Conference on Capitol Hill to meet face-to-face with key legislators highlighting issues to help ensure patients receive access to quality care and treatments, along with advocating that funds be made available to advance medical research and education.

“I feel fortunate that this opportunity has been made available to dermatology residents. Resident education should not be confined to textbooks, the clinic or laboratory. The same goes for patient care. By being able to address patient access to care and access to treatment issues with our Members of Congress so early on in my medical career, I feel that I can provide more well-rounded care for my patients,” says Dr. Sugai.

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GOING BEYOND THE EXPECTED DERMATOLOGIC SERVICES

WHAT IS LEARNED BY REACHING BEYOND OUR CLINIC WALLS CANNOT BE TAUGHT IN A CLASSROOM, ACADEMIC CLINIC, OR HOSPITAL. BEIDES BEING A REVERED DERMATOLOGIST, ERNESTO GONZÁLEZ, MD HAS PIONEERED OUTREACH BEYOND OUR CLINICS WALLS TO IMPROVE ACCESS TO OUR MOST VULNERABLE PATIENT POPULATIONS AND ESTABLISH EDUCATIONAL PROGRAMS TO DEVELOP THE FUTURE GENERATIONS OF PHYSICIAN LEADERS WHO ARE UNDERREPRESENTED IN MEDICINE.

Humble beginnings
González’s story has a humble beginning. Born in Aguadilla, Puerto Rico, he was raised by his mother, a single parent who worked as a maid to support her two children, and whom he credits with much of his success. “All that my mother hoped – because we were so poor – was for us to get out of the slums. She was always inspiring my brother and me to get out of the socioeconomic background in which we were raised,” he says.

The importance of being accomplished
“I have a strong advocacy and bonding for the people that continue to struggle – being accomplished is more important to me, than success,” says González. His accomplishments are many – here are a few highlights:

- More than twenty years ago, he established dermatologic clinics with the Boston Health Care for the Homeless Program where dermatologists and residents continue to provide dermatologic care to the homeless.
- After the Mitch disaster in Tegucigalpa, Honduras, in the early nineties he visited this embattled country and established a telemedicine program for dermatologic services with the Hospital Escuela of their medical school. The telemedicine program offered in-kind clinical services as well as pathologic services through the Dermatopathology Services of the MGH.
- In 1999, he founded the Hispanic Students Medical Program to mentor Hispanic medical students from the Massachusetts General Hospital Dermatology delivers state-of-the-art care to patients with rare and common conditions of the skin, hair and nails. Your generosity enables us to reach our one overarching goal: helping patients enjoy their everyday activities while minimizing or eliminating their symptoms.

If you would like to make a gift in support of our efforts, please feel free to reach out to: Sarah Church at schurch@partners.org or call 617-724-9411

Dr. González training another physician to provide care for the homeless. Photo Courtesy of David Stone.
How to Support This Department
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four medical schools in Massachusetts. The program was the model utilized by Harvard Medical School (HMS), now called the Minority Medical Students Program, which includes all minority medical students attending HMS.

• In 2002, he instituted an in-kind telemedicine program offering tele-consultations between the Pediatric Department of the MGH and the Emergency Services of a community hospital in his hometown in Puerto Rico on behalf of poor children from rural areas.

• In 2005, the MGH established the Ernesto Gonzalez Award at MGH to honor employees who provide Outstanding Service to the Latino Community.

What can be learned from reaching beyond our walls?
Physicians who work with underserved patient populations have a unique opportunity to be exposed to diseases that are not generally seen in our dermatology clinics, (frostbite, scabies, etc). Not only is their medical knowledge expanded, they learn important lessons that can’t be taught in a classroom or in a dermatology clinic. Perhaps, the most important lesson to be learned from this community outreach services is empathic behavior that is the essence of the pledge for health care providers.

According to González, “The greatest gift for a physician is to learn directly from the community around them – you learn important lessons in social awareness, humility, and humanity.

Over the years, you’ve fostered many residents and physicians to be involved in community health efforts. What differences do you see in those who have been actively involved in community initiatives?

“Most importantly, it is the level of the physician’s experience and knowledge; the physician’s commitment to underserved patient populations; and the physician’s ability to evaluate and provide excellent care. Social responsibility is an essential quality in every physician. We hope to teach all trainees that engagement with the local community is pivotal in providing the care that all patients deserve, including those that cannot readily afford healthcare,” says González.

Recent regulations can often bring barriers to providing care to those that are at greatest risk. We hope for physicians to always be able to provide empathic and compassionate care to all who need it, regardless of a quickly changing and difficult-to-navigate healthcare environment.

“As humanitarians we should learn to distinguish between sympathetic and empathic philanthropy. The first one is a detached form to provide good-will support for personal gain (financial, status, etc.) while the latter implies full engagement irrespective of the sacrifice made, and with the main goal to help others.” – Ernesto González, MD

— ADVOCATING FOR OUR PATIENT RIGHTS

(Continued from page 1)
This year, our physicians advocated with State Representatives and Senators to co-sponsor the following:

The Medicare Advantage Participant Bill of Rights Act, which makes certain that provider networks cannot be changed mid-year by terminating physicians without cause, and that networks will be finalized before open enrollment begins.

2) Patients Access to Treatments Act H.R. 460
Some medically necessary specialty medications can cost patients hundreds to thousands in out-of-pocket expenses yearly. This act would protect patient access to medically necessary treatments by lowering patient out-of-pocket costs for specialty drugs in commercial health plans to help ensure that patients with chronic, disabling and life threatening conditions have access to the treatments they need. Additionally, this act asks for a commitment to NIH funding to foster momentum in scientific research and advance medical knowledge.

3) Caucus Skin Cancer Prevention
This forum urges Congress to address the growing epidemic of skin cancer through public policy, awareness and educational activities focused on the dangers of indoor tanning, skin cancer prevention, and improving access to safe and effective sunscreens. To stop skin cancer, it’s vital to increase medical research funding and improve access to medical treatments.

“It has been rewarding to see the legislation that we as physicians have championed and that will protect and benefit our patients finally become law, and even more so, to take our residents to Capitol Hill and see them become advocates in that process.” – A. Shadi Kourosh, MD
SKIN HEALTH MATTERS

MILLIONS OF PEOPLE AROUND THE GLOBE SUFFER FROM SKIN DISEASES. LEARN HOW ONE SPOT ON THE SKIN COULD BE A SIGN OF A LIFE THREATENING DISEASE.

Like many physicians practicing in the United States, I was under the impression that diseases such as Kaposi’s sarcoma (an HIV related cancer that appears first on the skin) were becoming a thing of the past. Yet, Kaposi’s sarcoma is the most common HIV-associated malignancy in sub-Saharan Africa.

One Patient’s Story: East Africa

My patient can’t breathe. From across the busy, open ward you can see the plaques of Kaposi’s sarcoma riddling her skin. The impressive swelling that comes along with the skin lesions has enlarged her legs to the size of small tree trunks.

When she dies six hours later, we can be pretty sure that it is her Kaposi’s sarcoma which has spread to her lungs, along with her underlying HIV, that killed her. Her family tells us that she has had dark spots on her skin and swelling in her legs for over a year before she presented to the hospital. Like many of our patients in East Africa, she sought help from a traditional healer for many months before eventually turning to the biomedical health system, only hours before her death.*

Lack of Access – Lack of Training

My patient’s story may have had turned out differently if she had known to seek care earlier or if local health care workers were able to diagnosis the spots on her skin promptly as Kaposi’s sarcoma. In most cases, Kaposi’s sarcoma can be diagnosed through a skin biopsy, in the same way that we diagnose skin cancer here in the United States. Earlier diagnosis can lead to earlier treatment, and ultimately improved survival.

Some of the issues we face in resource-poor settings include:

- Limited training of healthcare workers
- Lack of diagnostic tools and equipment
- Poor patient access and transportation to sites providing quality care

One of the most critical factors in patient outcomes is the challenge of rapid and accurate diagnosis in an environment with little technology, wrenching poverty and harsh travel conditions. Fortunately, by sharing our knowledge we can help advance early diagnosis and treatment for diseases such as Kaposi’s sarcoma.

Lives Can Be Saved by Early Diagnosis

We have developed our version of a Kaposi’s sarcoma “SWAT” team: by training healthcare workers in rural areas of Kenya and Uganda to do skin exams and skin biopsies on patients far from larger hospitals, we are diagnosing patients earlier in their disease, leading to earlier treatment and lives saved. In addition, we are currently researching novel rapid, point-of-care diagnostic strategies. We are evaluating if existing technologies and concepts can be adapted from other areas of medicine, to make diagnosis for patients in some of the poorest areas of the world even faster.

Dr. Freeman says, “I realize the pace will be slow, but the result will be that no patient anywhere in the world will slowly suffocate from Kaposi’s sarcoma because the care needed simply wasn’t part of the community’s training.”

To learn more about our mission, visit www.massgeneral.org/dermatology/globalhealth

Footnote: Dr. Freeman does not currently work in Ebola-affected areas. For MGH information visit http://mghcgh.org/

*Story adapted from Dr. Freeman’s editorial in the Journal of Investigative Dermatology, 2014, Volume 134.