

# COMPLEX WOUNDS IN ECTODERMAL DYSPLASIAS



NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS

SPONSORS:



ORACLE

Bruce & Alice Geismar

## NOV 3-5

CHILDREN'S HOSPITAL OF PHILADELPHIA (CHOP)  
CONFERENCE ROOM - HUB-CR-01-1632

Windsor Suites Philadelphia  
1700 Benjamin Franklin Pkwy, Philadelphia, PA 19103

CONFERENCE ORGANIZERS:  
*BECKY M. ABBOTT, M.P.H.; MARY FETE, M.S.N., R.N., C.C.M.; MARANKE I. KOSTER, PH.D.; AND ERIC C. LIAO, M.D., PH.D.*

SUN  
3

### NOVEMBER

7:00 PM Dinner & Introductions at  
Con Murphy's Pub

MON  
4

### NOVEMBER

7:30 AM Leave from Hotel  
8:00 AM Breakfast and Welcome  
8:15 AM Brief Presentations by  
Participants  
12:00 PM Lunch  
1:00 PM Breakout Sessions  
4:00 PM Presentations of  
Takeaways from  
Breakout Sessions  
5:00 PM Future Tissue Collection  
Discussion  
7:00 PM Dinner at  
Maggiano's Little Italy

AGENDA

The overall objective of this conference is to accelerate the development of novel therapeutics for complex wounds associated with ectodermal dysplasias. To this end, this conference will bring together experts in the fields of normal wound healing, chronic non-healing wounds, and wounds associated with genetic disorders.

This group of experts will identify significant gaps in our knowledge of complex wound biology and define the next steps in addressing wound healing challenges in patients affected by ectodermal dysplasias and other disorders associated with complex wounds.

The conference will combine brief presentations by participants with breakout sessions to define future research priorities and deliverables. In addition, we will address needs for the collection of patient skin and other biological materials necessary to facilitate future research endeavors.

#### PARTICIPANTS

Internationally recognized clinicians, researchers, and young investigators with expertise in developing and applying novel treatments in relationship to complex wounds in ectodermal dysplasias and other rare diseases.

#### TRAVEL ACCOMMODATIONS

The NFED will provide Uber vouchers to participants for ground transportation from/to the airport to Windsor Suites and to/from the Windsor Suites to CHOP. The NFED will cover the cost of 2 nights hotel at Windsor Suites. Please let us know if you require an additional night to accommodate your travel. The NFED staff will reach out to participants for travel dates.

TUES  
5

### NOVEMBER

7:30 AM Leave from Hotel  
8:00 AM Breakfast  
8:15 AM Define Next Steps  
11:00 AM Wrap-up Session &  
Deliverables  
12:00 PM Lunch

NFED.org · 618-566-2020

Mary Fete, M.S.N., R.N., C.C.M. - mary@nfed.org

# COMPLEX WOUNDS IN ECTODERMAL DYSPLASIAS



## PARTICIPANTS

**Becky M. Abbott, M.P.H.**

Director, Treatment and Research Advocacy  
Family Affected by Ectodermal Dysplasia  
National Foundation for Ectodermal Dysplasias

**Brad A. Amendt, M.S., Ph.D.**

Professor  
Anatomy and Cell Biology  
Carver College of Medicine  
Orthodontics  
College of Dentistry  
University of Iowa

**Bogi Andersen, M.D.**

Professor of Medicine and Biological Chemistry  
University of California, Irvine

**Jenette Arreola, M.S.**

Graduate Student  
Department of Biochemistry and Molecular Biology  
Brody School of Medicine  
East Carolina University

**Daniela Di Girolamo, Ph.D.**

Researcher (Molecular Biology)  
Center for Genetics Engineering (CEINGE)  
University of Naples Federico II  
Italy

**C. Michael DiPersio, Ph.D.**

Vice Chair of Research, Department of Surgery  
Professor, Department of Molecular & Cellular Physiology  
Albany Medical College

**Fateme Fayyazbakhsh, Ph.D.**

Assistant Research Professor  
Department of Mechanical and Aerospace Engineering  
Missouri University of Science and Technology

**Mary Fete, M.S.N., R.N., C.C.M.**

Executive Director  
National Foundation for Ectodermal Dysplasias

**Timothy J. Fete, M.D., M.P.H.**

Emeritus Professor  
Department of Pediatrics  
University of Missouri School of Medicine

**Ruth Geismar**

Family Affected by Ectodermal Dysplasia

**Smail Hadj-Rabia is M.D., Ph.D.**

Professor of Dermatology and Genetics  
Department of Dermatology and Reference Center for Rare Skin Diseases  
Hôpital Necker-Enfants Maladies  
Institut Imagine  
University of Paris-Cité

**Maranke I. Koster, Ph.D.**

Professor, Department of Biochemistry and Molecular Biology  
Brody School of Medicine  
East Carolina University

**Eric C. Liao, M.D., Ph.D.**

Director, Center for Craniofacial Innovation  
Surgery Vice Chair of Academic Affairs  
Presidential Scholar Endowed Chair  
Children's Hospital of Philadelphia  
Professor of Surgery, University of Pennsylvania

**Whitney Longmate, Ph.D.**

Assistant Professor  
Department of Surgery  
Department of Molecular & Cellular Physiology  
Albany Medical College

**Anna Mandinova, M.D., Ph.D.**

Vice-Chair for Research, Department of Dermatology  
Associate Director, Cutaneous Biology Research Center  
Associate Professor, Harvard Medical School  
Broad Institute MIT/Harvard, Associate Member  
Harvard Stem Cell Institute, Affiliate Faculty  
Massachusetts General Hospital  
Harvard Medical School

NFED.org · 618-566-2020

Mary Fete, M.S.N., R.N., C.C.M. - mary@nfed.org

# COMPLEX WOUNDS IN ECTODERMAL DYSPLASIAS



## PARTICIPANTS

**M. Peter Marinkovich M.D.**

Associate Professor and  
Clinic Director: Bullous Diseases  
Department of Dermatology  
Stanford University School of Medicine

**Caterina Missero, Ph.D.**

Professor of Molecular Biology  
Center for Genetics Engineering (CEINGE)  
University of Naples Federico II  
Italy

**Shirley Parraga, B.S.**

Medical Student  
Brody School of Medicine  
East Carolina University

**Irena Pastar, Ph.D.**

Professor  
Dr. Phillip Frost Department of Dermatology & Cutaneous Surgery  
Wound Healing and Regenerative Medicine Research Program  
University of Miami, Miller School of Medicine

**Maddison N. Salois, B.S.**

Graduate Student  
Department of Biochemistry and Molecular Biology  
Brody School of Medicine  
East Carolina University

**Elaine Siegfried, M.D.**

Professor of Pediatrics and Dermatology;  
Director, Division of Pediatric Dermatology  
Saint Louis University and SSM Cardinal Glennon Children's Hospital

**Cory L. Simpson, M.D., Ph.D., F.A.A.D. (he/him)**

Assistant Professor  
Department of Dermatology  
Institute for Stem Cell and Regenerative Medicine  
University of Washington

**Stefano Sol, Ph.D.**

Anna Mandinova Lab  
Postdoctoral Research Fellow  
Massachusetts General Hospital Cutaneous Biology Research Center  
Harvard Medical School

**Marjana Tomic-Canic, Ph.D.**

Professor and Vice Chair of Research  
William E. Eaglstein MD Chair in Wound Healing  
Endowed Frost Investigator  
Director, Wound Healing and Regenerative Medicine Research Program  
Dr. Phillip Frost Department of Dermatology and Cutaneous Surgery  
University of Miami Miller School of Medicine

**J. Timothy Wright, D.D.S., M.S.**

Editor-in-Chief  
The Journal of the American Dental Association  
Pediatric and Public Health  
Adams School of Dentistry  
The University of North Carolina

NFED.org · 618-566-2020

Mary Fete, M.S.N., R.N., C.C.M. - mary@nfed.org