2018 Philadelphia

PATIENT CONFERENCE

CARF

SHERATON SUITES PHILADELPHIA AIRPORT

June 8 - 10, 2018

Conference Advisory Committee

George Cotsarelis, MD
University of Pennsylvania
Philadelphia, PA

Michael Ioffreda, MD
Penn State University
Hershey, PA

Maryanne M. Senna, MD
Massachusetts General Hospital
Boston, MA

Welcome to beautiful Philadelphia!

To many, Philadelphia is known as the “City of Brotherly Love” however, it could also be called the City of Firsts! You probably know that both the Declaration of Independence and the Constitution were written in Philadelphia. But did you know that many American firsts like the public library, fire department, university, stock exchange, zoo, and Mint were created in this great city?

Perhaps it’s of interest to you as patients that Philadelphia is also home to the first hospital and first medical school. The University of Pennsylvania School of Medicine was the first and only medical school in the thirteen American colonies when, in the fall of 1765, students enrolled for "anatomical lectures" and a course on "the theory and practice of physik."

Can you imagine what those students from the Class of 1765 would say about the CARF Patient Conference today? Of course, they would be impressed by our advances in technology and medicine, but we like to think they would also be amazed by the collaborative environment between physicians and patients. Patients, we encourage you to take advantage of being among the country's leading researchers and physicians for cicatricial alopecia. But also realize, that these doctors value the chance to meet, listen and learn from you as patients who live and cope with cicatricial alopecia in your daily lives.

We are confident that this weekend will be filled with intelligent conversation, learning opportunities and hope toward advancing science and treatments for scarring alopecia. After all, Ben Franklin did say, “An investment in knowledge pays the best interest.”

This weekend would not have been possible without the help of our Medical Advisory Committee, Drs. George Cotsarelis, Michael Ioffreda and Maryanne Senna. And, a heartfelt thank you to our Patient Committee, Marilyn, Hatcho and Nancy, for your guidance and support, and to everyone else who helped make our 8th Patient Conference a huge success!

Jean Pickford
Executive Director

Madeline Miller
Patient Outreach Coordinator

FRIDAY

Rosemont Foyer

4 - 6 pm Check-In
6 - 9 pm Reception

SATURDAY

Terrace Landing

7 - 8 am Breakfast

Rosemont Ballroom

8 - 8:15 am
Welcome.....Rita Wanser, CARF President

8:15 - 8:30 am
CARF Update.....Jean Pickford, CARF Executive Director

8:30 - 9:00 am
Basics of Primary Cicatricial Alopecia: LPP, FFA,CCCA..... Kathie Huang, MD

9:00 - 9:30 am
Basics of Primary Cicatricial Alopecia: DLE, DC, FD.....Kim Salkey, MD

9:30 - 9:50 am
Question & Answer

overview

9:50 - 10:10 am
Break

10:10 - 10:40 am
The Usefulness of the Scalp Biopsy.....Michael Iofferda, MD

10:40 - 11:10 am
So What is Causing these Conditions? .....Jeff Donovan, MD, PhD

11:10 - 11:30 am
Question & Answer

workup & cause

Terrace Landing

11:30 - 1 pm Lunch

CARF

Rita Wanser
MedClin
South Amboy, NJ

Kathie Huang, MD
Brigham & Women's Hospital
Boston, MA

Kim Salkey, MD
Virginia Commonwealth University
Richmond, VA

Jeff Donovan, MD, PhD
University of Toronto
Ontario, Canada

SATURDAY

Brigette Sallee, MD
Columbia University
New York, NY

Sarina Elmariah, MD, PhD
Massachusetts General Hospital
Boston, MA

Lynne Goldberg, MD
Boston University
Boston, MA

Ronda Farah, MD
University of Minnesota
Minneapolis, MN

Rosemont Ballroom

1 -2 pm
Research Review Panel.....George Cotsarelis, MD, Brigette Sallee, MD
Maryanne Senna, MD, Ronda Farah, MD

research

2 - 2:30 pm
Medical Treatments.....Lynne Goldberg, MD

2:30 - 3 pm
Surgical Treatments.....Nicole Rogers, MD

3 - 3:20 pm
Question & Answer

treatments

3:20 - 3:50 pm
Break

3:50 -4:20 pm
Treating Itch & Pain.....Sarina B. Elmariah, MD, PhD

4:20 - 4:50 pm
Laser Treatments for Primary Cicatricial Alopecia.....Ronda Farah, MD

4:50 - 5:10 pm
Question & Answer

treatments

Wynnewood Room

5:15 -6 pm
Newly Diagnosed.....Marilyn & Nancy, Patient Outreach Volunteers

support

Rosemont Foyer

6:30 - 7 pm Pre-Dinner Reception & Cash Bar

Rosemont Ballroom

7 - 7:30 pm
Dinner & Volunteer Awards.....Madeline Miller, Jean Pickford

7:30 - 8:15 pm
Finding JOY.....Lori Bertella

8:15 - 10 pm
Social & Music

social

SUNDAY

Terrace Landing
7 - 8 am Breakfast

Lower Restaurant
7 - 8 am Private Breakfast

For Support Group Leaders
& Those Interested In Starting a Support Group

Rosemont Ballroom

8 - 8:20 am
Optimizing Nutrition for Hair Growth.....Yolanda Lenzy, MD, MPH

8:20 - 8:40 am
The Mind-Body Connection.....Maryanne Senna, MD

8:40 - 9:20 am
Finding the Care You Need.....Hatcho Semerciyan, Jean Pickford

9:20 - 9:50 am
Question & Answer

stress & nutrition

Wynnewood Lars Brichta, PhD	Rosemont Yolanda Lenzy, MD, MPH	Merion Nicole Rogers, MD
9:50 - 10:20 am Working with a Compounding Pharmacy	9:50- 10:20 am Safe Hairstyling Practices & Tips for Selecting Wigs and Hairpieces	9:50 - 10:20 am Hair Thickeners, Hair Camoflauge, and Cosmetic Tattooing

Choose One **breakouts 1**

10:20 - 10:40 am
Break

Wynnewood Lars Brichta, PhD	Rosemont Yolanda Lenzy, MD, MPH	Merion Nicole Rogers, MD
10:40 - 11:10 am Working with a Compounding Pharmacy	10:40- 11:10 am Safe Hairstyling Practices & Tips for Selecting Wigs and Hairpieces	10:40 - 11:10 am Hair Thickeners, Hair Camoflauge, and Cosmetic Tattooing

Choose One **breakouts 2**

CARF

Yolanda Lenzy, MD
Lenzy Dermatology
Chicopee, MA

Nicole Rogers, MD
Tulane University
New Orleans, LA

Lars Brichta, PharmD, PhD
Chemistry Rx
Philadelphia, PA

Lori Bertella
FedEx
McDonald, PA

SUNDAY

Rosemont Ballroom

11:20 - 11:40 am
Future Goals & Conference Wrap-Up.....Maryanne Senna, MD

11:40 - 12 pm
Question & Answer

today & beyond

Terrace Landing

12 - 1 pm Lunch

Wynnewood Room

1:00 -2:30 pm
Show & Share .....Marilyn & Nancy, Patient Outreach Volunteers

Please bring any products that help treat your cicatricial alopecia

support

Tell me
and I forget.
Teach me
and I remember.
Involve me
and I learn.

-Benjamin Franklin

Get To Know CARF's Team

With over 27 years of nonprofit management experience, Jean became CARF's Executive Director last summer. She is a lifelong supporter for individuals and families affected with rare and chronic disease and has devoted her career to patient advocacy. Prior to taking over the leadership at CARF, Jean was employed as CEO at the Foundation for Ichthyosis & Related Skin Types, Inc. (FIRST) for 18 years. Jean was also employed at the American Heart Association as Special Events Director, and began her non-profit career at the National Tay-Sachs & Allied Diseases Association of Delaware Valley as Assistant Executive Director. Jean recently served a four-year term as Advisory Council Member at the National Institute of Arthritis, Musculoskeletal and Skin Disease (NIAMS), a branch of the NIH and was Treasurer of the Coalition of Skin Diseases for five years. Jean is a married mother of three children and enjoys yoga and biking.

Madeline Miller joined CARF in October 2017 as the Program Outreach Manager. Madeline developed her love for non-profit organizations while interning in college with the Philadelphia Ronald McDonald House. After graduating from Drexel University in 2009 with a BA in Communications and Public Relations, Madeline worked with four organizations including Best Buddies Delaware, the Epilepsy Foundation, North Penn School District and Foundation for Ichthyosis & Related Skin Types. She has experience in program development, volunteer management and fundraising. Outside of work, Madeline enjoys cooking and traveling with her husband, Brady. They are proud parents to a 8-year-old mutt, Linus.

MY CONNECTIONS

Living with cicatricial alopecia can be an emotional journey. CARF encourages you to take notes and forge new friendships with other members at the conference. Stay connected with each other by sharing your contact information. Understanding, encouragement and camaraderie is only a phone or email call away!

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