

Profile in Giving: From Hope Lost to Hope Realized: Gwendolyn Powell Todd, EdD

As patients with hair loss, our hopes for recovery are often dashed at the time we receive a diagnosis of cicatricial alopecia. We walk into the doctor's office thinking that something can be done to remedy the hair loss and instead find that there is no known cause, no consistent treatment protocol, and no cure. After living with the disease, some of us realize that in order to move out of our despair, we must join the journey that will lead to answers.

Our first step is assisting CARF however we can (by donating and volunteering) because it is the only organization that supports relevant research and provides patient support and education on current treatment, research, and hair alternatives. Our second step often involves learning how to become an advocate for cicatricial alopecia. Advocacy includes introducing people to the concept of cicatricial alopecia, promoting CARF, and providing information to others about our disease.

I became an advocate when I went to the Annual Meeting of the American Academy of Dermatology (AAD), held in Washington D.C. in early February, 2007. More than 10,000 physicians and medical professionals were present. I was privileged to attend the conference with our CARF founders, Sheila Belkin and Dr. Vera Price. Our advocacy-focused activities included education, education, education. There were 11 hair loss sessions during the conference, a notable increase in interest and visibility for cicatricial alopecia. Several of CARF's highly respected scientific advisors were speakers. Dr. Price lectured on the diagnosis of approximately 100 physicians. The attendees were enthusiastic and asked many questions. I asked one physician who does not treat hair loss why he was attending Dr. Price's session. He replied, "Because she is world famous, don't you know?!" Our very own internationally renowned specialist educated people not only with lectures and personal conversations, but also with a video that was played at the entrance to the conference.

Networking: There were countless opportunities to meet people and discuss the latest information about CARF and cicatricial alopecia. We shared information when we attended receptions, luncheons, award ceremonies, or just walked to the conference with other attendees. We were able to learn how other organizations have grown by attending their gatherings. The Women's Dermatological Society (WDS) held both a reception and luncheon, the Coalition of Skin Diseases (CSD) held a luncheon meeting, and there were numerous other receptions.

CARF Goals: The goals of the organization are always on the minds of our co-founders. They held a meeting with our scientific advisors to discuss how to meet CARF objectives and to share treatment strategies. Drs. Lloyd King, Len Sperling, Paradi Mirmirani, Ken Washenik, Kurt Stenn, Jerry Shapiro, and Maria Hordinsky attended. A major goal of CARF was realized at the conference: expanding the list of physicians who treat hair loss. During the various lecture sessions, physicians who are willing to treat hair loss patients gave us their contact information. This is so important for the

many patients who are seeking physician referrals. As a cicatricial alopecia patient, my hope was lost with the initial diagnosis but the more involved I have become with CARF activities, the more I believe that one day soon my hope for a cure will be realized!