



C . A . R . F .

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Megawatt Living: Powering up for an Energized Way of Life

Nancy Balik FitzGerald



Nancy Balik FitzGerald

Sheila Belkin and I first met five years ago at the California Governor and First Lady's Conference on Women and Families. We were both there on behalf of the Women's Dermatologic Society, promoting sun safety. Suddenly, opportunity struck. There we were, our entourage - Sheila, Dr. Paradi Mirmirani, her five-year-old daughter Leila, three TV camera crew guys, and I—chasing after former tennis pro Billie Jean King and the actress and fitness guru Jane Fonda in the hopes of nabbing them for a television news segment we were crafting.

We rushed with high speed and even higher hopes. And in that instant, we were bonded as a sort of "Yes Troop." We were on

a mission, ignited by the power of potentiality, acting like *possibilitarians*, as Norman Vincent Peale, the great advocate of positive thinking would say. We believed we could, and thus we could indeed. And we have some priceless footage to prove it!

As I came to know Sheila, Dr. Vera Price, Dr. Pearl Grimes, and many cicatricial alopecia patients and doctors, I have seen over and over again the great impact and meaning of what CARF can do and how it touches so many lives. I am in awe. It is a testament to the power of a shared vision, the power of believing, and the power that comes from saying, "Yes, we can."

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Bald is Beautiful

by a CARF Contributor



Sandra Dubose-Gibson

Sandra Dubose-Gibson, a married mother-of-two, laughed when an acquaintance suggested that she enter a "Mrs. Black North Carolina" beauty pageant.

"Absolutely not," was Dubose-Gibson's initial response. In her mind, beauty pageant participants fit a stereotypical mold. They are tall and slender with lavish locks.

Dubose-Gibson is five feet tall.

And she is bald! But the charismatic woman with the infectious laugh was ultimately convinced to enter the competition. Her confidence, poise and powerful singing wowed the judges. And Dubose-Gibson won.

On March 26, 2011, she was crowned Mrs. Black North Carolina—the first bald woman ever to take this particular beauty queen title. "I was just really excited, and really excited for my family," said the 37-year-old

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Megawatt Living: Powering up for an Energized Way of Life

Nancy Balik FitzGerald

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And that's what I want to discuss: how we can lead our best lives with mindfulness, a heart, and a spirit that scream out, "Yes! Yes! Yes!" That little word, and all it means, has the power to transform your life. An overarching attitude of "Yes!" encourages authenticity; that is, being true to who you are, learning self-acceptance, and allowing yourself to be open to receive and give the gifts that can enhance your life beyond your wildest imagination. These ideas, charged with positivity are the yes words that make up the language of lasting joy and fulfillment. Through a safe haven such as CARF, an attitude of yes can lead to mutual support, self-discovery and personal growth that take you to exceptional heights. For example:

Yes, I want to help
 Yes, I need your help
 Yes, I will join you
 Yes, I will tell you
 Yes, I will listen
 Yes, I understand
 Yes, I am willing to try
 Yes, I can look at things differently
 Yes, I am going to go for it
 Yes, I can

Of course, many of us know all too well what it's like to go overboard saying yes to too many things, but this kind of "yes-making" is not designed to burden your schedule. To the contrary, it will lighten your load, uplift you, and enrich your life in unimaginable ways.

You really cannot say the word "yes" without smiling and feeling good. Your mouth has to open upward, and you'll find your face more animated. It's practically impossible to even utter this word without smiling and feeling the tingle of empowerment. Saying yes to life and everything in it means swinging the doors wide open and awakening your senses. It's jumping in with both feet and going for it with all your heart, with all your soul, and with all your might.

The Irish writer and poet Oscar Wilde said there is nothing that will cure the senses but the soul, and nothing that will cure the soul but the senses. And the fact is, when it comes to stimulating your senses and freshening your perspectives, there is inspiration everywhere in this magnificent world of ours. The universe will completely cooperate with your desire to see beauty, find joy, and get excited about life as long as you make up your mind it is yours for the taking. Positive thinking is very cool that way!

So use all of your senses to reconnect with who you are and what you cherish. See the beauty of the ocean on a gloomy, cloudy day, as the sun is peeking through with the promise of a better day. Watch your loved ones mindfully, and appreciate them for who they truly are. Enjoy the delightful sights and sounds of children playing and laughing. Listen wholeheartedly to a Stravinsky symphony or put on some Beyoncé or Barbra Streisand and dance!

Really hear what people are saying (and not saying) to you with attentive ears. Smell the stargazer lilies and roses in life, and have a nose for new discoveries. Have a nose for news! That keeps life super-interesting. Taste not only all the spices and seasonings in your savory dishes and sweet desserts but also all the wonderful flavors that life can cook up for you. Reach out and touch people in your life with your kindness and caring. Hug regularly. And speaking of touch, keep in touch with friends old and new because we all need someone to lean on, as the song goes! Stay in touch with all the fascinating developments in the world of science, the arts, technology, design, neuroscience, leadership and so much more. Now I've covered the five senses. As for the sixth sense of inner knowing and perceptivity, honor your intuition and that quiet little voice inside you that is there to guide you and to help

you lead your best life. Listen to yourself.

And there's a seventh sense, one that's there to help you experience the world in a refreshing way. It's your sense of humor. Invite that side of you to join you in the situations you face and give yourself permission to interpret not-so-funny happenings in a funny way. Experience the liberation you feel when you can bring back the fun. After all, laughter is the best medicine. In fact, chucklers live longer and better!

Get perspective by going up to 30,000 feet in your mind to look at the overall landscape of your life. Think about your life as a story that has all the makings of a masterpiece. Think of this time you are facing as a chapter in that great book, and consider how you would like your character to be shaped by your story. What a great opportunity each one of us has to round out our own growth through the things we experience.

Remember, we are not defined by our circumstances nor measured by what happens to us. It's all about how we deal with what life deals us.

Author Linda Noble Topf, who wrote *You Are Not Your Illness*, says that with a shift in perception she discovered her condition became a journey of self-discovery. Now she believes there are no disasters or catastrophes, but only our interpretation of events; how we choose to interpret these events determines how we act toward them. Therefore, in interpreting life's challenges, there is much to be gained ultimately, such as renewed purpose, vision, self-love, acceptance, perspective, insight, forgiveness, relationship with others, inner peace, and gratitude.

This kind of transformation takes lion-hearted courage and the lion's share of "Yes, I can." It takes miles and

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News Flash! CARF Awards Research Grant to Professor Thomas Franz



Thomas Franz, MD

CARF has awarded Dr. Thomas Franz, professor at the University of Bonn's Institute for Anatomy, a research grant to characterize a novel mouse mutation that leads to a neutrophil-rich form of cicatricial alopecia.

Primary cicatricial alopecias are classified into two groups: lymphocyte-rich and neutrophil-rich subtypes. Molecular and cellular biologists have studied mouse models of the former but not the latter. This new laboratory model promises to offer insight into the poorly-understood group of neutrophil-rich forms.

Professor Franz was born in 1954. He studied medicine in the German cities of Bochum and Hamburg from 1973 to 1980. For his medical doctoral thesis, he investigated myelin proteins and the maturing process of nerves in the central nervous system.

Dr. Franz conducted immunological

studies with Professor Thomas V. Waehnelndt at the Max-Planck-Institute for Experimental Medicine in Goettingen between 1980 and 1981. During this period, he also carried out studies of leukemogenic murine retroviruses and retroviral vectors at the Heinrich-Pette-Institute in Hamburg.

From 1985 to 1987, Dr. Franz studied murine embryonic stem cells under Sir Martin Evans at the Department of Genetics at Cambridge University in England. After Cambridge, he spent eight years at the University of Hamburg's Institute of Anatomy investigating morphological aspects of several mouse mutants with developmental defects of the neural crest and limb musculature.

Dr. Franz earned his postdoctoral degree and received his *Venia Legendi* in anatomy in 1994. The following year he became a professor at the University of Bonn's Institute for Anatomy.

A Big Welcome to Our New Medical Editor!



Jennifer Fu, MD

Jennifer Fu, MD, received her undergraduate degree in biology from Harvard University. She attended medical school at Cornell University and completed her residency in dermatology and fellowship in Mohs micrographic surgery and procedural dermatology at the University of California, San Francisco.

While at UCSF, Dr. Fu had the privilege of working with renowned California dermatologist Dr. Vera Price. As a mentee of Dr. Price she was introduced to the field of hair and nail disorders. In 2006, she received a Women's Dermatologic Society mentorship to study dermoscopy of the scalp with distinguished Italian physician and scientist Dr. Antonella Tosti in Bologna, Italy.

Dr. Fu's current practice with Solano Dermatology Associates encompasses both medical and surgical dermatology. Her areas of special interest include non-scarring and scarring forms of hair loss; nail disorders and nail tumors; and Mohs micrographic surgery, a microscopically controlled surgical procedure used to treat common types of skin cancer.

Dr. Fu serves as volunteer clinical faculty in the Department of Dermatology at UCSF and the San Francisco Veterans Administration Hospital.

She lives in San Francisco with her husband and son.

Meet CARF's New Scientific Advisor Dr. John Sundberg

John Sundberg, DVM, PhD, is a professor at The Jackson Laboratory in Bar Harbor, Maine. He received a Bachelor of Science degree in Animal Sciences from the University of Vermont in 1973, and a Doctorate in Veterinary Medicine from Purdue University School of Veterinary Medicine in 1977. He practiced in Meadville, PA, before completing an anatomic pathology residency and a PhD in experimental pathology and virology at the University of Connecticut in 1981. His concentration was papillomaviruses in animals.

professor running an independent research laboratory that focuses on genetic-based mouse models of human skin, hair, and nail diseases. This work is done in collaboration with distinguished dermatologists, including members of CARF's scientific advisory board -- namely Drs. Lloyd E. King, Jr., Kurt Stenn, Vera Price, and Leonard Sperling.

Dr. Sundberg's influence on non-dermatology research is highly recognized. For the past 10 years, he has been the primary organizer of an

on mouse models for human skin and hair diseases.

Dr. Sundberg later defined the alopecia and scarring dermatitis seen in C57BL/6 mice as being a complex genetic disease caused by inability of these mice to detoxify vitamin A due to a mutation in the alcohol dehydrogenase 4 gene (*Ald4*). This defect was exacerbated by other genes resulting in a form of cicatricial alopecia resembling central centrifugal cicatricial alopecia. He recently identified the sterol O-acyltransferase 1 (*Soat1*)



For the next five years, Dr. Sundberg worked as an assistant professor of pathology at the University of Illinois' Champaign-Urbana College of Veterinary Medicine. Here, he continued his study of papillomavirus-induced cancers in animals, focusing on developing a dog oral papillomavirus model. This research provided the proof of concept data that lead to the human cervical cancer vaccine.

In 1982, while at the University of Illinois, Dr. Sundberg passed the veterinary anatomic pathology specialty board examination.

In 1986, he became an associate professor and head of the pathology program at The Jackson Laboratory where he is currently a full-fledged

annual meeting on the Pathology of Mouse Models for Human Diseases, held in cities across the nation.

Dr. Sundberg's studies at The Jackson Laboratory initially involved reviewing existing spontaneous mouse mutations affecting the skin and adnexa. He recognized several of the mutants now considered important models for cicatricial alopecias, including mutations in stearoyl-Coenzyme A desaturase 1 (*Scd1*, the asebia mouse), gasdermin A3 (*Gsdma3*, the bareskin mouse) and other allelic mutations of this gene. These studies are described in the first of his seven books, which was published in 1994 following a groundbreaking meeting he hosted at The Jackson Laboratory the year before

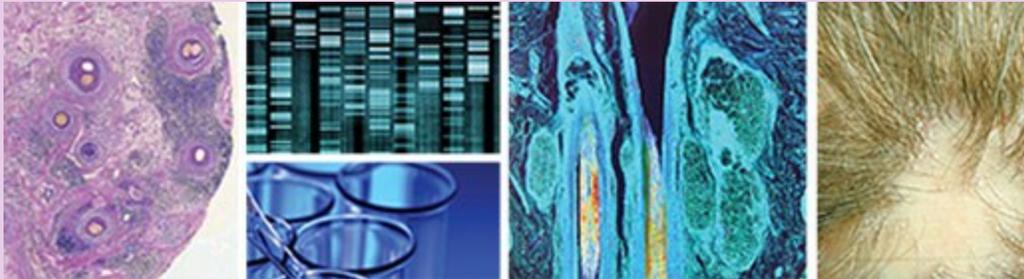
gene as being responsible for the hair interior defect mutation in AKR/J mice. While this specific mutation does not directly induce cicatricial alopecia, it is in the same gene network as many of the other single gene mutations thought to play a causative role in some cicatricial alopecias.

Dr. Sundberg is investigating several novel genes that do cause cicatricial alopecia. At the same time, he continues to provide mentorship training opportunities to young investigators to learn how to use mouse models to study skin diseases. He brings a wealth of experience working with laboratory mice, as both a principal investigator and pathologist, to investigations of cicatricial alopecia. And he is an invaluable resource for CARF.

CARF Sponsors Symposium for the Medical Community

Cicatricial Alopecia Research Symposium 2011: Current Progress and Future Challenges

Thursday and Friday, October 27-28, 2011, Bethesda, MD



This symposium will feature world-class experts presenting the latest research in cicatricial alopecia. It will bring together hair biologists, immunologists, dermatologists, environmental toxicologists and hair trans-

plant surgeons in their common pursuit of a deeper understanding of the etiology and pathogenesis of cicatricial alopecia. The symposium will facilitate the exchange of ideas and information between laboratory and

clinical researchers, in an effort to accelerate the translation of basic scientific discoveries into clinical applications. Registration is open to the medical community only. Please visit: www.cicatricialalopecia.org.

CARF's New Facebook Friend



Nathaniel Malcolm

Nathaniel, officially David Nathaniel Malcolm, was born and raised in the San Francisco Bay Area and currently resides in Cambridge, Massachusetts.

Nathaniel first became affiliated with CARF through a family connection. He was struck by the dedication, passion, bravery and diligent efforts of the CARF doctors, staff and patients, all of whom work tirelessly to increase global outreach and awareness of hair-loss disease.

Since 2008, Nathaniel has periodically helped CARF with event planning, and he recently became CARF's Facebook site manager. He is excited to contribute to CARF's efforts in this new capacity and is looking forward to continuing to meet and work with the

CARF community.

Nathaniel graduated from the University of California, Berkeley (GO BEARS!), in 2004 with a Bachelor of Arts degree in history.

After graduating, he first worked as a legal assistant/paralegal in the field of telecommunications regulatory law for a firm in San Francisco. He then entered the sphere of medical malpractice litigation at a Boston-based law firm.

In 2008, Nathaniel spent a year traveling around the world, exploring a host of countries including Hungary, Turkey, Egypt, Ethiopia, Kenya, Sweden, and the United Arab Emirates. Nathaniel is planning to attend law school in the Boston area this fall.

American Academy of Dermatology Meeting, May 2011

CARF's presence at the AAD meeting included our participation in an array of enjoyable events:

- ◇ Annual Scientific Advisors meeting in which the latest cicatricial alopecia research was discussed
- ◇ Manning the Coalition of Skin Disease booth and disseminating information about all skin diseases
- ◇ The North American Hair Research Society and the Women's Dermatologic Society luncheons

Congratulations to our team members:

Suzanne Connolly, MD, became the Vice President of the American Academy of Dermatology

Pearl Grimes, MD, received two prestigious awards: 1) The Practitioner of the Year Award from the American Academy of Dermatology Foundation, and 2) The Mentor of the Year Award from the Women's Dermatologic Society

Vera Price, MD, was named an honorary member of the American Academy of Dermatology Foundation



CARF Extravaganza! Sunset Reception on Lake Pontchartrain

In a first of its kind event for CARF, Board Member Sharon Potter and her husband, Henry, generously hosted a spectacular party on their New Orleans houseboat. The unique lake setting and coziness of the boat provided the perfect ambience for guests as they feasted on regional Cajun food, socialized, and watched the Super Bowl. What a memorable evening!

Having a reception during the five-day annual meeting of the American Academy of Dermatology provided CARF an ideal opportunity to establish itself as a major player in the dermatology community, and strengthen its relationships with all who attended. It was also a chance for us to show our gratitude to our sponsors for their commitment.

The sponsors whose company leaders and executives attended the function were Allergan, Bosley, DermaGenoma, Follica, Hill Dermaceuticals, and Johnson & Johnson.

In addition, our Scientific Advisors invited young doctors and researchers who are interested in cicatricial alopecia and CARF's work.

The list of esteemed guests included Dr. Lynne Goldberg, host of the 2012 CARF Patient Doctor Conference; Barbara Starr, Editor-In-Chief of the *Journal of the Dermatology Nurses' Association*; Dr. Shadi Kourash, representing Dr. Bergstresser of the *Journal of Investigative Dermatology*; Dr. Nicole Rogers, medical advisor for CARF's New Orleans support group; Dr. Adriana Schmidt, co-leader of CARF's Los Angeles support group; and Drs. Jeffrey Callen, Carolyn Goh, and Yolanda Lenzy.



The Power of ONE

Marilyn Ey



Marilyn Ey

When diagnosed with cicatricial alopecia, I had no ONE to provide the knowledge I so desperately needed. Sorrow took over as hundreds of questions raced through my mind. Should I keep my diagnosis a secret? How would my friends and loved ones react? If others found out, how would they treat me? How fast would my hair disappear? Would the itching ever stop? I felt like a freak.

Guilt set in as I wondered if my disease was genetic. Would my daughter and granddaughters get it?

As I mentally withdrew from the world, depression set in. My doctor provided outdated websites that alarmed and frustrated me. My husband didn't know how he could help me, and neither did I. I lost sleep at night wondering: Isn't there some ONE out there who can provide the knowledge and support I so desperately crave? I felt lost and alone as if tossed into the Pacific Ocean with no land in sight. I knew I wouldn't give up, but who would provide answers to aid in my rescue? I silently screamed for help. Oh, please let there be ONE person, ONE entity out there to help me find my way through this nightmare.

Fortunately, my doctor referred me to Dr. Vera Price. She was the first ONE to answer my questions. When I learned this disease was not genetic, my fear for my daughter and granddaughters evaporated. Dr. Price told

me that more information was available at www.carfintl.org and invited me to a support group meeting. Dr. Price was the ONE to give me hope.

The CARF website provided the name of ONE patient who lived nearby. When Donna Weaver and I spoke for the first time, she calmed my fears. I cried tears of joy knowing I was no longer alone. Between Donna and the website information, I gradually began learning how to handle the emotional aspects of my disease.

Later that year, Donna and I attended the very first cicatricial alopecia support meeting, where we shared our stories with other patients. There I learned how ONE person's determination sparked an idea. That someone persuaded Dr. Price to champion this disease and it was their combined effort that laid the foundation for CARF. Who was that ONE determined individual? It was Sheila Belkin, CARF's spark plug.

Soroptimist International of Chico is an

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Nancy Balik FitzGerald

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miles of heart and hope. It takes strength, and it takes support, such as we have from CARF. This is the essential journey of freedom. And you do not have to make that journey alone. In that spirit, I leave you with an excerpt of a favorite poem by Emily Dickinson:

Hope is the thing with feathers,
That perches in the soul,
And sings the tune without the words,
And never stops at all...

So as you lead your best life, may you fill your senses with the power of yes and fill your heart with a hopeful song to hum along with and to empower you on the way.

Editor's note: This article is adapted from a talk given by Nancy Balik FitzGerald at the 4th CARF International Patient Doctor Conference. After the talk, attendees joined in a *Gleeful* rendition of "Lean on Me" in a moving and memorable ending to an enlightening and inspiring weekend.

The Importance of Corporate Citizenship: One Company's Approach



Jim O'Connell

We were honored to have Jim O'Connell attend the recent CARF conference as the representative of one of our sponsors. Jim is Senior Manager of External Relations at the Procter & Gamble Company. Addressing attendees on the last day of the conference, he said:

The needs of underserved populations cannot be met by government alone in today's world. Be-

cause of this, companies have an opportunity—some say an obligation—to help satisfy these basic needs. The Procter & Gamble Company believes it has a responsibility to help in this area. Our Purpose Statement says, "We will provide branded products and services of superior quality and value to improve the lives of the world's consumers, both now and in the future." Improving lives is what we strive to do.

His presentation showed how P&G views its responsibilities in this area, and what P&Gers around the world are currently doing to improve lives.

For many years, Jim's main area of concentration was in consumer and trade cause marketing, which involves working with a number of important and well-known causes such as Special Olympics, the American Heart Association, the Juvenile Diabetes

Research Foundation, Big Brothers/Big Sisters, the Susan G. Komen Foundation, and Give Kids the World.

His interest in causes and charities, however, has always extended beyond purely marketing. He serves on the Corporate Steering Committee of P&G's local Cincinnati United Way effort and as President of the Board of Trustees of Hamilton County (Ohio) Special Olympics. In his closing remarks, he encouraged everyone to be a volunteer.

In addition to his public relations position at P&G, since 2004, Jim has served as Senior Manager of Dermatology Relations. The assignment gives him responsibility for maintaining and developing relationships with dermatologists and various dermatology-related associations.

We thank Jim and P&G for their interest in our disease and their generous support of CARF.

Did You Know Volunteering Is Good for Your Physical and Emotional Health?

In an article called "Volunteering Does a Body Good," featured in the November 2010 issue of *U.S. News & World Report*, journalist Angela Haupt writes about various studies that explain why volunteers enjoy significant physical and emotional benefits and tend to live longer.



It turns out that helping others not only takes our minds off our own challenges, but it increases our levels of oxytocin, endorphins and dopamine, all of which relieve stress, give us more physical energy, and make us happier. In other words--give a little and you'll get a lot back.

As the lone voice for patients with a rare disease, CARF depends on volunteers. We thank all our wonderful volunteers for their generous efforts and contributions. Each helping hand brings us closer to finding a cure for our rare disease.

If you would like to boost your "happy" hormones and help us out in any way, please contact CARF's volunteer coordinator, Marilyn, at volunteer@carfintl.org.

You can read Angela Haupt's article and learn more about the studies that show the amazing benefits of volunteering at <http://www.isreligion.org/2010/11/volunteering-does-a-body-good/>.

It Works for Me

It Works for Me provides tips from our CARF community!

Please be advised that CARF does not endorse any of the products or suggestions given below. The recommendations are solely those of the contributors and are not intended as medical advice. Patients with questions regarding specific symptoms or treatments should consult a professional health-care provider.

"Itching is the maddening culprit that bothers me. There are two products that give relief.

To control itching, I shampoo with Head and Shoulders Intensive Solutions with 2% pyrithione zinc. I leave it on for five minutes, rinse it out, and then use a conditioner. That seems to work. Other pyrithione zinc shampoos I have tried do not relieve the itching. Head and Shoulders Intensive Solutions is found in local drug stores and at other places where shampoos are sold.

For itching on the body, and in my case behind the ears and on the chest area, I use MoroccanOil. It is non greasy, immediately absorbs into the skin, and halts the itch. It is made in Israel and can be found in most beauty supply shops. Hope this helps."

Patient in Los Angeles

"My doctor recommended using a salicylic acid shampoo, such as Nizoral or Neutrogena's T/Sal, to reduce the scaling and flaking on my scalp. She recommended I alternate between using the salicylic acid shampoo and a mild shampoo on a weekly basis, and that I vigorously massage it into my scalp.

I was afraid it might hurt my already sore and tender scalp. However, when I massaged my scalp vigorously the pain actually went away. Now I always scrub hard when I'm washing my hair. I find it helps control pain and scaling even now that I'm using a mild shampoo most of the time."

Patient in Granada Hills, CA

"I have found DermMatch to be the best help for areas of hair loss. I don't wear my wiglets anymore since this solution provides much better coverage and DOES NOT hurt. You need to use the color of your roots and dab it on the bald areas."

Patient in Middleton, MA

I have a few patches of hair loss that can be camouflaged by sprinkling Toppik hair fibers over them.

Getting the right color is important. I've learned that it's best to buy directly from Spencer Forrest at <http://www.toppik.com>.

Recently, I tried light brown instead of auburn, and the result was terrible. When I called Toppik, they told me that if I had bought the fibers directly from them they would have exchanged the light brown fibers for auburn. My local beauty supply would not do it. I had spent about \$40 on the wrong color and ended up donating it to my hairdresser in the hope that she would give it to someone else who needed it.

So, my tip is to purchase the hair fibers online directly from Toppik and to try the small travel-sized packages until you are sure you have the correct color."

Patient in Hollywood, CA

Do you have a tip to share about how you cope with hair loss and the symptoms of cicatricial alopecia? Email your submission to itworksforme@carfintl.org.

Please type "It Works for Me tip" in the subject line of your email; and include your city, state and country in the body of the email. All tips will be published anonymously.

The Power of ONE

Marilyn Ey

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All-volunteer organization of which I am a member. My Soroptimist sisters share the highs and lows of my cicatricial alopecia journey. When my scalp stopped itching, they cheered! When the raw, tender areas on my scalp reappeared, they were concerned. When asked to donate to CARF, they responded generously. This

is ONE great group of volunteers dedicated to helping others.

The emotional turmoil that once overwhelmed me has vanished. CARF support groups and friendships with patients, physicians and volunteers led me to this point. At my first CARF conference, I was asked to be a greeter

and learned the joy of welcoming patients. What a wonderful feeling ONE gets when ONE gives.

Please consider helping thousands worldwide by being ONE of the CARF volunteers. You will make a difference in more than ONE life.

Bald is Beautiful

by a CARF Contributor
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Dubose-Gibson. “It wasn’t just for me; it was for all of us.”

The victory has led to interviews with news publications, television appearances, and motivational speaking engagements. “I didn’t know that I was making history,” Dubose-Gibson said. “This was just another blessing.”

But the road from agonizing over her baldness to accepting it—and subsequently being crowned a beauty queen—has not been easy. At age 25, Dubose-Gibson was diagnosed with alopecia areata, a condition that causes hair loss from some or all areas of the body, including the scalp where round patches typically appear. A few years later, she found out she also had cicatricial (scarring) alopecia, a disorder that destroys the hair follicle and replaces it with scar tissue, thereby causing permanent hair loss.

“I was depressed,” Dubose-Gibson recalled. “I felt ugly. I just wanted to cover it up.” She also fretted because her father had died of lupus, an autoimmune disease. Could she possibly succumb to this disease? Might it affect her daughters, Miyah, 13, and Elajah, aged nine?

“I was afraid of the unknown,” Dubose-Gibson said. It took years for her to feel comfortable enough to allow even family members to see her when she wasn’t wearing a wig.

Her breakthrough came in 2008, about a year after Dubose-Gibson and her family moved from New York to Apex, North Carolina. She had an opportunity to start anew. “I really wanted to be liberated in this experience,” Dubose-Gibson said. “I realized that I was still harboring emotional baggage. I was still hurt about it, but I was tired of carrying this baggage around.”

So she made the most critical of all decisions. “I decided to accept this new identity as a bald woman,” Dubose-Gibson said. She dared herself to confront her fears; dared herself to embrace her beauty; dared herself to step outside—bald.

It was that same courageous spirit that ultimately propelled Dubose-Gibson to enter the beauty pageant—despite the self-doubt, discomfort and terror-tinged excitement that consumed her before the event.

“I dared myself to do it,” said

Dubose-Gibson, who runs a support group called the Alopecia Community of the Triangle. “It was another rung on the ladder of liberation for me.”

But she also knew it was bigger than her. “It would mean something to so many people if I had the audacity to stand up there and win,” Dubose-Gibson said. And that’s exactly what she did.

Strutting across the stage in a stunning floor-length turquoise gown with beading and, as Dubose-Gibson joked, “a very forgiving mid-section,” the little lady with the big voice was able to send a poignant message to all women with alopecia.

“You have to find your way to fight back,” said Dubose-Gibson, who was the inspirational speaker at the Cicatricial Alopecia Research Foundation’s Patient Conference in 2010. “You have to find your way to be liberated. I felt that alopecia took something from me. I felt like I had been robbed. But the fighter, the warrior in me, made me feel that I needed to take it back.”

(For more information on the Alopecia Community of the Triangle, go to: <http://alopeciaincommunity.org>).

Don’t Miss Out! Keep Your Contact Info Current

Receive newsletters and updates about cicatricial alopecia and future CARF events by keeping your contact information current.

When you move or change your email address or phone numbers, please update your contact information.

Act now by going to the page entitled “Update Your Info” on the CARF website.
<http://www.carfintl.org/update.html>.

A Patient's Perspective Hair Today, Gone Tomorrow Anonymous

I was diagnosed with cicatricial alopecia in December of 2008—to be precise, the conclusion was lichen planopolaris and probable central centrifugal cicatricial alopecia, CCCA.

I have no idea exactly when it started, but the first time my partner and I really noticed it was a few years ago in the islands when I got a sunburn on my scalp. It was in a specific spot that was very smooth and round, right on the top, near the front of my head. Anytime I traveled after that, I made sure to cover it with my hair (pulled into a ponytail most of the time). Finally, in November of 2008, I was getting a haircut and the hairdresser said I should see a doctor because those 'spots' were everywhere.

After I was diagnosed, I went through the typical sadness and shame. It was ironic, this diagnosis, because my hair has always been thick and curly. Eventually I realized that I shouldn't be embarrassed. This isn't something I chose or did to myself. It's a fluke, a strange and inexplicable inflammatory disease that I cannot control.

There is no cure (although thanks to CARF there is a lot of research going on), no definitive understanding of why it happens, and no idea when or if there might be fully effective treatment. I used to just deal with the spots, referred to as "footprints in the snow" by a dermatologist I saw for a second opinion. I then opted for steroid shots in my scalp to see if it would slow down the process. Not only did it not slow down, but the shots

seemed to spark pain that did not go away. The pain felt like a bad sunburn with the hair all over the crown of my head being pulled really hard. I was miserable. I wanted to cry all the time. I tried icing. I tried lidocaine ointment. I tried anti-inflammatory oil all over my scalp. Nothing worked.

I am still losing a lot of hair. I shed constantly. Every time I shower, tons of hair ends up in the drain. We bought a hair catcher to cover the shower drain and it seems to work well. Every time I touch my pony tail, a bunch of hair comes out in my hand. It's not connected. I don't pull it. It's just sitting there. The top of my head stays covered, for the most part, by the loose pony tail I wear, but when I dress up at all, we spray Bumble and Bumble brown powder on the bald spots. Who knows how long I have before I lose it all, if ever, but I am starting the process of looking at all my options.

Things I think about each day, in no particular order: To shampoo or not to shampoo? Wetting my hair helps with the discomfort, but washing or conditioning it may make the hair shed even faster. Needless to say, I wash my hair, but each shower is a dilemma. Is my hair covering the bald spots? Each day I have to check and double check. Has anyone noticed? At work I am always conscious of people walking by and looking down at my head when I am working at my desk. Is today going to be a painful day or a tolerable day? Should I cut my hair shorter, or will that make it more noticeable? Wearing it in a ponytail is getting old, and the pulling and the

weight of it aren't so comfortable, even though I wear it loose. Shorter could be cute, but maybe not? How and when can I start wearing hats without being teased? It would definitely be a new look for me. How much hair is clogging the shower drain today? I cannot forget to clean it out. (Gross!) Can anyone see my shiny scalp when I sweat? I set a new goal in December of 2009. I wanted to track changes in my hair loss and scalp pain, so I adopted a new way of living to see if it had any impact.

Background: I'm 38 and have struggled with my weight my whole life. A few years ago, I got myself in very good condition and lost a bunch of weight. I looked better and felt good. I was running three miles every day and eating healthily. The scarring alopecia had not yet been diagnosed, but I had a couple of bald spots that did not get worse and did not bother me.

The year 2009 was extremely hard, however. Our cat (our son) was very ill and then had to be put to sleep. My parents were going through a stressful time. Work was rough. I had never been more stressed, and all I did was eat like a pig and lie around like a lump. Needless to say, I gained back pretty much all the weight I had lost, didn't exercise at all, and my hair loss and scalp discomfort was much worse. I was miserable.

For my birthday in November, my loving partner got me a personal trainer and, as a result, got me back on track. The most generous gift in the world really helped me in so many ways. Since December 1, 2009, I have been working out

A Patient's Perspective Hair Today, Gone Tomorrow

Anonymous

(continued from page 12)

five or six times a week, eating perfectly (low- or no-fat, tons of veggies and fruits, whole grains, very little meat, etc.), and taking much better care of myself. My stress level is better overall, thanks to the exercise and healthier food intake—not to mention a little R&R in the Caribbean. And my head has stopped hurting all over all of the time; now it is just bad in specific areas.

Does the healthier lifestyle have any impact on alopecia and its symptoms? Who knows? But I am committed to continuing on this path. Life's stresses are still very much there, but I have to figure out ways to handle them better.

With that said, I have become more and more involved in CARF. I helped start a support group in the Washington, DC, area and seem to be in a pretty good state-of-mind overall about this. I am off any and all medications related to hair loss for a variety of reasons. The Plaquenil started giving me weird vision issues. It wasn't helping with the alopecia anyway, and why risk my eyesight? I don't use Clobetasol anymore. It doesn't help with the pain, so why bother? On the very rare occasion that my scalp is itchy, however, I use it and it seems to help. No more antibiotics either. They didn't help, so why put them in my system?

I have lost about 40 pounds by eating perfectly, exercising five or six times each week (I love going to the trainer—best present ever), and taking excellent care of myself. Has there been a change in the rate of hair loss? Nope. Each shower brings about more and

more shedding. My scalp pain seems a little better; it's not as frequent, but it's still there. I think I have adjusted to it, even though I'm still in a bit of pain. Why dwell on something that is not changing? I live my life and go about my business. My scalp is what it is.

So, yes, I'm in a very good place emotionally, even though my experiment with my new way of living seems to have failed for the most part; let me rephrase: failed in the hair loss area. On the other hand, I feel great. My body has changed dramatically. I am stronger and in much better shape. I hope to run a 5k sometime in the fall. I love feeling this way. Working out definitely agrees with me in every way.

The CARF support group also ended up being more helpful than I thought it would be. Everyone there understood and could commiserate with each other's experiences and feelings. Some of us are in a better frame of mind about our hair loss than others, but we all felt comfortable enough sharing and were very happy and relieved that the group finally got going. Each time we meet, we will have a different topic, such as medical issues (medications, etc.), psychological issues, research, coverage options (hats, scarves, toppers, wigs, etc.). Dr. Callender, the medical advisor, said that the group can bring in guest speakers. This will be very informative, and I look forward to all of it.

I also attended the CARF conference in California in September. There were lectures and breakout groups on everything related to

cicatricial alopecia. I learned a lot and met the people who are working so hard to make CARF a success. My partner attended the conference with me. She has been my rock throughout all of this. We made a mini-vacation out of our trip and had a lot of fun.

It is so annoying having to think about this issue in life, but I am honestly very grateful. There are much, much worse things. In the grand scheme of things, this is minor. So that's where I am now, dealing with it the best I can and learning not to be ashamed or embarrassed. I am fortunate. I really do have an incredible support system. My partner couldn't be more compassionate, sympathetic, loving and supportive. She is able to make me laugh about it—really the best medicine. My parents are wonderful. My mom, who is possibly going through some sympathy balding, hates it when I'm in pain and is more than understanding about the range of feelings I experience. My sister-in-law has become my new hairdresser. She is self-taught and great at it. She cuts my hair for me so I don't have to go to a salon and explain and suffer through the hair washing. All in all, I couldn't be luckier. I am very grateful.

By the way, my mom suggested I start a blog. So, I guess I'll keep writing. Check it out: <http://hairigo.blogspot.com/>.

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If you have named CARF in your estate or as a trust beneficiary, or if you are just considering plans to do so, please let us know.

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Cicatricial Alopecia Research Foundation
P.O. Box 60158, Los Angeles, CA 90064

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