

# JDPA

Journal of Dermatology for Physician Assistants



## DERMATOLOGY PA NEWS & NOTES

Student Corner 18

---

## CLINICAL DERMATOLOGY

Dermoscopy 28

---

## SURGICAL DERMATOLOGY

Journal Club 36

---

## COSMETIC DERMATOLOGY

Cosmetic Pearls 41

---

## PROFESSIONAL DEVELOPMENT

An Innovative Dermatology Education  
Tool for Physician Assistants 42



» Earn CME credit with this issue

**CME**

Allergic Contact Dermatitis from  
Topical Corticosteroids 19

**SUPPLEMENT**  
for Midwest Melanoma  
Partnership

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# FROM THE PATIENT'S PERSPECTIVE

## *A Son's Words Shared*

*The Midwest Melanoma Partnership's Inaugural Melanoma Symposium  
March 24, 2012*

By Scott Raecker

Thank you Dr. Milhem and Dr. Weiner for the invitation to say a few words today at the Midwest Melanoma Partnership's first Melanoma Symposium. I am honored to be invited. I have been thinking for months about what I wanted to say to you today, and it was not until yesterday afternoon when I spoke with my mom that my thoughts came to mind.

In July of 2008 my dad was diagnosed with Stage IV Melanoma with no external source point ever identified. It was in that month that my father and our family met Dr. Milhem. My father was a man of science, an accomplished and recognized dentist, and a man of faith who believed that "... God causes all things to work together for good to those who love Him, to those who are called according to His purpose." I share this with you, because I remember the day that we sat with Dr. Milhem at the University of Iowa Hospitals and Clinics and discussed the science of melanoma, the faith necessary to approach treatment, and the research necessary to find a cure. I remember it like it was yesterday; in fact, it was Wednesday, July 30th 2008. Like my dad, I pay attention to details.

I remember our family talking about how unbelievable it is that with all of the wonderful progress and awareness of so many cancers such as breast cancer and prostate cancer that there are still cancers such as melanoma and pancreatic cancer that we are still in the dark ages of research with standard treatment protocols that are decades old. I remember when Dad asked Dr. Milhem, "Where do you go to meet your peers and learn about the most recent advances in research?" His answer, "We

*"(Dr. Milhem) has correlated my disease to a runaway railroad train, racing for the station. It can either crash at full speed or hopefully, be slowed for a more gentle arrival - he is trying to slow the train."*

don't." In some small part, it is from that discussion that you are all here today. My father would believe that it is not happenstance, but for a purpose that you have been drawn together. I am not a man of science. I don't understand the world you work in. I am a director of a non-profit organization, a state legislator, a husband, father, and son. In my worlds, I have come to understand and appreciate the essential necessities of collaboration and leverage to accomplish the tasks that on the surface seem impossible.

My son is taking advanced biology in high school and had a recent project that included watching the movie *Lorenzo's Oil*. I highly recommend it. If you don't know the story, it is about a family's unending quest to find an answer for their son's rare disease, adrenoleukodystrophy (ALD). As we watched the movie I thought about this symposium. The parents set out on a mission to find a treatment to save their child. Throughout their quest, they clashed with



It is the mission of the Midwest Melanoma Partnership to facilitate the sharing of ideas, clinical trials, and resources in an effort to improve the diagnosis, treatment, and long-term care of melanoma patients.

Contact Information: [www.midwestmelanoma.org](http://www.midwestmelanoma.org)

Anyone interested in becoming a member, making a donation, or who has questions can contact the MMP Administrative Coordinating center at [rstmmpadmin@mayo.edu](mailto:rstmmpadmin@mayo.edu).

## FROM THE PATIENT'S PERSPECTIVE

doctors, scientists, and support groups, who were skeptical that anything could be done for ALD, much less by laypeople. But the parents persisted, setting up camp in medical libraries, reviewing animal experiments, badgering researchers, questioning top doctors all over the world, and even organizing an international symposium about the disease.

Despite dead ends of research, the horror of watching their son's health decline, and being surrounded by skeptics, they persisted until they finally hit upon a therapy involving adding a certain kind of oil (actually an oil containing two specific long chain fatty acids), both isolated from rapeseed oil and olive oil to their son's diet. Miracle! Lorenzo's Oil has extended thousands of lives beyond expectations. The lessons I took away and the reason I thought of you were two-fold. First, the researchers of that time were in silos doing their work and lacked collaboration, innovation, creativity, and listening for the simple within the complex. Second, there is this great scene in the movie where the researchers at the symposium are visiting during a social gathering and drawing rich discussion on the connectivity between and among their efforts.

I believe there may be two or three or four of you at this symposium who have never had the time to connect before. Your lives are so full with the day-to-day demands on your time and the pressure of balancing the business of being a doctor and a researcher (let alone the compassion of caring for patients) that you have not had the time to share notes, to correlate data, or to learn from each other what may be the possible from the impossible.

What may be possible from the impossible made me think of polio, Jonas Salk, and Albert Sabin. I believe that the Salks and Sabins of melanoma may be in this room. And if not, then the John Enders, Fredrick Robbins, and Thomas Wellers of melanoma research may be in this room. You know them of course. Years before Salk or Sabin, it was this group of three researchers who had a breakthrough in 1948 when they successfully cultivated the poliovirus in human tissue in the laboratory. In March 1948, Weller was attempting

to grow varicella virus in embryonic lung tissue. He had inoculated the planned number of tubes when he noticed that there were a few unused tubes. He retrieved a sample of mouse brain infected with polio virus and added it to the remaining test tubes on the off chance that the virus might grow. The varicella cultures failed to grow, but the polio cultures were successful. This development greatly facilitated vaccine research and ultimately allowed for the development of vaccines against polio. Enders and his colleagues were recognized in 1954 for their labors with a Nobel Prize in Physiology or Medicine.

I look out on this esteemed group, and I wonder to myself, "Which of you see yourself as Salk or Enders?" Who among you will it be? Then I think, "Maybe it will not be one among you, but two or a group of you who meet at this symposium, strike up a relationship, get each other's cards, and make a commitment to connect." Which of you are using the mouse brain, the rape seed, or the olive oil of today that will allow you to stumble upon the missing step that unlocks the new treatment that extends quality of life or provides the cure itself? Which of you will have grandchildren who will speak with pride of their grandfather or grandmother who won the Nobel Prize for finding the cure for melanoma?

Is it you? I believe it is. And this is why. You are here. Each of you has a vision of that day or you would not be here, and this would not be your life's work. So this is what I want to share with you. I want you to be inspired. I want you to be challenged. I want you to build bridges that break down barriers. I want you to work together. I want you to not be satisfied with the opportunity to extend the quality of life; I want you to hunger with an unquenching desire to save lives. I want you to wake every morning with words like determination, grit, perseverance, creativity, curiosity, drive, imagination, and courage as the starting point and guiding focus of your day.

Towards the end of my dad's eighteen-month battle he wrote this in an e-mail: "Dr. Milhem says, 'Even though there is no reason for you to be alive, I did give you hair' - he is funny. He has correlated my disease to a runaway railroad train, racing for the station. It can either crash at full speed or

## FROM THE PATIENT'S PERSPECTIVE

hopefully, be slowed for a more gentle arrival - he is trying to slow the train.” Our family believes that Dr. Milhem gave our family a tremendous gift by extending my dad’s life beyond expectations and by bringing the train into the station as slowly as he could, and we are forever grateful. We are also inspired to ask you for more. How can you use the experiences of patients like my dad, not to slow or stop the train, but to get the train off the tracks in the first place? I want you to know that each one of you individually, working together collectively, has the capacity to change the world.

As I said, I don’t comprehend the complexities of the science of melanoma. Another e-mail from my dad stated, “Dr. Milhem continues to believe ‘something’ is impacting the growth pattern - and he would like me to continue with the experimental chemo treatment. At this time that includes a combination of an HIV-inhibitor and an anti-rejection drug for organ transplants. And if nothing else, I believe my continued treatment may lead to advances that will help other people.” That was the day that Dr. Milhem told my dad he was a “hero.” That was also the day that Dad told Dr. Milhem that he would make him famous for helping him find the cure. Every person in this room is a hero, as was my father.

I close today with words directly to you from my father, a portion of his final update to his family that was delivered by our family pastor after Dad had left this world for the next. “We have fought the good fight against cancer but we are losing. I have friends who are winning the race against cancer and for that I am grateful. I have also lost many friends to this disease. I have not been praying that cancer would leave my body; I have prayed to accept whatever happens. The time came when I knew I was not going to have a cure. I wanted instead to have the faith to accept all things with God at my side. I also prayed for Dr. Milhem at the University of Iowa as he is working on ways to cure melanoma so none of my children or grandchildren will go through what I have. I prayed that when my grandchildren are my age, cancer will be cured just as polio was conquered.”

Thank you for this honor. **J**



*Scott Raecker* serves as Executive Director of Character Counts In Iowa (CCII) – a position he has held since the organization was founded in 1997.

*Scott’s* commitment to positively impact Iowa was also reflected in his 14 years of public service as a member of the Iowa House of Representatives from 1999 through 2012.

*In the legislature, Scott served in numerous leadership roles including chair of the House Appropriations Committee, chair of the Ethics Committee, and chair of the Midwest Council of Government’s Legislative Leadership Institute.*

*Scott and his wife, Martha, live in Urbandale, Iowa with their children, Emily, 20, and Max, 17.*

### Take Home Points for Derm PAs:

*By Steven K. Shama, MD, MPH*

- 1. How wonderful and refreshing it is for us as clinicians/researchers to hear the message of hope and inspiration sent from a patient or a family member of a patient. The next time we give hope to a patient, let us try to put ourselves on the same side of the table as the patient. Let’s see how really good it feels.*
- 2. Imagine someone believing that you are a hero with an unquenchable desire to extend life, to relieve pain, and to cure a deadly disease.*
- 3. In creatively trying to problem solve, one of the most effective techniques is to brainstorm. This involves a number of people who bring their different perspectives and suggest many possible answers. Isn’t this collaboration? So why don’t we do it more often? How many cures for diseases could be discovered more quickly if we all came down from our silos (Ivory Towers) and met on ground level?*

# Dermatology Physician Assistants



**Physician Assistants (PAs) in dermatology play a number of varied and vital roles.**

PAs are medical providers licensed to practice medicine with physician supervision. From patient care and education, to skin surgery, treatment of chronic skin conditions, and cosmetic procedures, PAs are dynamic members of the healthcare team. PAs practice in every medical and surgical specialty and have been collaborating with dermatologists for 30 years, providing a wide variety of services. These include diagnosing, prescribing medications, ordering and interpreting lab tests, wound suturing, and medical or surgical treatment of a wide variety of clinical diseases. As with all PAs, dermatology PAs are legally and ethically bound to practice only under physician supervision.

**PAs are trained in intensive, accredited education programs.**

Because of the close working relationship that PAs have with physicians, PAs are educated in the medical model designed to mirror and complement physician training. PAs take a national certification examination and to maintain their certification, they must complete 100 hours of continuing medical education every two years and take a recertification exam every six years. Graduation from an accredited PA program and passage of the national certifying exam are required for state licensure.

How a PA practices dermatology varies with training, experience, and state law. In addition, the scope of the PA's responsibilities corresponds to the supervising physician's scope of practice. In general, a PA will see many of the same types of patients as the physician. Referral to the physician, or close consultation between the PA and physician, is based on the dynamic relationship between the physician and PA.

**The Society of Dermatology Physician Assistants (SDPA)** is a non-profit professional organization, composed of members who provide dermatologic care or have an interest in the medical specialty of dermatology. Fellow members provide medical services under the supervision of a board certified dermatologist.

More information can be found at [www.dermpa.org](http://www.dermpa.org) and [www.aapa.org](http://www.aapa.org).

