

Collaboration, Innovation and Community

August 28 & 29, 2021

**MEETING PROGRAM** 

# Meeting Chairs



Elizabeth J. Phillips

MD, FIDSA, FAAAAI
Professor of Medicine,
Pathology, Microbiology
Professor of Pharmacology
John A. Oates Chair in Clinical
Research
Center for Drug Safety and
Immunology
Vanderbilt University Medical
Center



Sherrie J. Divito

MD, PhD
Assistant Professor
Department of Dermatology
Harvard Medical School
Brigham and Women's Hospital
Dana Farber Cancer Institute
Boston Children's Hospital



Charles S. Bouchard

MD, MA
John P. Mulcahy Professor
and Chairman
Department of Ophthalmology
Loyola University Medical
Center

# Message from the Chairs

We would like to welcome back friends and colleagues new and old to our third biannual SJSTEN meeting: SJSTEN2021: Collaboration, Innovation and Community! We started brainstorming about this meeting after SJSTEN2019 in Vancouver, Canada taking the valuable and insightful comments from our scientific and community members. When initial discussions on planning this meeting started in 2019 we could not have conceived it as an 100% virtual meeting however COVID-19 has built new muscles and capabilities on several fronts and this is allowing us to bring together a much larger contingency of trainees, scientists, clinicians and community members than we would have dreamed of. We hope that you will take full advantage of attending all sessions including the virtual poster hall where you can listen, learn and send comments to the presenters, the oral abstracts sessions, the pharmacogenomic and community workshops and the scientific sessions. We hope that you will also network with each other in the "virtual lounge". The meeting and all features which will be open from 7 am US Central time on August 28. Please do not hesitate to contact us prior to or during the meeting

# SISTEN 2021 General Information

# Continuing Medical Education (CME)

The Vanderbilt Office for Continuing Professional Development has approved the meeting for a maximum of 14 AMA PRA Category 1 Credit(s)<sup>TM</sup>. **Instructions on how to obtain CME credit will be on website**.

# Funding Acknowledgements

This conference was funded by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) R13AR078623

### Oral Abstract Session

Saturday, August 28, 5:30 – 7:15 pm

There will be 12 oral abstract presentations during the session. All posters will be available for viewing throughout the meeting in the virtual poster hall.

### Release

Registration to attend or participate in SJSTEN 2021 meeting constitutes an agreement by the registrant to the meeting organizers' use and distribution (both now and in the future) of the registrant or attendee's image or voice in photographs, videotapes, electronic reproductions and audio tapes of such events and activities, unless expressly communicated in writing to the meeting organizers at drugsafetyresearch@vumc.org

# Feedback

Please don't forget to fill out the evaluation and feedback for the meeting. A REDCap questionnaire link will be emailed to all registrants.

# Other Questions

drugsafetyresearch@vumc.org

# Scientific Program

All times listed are in US Central Time (CT), 5 hours behind UTC.

# Saturday, August 28, 2021 (Day 1)

7:00 AM – 9:00 AM Arrivals, Virtual Lounge Networking, Poster viewing

### **Day 1 Webinar #1 - 9:00 AM - 12:30 PM** (US Central Time)

9:00 AM - 9:15 AM

**Welcome and Introductions** 

Elizabeth Phillips, MD, Sherrie Divito, MD, PhD and Charles Bouchard, MD, MA

#### 9:15 AM - 12:30 PM

**Pharmacogenomic Workshop** 

Facilitators: Kathy Chang, PhD and Bruce Carleton, BSc, PharmD, FCP, FISPE

9:15 AM-9:30 AM	New Insights into Antiepileptic Drug- induced SJS/TEN	Wen-Hung Chung, MD, PhD (Taiwan)
9:30 AM-9:45 AM	Pharmacogenomic testing to prevent SCAR in Thailand: update on health policy and clinical practices	<u>Chonlaphat Sukasem</u> , Bpharm, PhD (Thailand)
9:45 AM-10:00 AM	Technology-driven implementation of HLA genotyping	Professor Sir Munir Pirmohamed  MB ChB (Hons), PhD, FRCP, FRCP(E), FBPhS, FFPM, FMedSci
10:00 AM-10:15 AM	Meta-GWAS of SCAR induced by anti- epileptic drugs	(United Kingdom) <u>Isabelle Boothman</u> , PhD (Ireland)
10:15 AM-10:30 AM	HLA and LTA testing for SCAR	Kathy Chang, PhD (Canada)

10:30 AM-10:45 AM	Regulatory Hurdles a <mark>nd succ</mark> ess stories	Jhih-Yu Syu, Taiwan FDA
	in Taiwan	and the
10:45 AM-11:00 AM	Regulatory Hurdles and success stories	Christian Grimstein, PhD US FDA
10.43 IIII 11.00 IIII	Regulatory Haranes and success stories	Christian Grimstein, The Ob February
11:00 AM-11:30 AM	Networking and Break	
11:30 AM-12:30 PM	Working Group Panel Discussion	All speakers and Bruce Carleton,
		<u>Simona Volpi</u> , <u>Elizabeth Phillips</u>

# Day 1 Webinar #2 - 10:15 AM - 1:30 PM (US Central Time)

10:15 AM - 1:30 PM

SJS Survivor, Family and Community Working Group

Round table leader: Helena Pasieka, MD, PhD

Community Group facilitators: Jean McCawley, Julie McCawley, Sonia Whyte-Croasdaile, Douglas

Oboh, Angie Lowe, Nicole Chapman, Paul and Wanpen Anderson

Theme 1	SJS/TEN and Mental Health	Daniel M. Schneider, PsyD (USA)
Theme 2	SJS/TEN and Long-term Health complications	Arturo Dominguez, MD, PhD (USA)
Theme 3	SJS/TEN Eye care	Jim Chodosh, MD (USA) and Charles Bouchard, MD (USA)
Theme 4	Managing Long-term scarring	Tom Beachkofsky MD (USA), Maj USAF, MC,FS
Theme 5	SJS/TEN in children and when a drug cause cannot be identified	Allison Norton, MD (USA)
Theme 6	What is new in the science of SJS/TEN	Sherrie Divito, MD, PhD (USA)
Theme 7	Special considerations in skin of color	Helena Pasieka, MD, PhD (USA)
Theme 8	Safety of COVID-19 vaccines in SJS/TEN	Elizabeth J. Phillips, MD (USA)

# 1:30 PM – 2:00 PM Networking and Virtual Lounge Break

# Day 1 Webinar #3 - 2:00PM - 3:00PM (US Central time)

2:00 PM - 3:00 PM

**NIH Funding and Priorities for Research** 

Moderators: Sherrie Divito MD, PhD and Elizabeth J. Phillips, MD

2:00 PM-2:15 PM	National Institute of Arthritis,	Ricardo Cibotti, PhD
	Musculoskeletal and Skin Diseases (NIAMS)	
2:15 PM-2:30 PM	National Institute of Human Genome Research Institute (NHGRI)	<u>Simona Volpi</u> , PhD
2:30 PM-2:45 PM	National Institute of Allergy and Infectious Diseases (NIAID)	Patrice Becker, MD
2:45 PM-3:00 PM	Q&A Discussion	

3:00 PM – 4:00 PM Networking and Virtual Lounge Break

# **Day 1 Webinar #4 - 4:00 PM - 5:00 PM** (US Central Time)

4:00 PM - 4:45 PM

Opening Session: A Memoir of Surviving SJS/TEN, Immunotherapy and Cancer

Alicia Bianco, SJS and Cancer Survivor, Author of "The Miracle of Me"

4:45 PM - 5:00 PM

Ten for TEN: raising awareness for SJS/TEN 2022

Louis Chaix, SJS Survivor

5:00 PM - 5:30 PM

**Networking and Virtual Lounge Break** 

# Day 1 Webinar #5 - 5:30 PM - 7:15 PM (US Central Time)

#### 5:30 PM - 7:15 PM

# **Poster Discussion Session**

Moderators: Amy Palubinsky, PhD and Neil Shear, MD

5:30 PM-5:37 PM	Limited adjunctive diagnostic utility of IFN-gamma ELISpot to identify offending drug(s) in severe cutaneous ADRs to first-line TB drugs	Mireille Porter, MBChB, MPH (South Africa)
5:37 PM-5:44 PM	SJS/TEN case finding in a large EHR Database and Clinical Characteristics of 74 Validated Cases	Fatima Bassi <mark>r, MPH (USA)</mark>
5:44 PM-5:51 PM	Successful creation of a prototype machine learning algorithm to distinguish SJS/TEN from other dermatoses	Trevor Champagne, MD (Canada)
5:51 PM-5:58 PM	Immune-mediated over activation of coagulation in SJS/TEN	Jake Goldstein, BS (US <mark>A)</mark>
5:58 PM-6:05 PM	Risk factors and outcomes associated with leukopenia in SJS/TEN	Leo Wang, MD, PhD (USA)
6:05 PM-6:12 PM	A review of SJS and TEN cases with Checkpoint Inhibitor Therapy	Mavra Masood, BA (USA)
6:12 PM-6:19 PM	Variations in the Medical Management of SJS/TEN: A survey study among North American Dermatology Hospitalists	Jane J. Han, B.S. (USA)
6:19 PM-6:26 PM	Implementation of Pharmacogenetics into clinical practice - a rapid pharmacogenetic test panel for cutaneous adverse drug reactions	Wan-Chun Chang, PhD (Canada)
6:26 PM-6:33 PM	Investigating the role of memory T cells in delayed-onset drug hypersensitivity reactions	Pranali Shah, PhD (USA)
6:33 PM-6:40 PM	Regulation of innate immune response by miR-628-3p upregulated in the plasma of SJS/TEN with severe ocular complications (SOC)	Mayumi Ueta, MD (Japan)

6:40 PM-6:47 PM	Single-cell studies of TMP-SMX associated SJS/TEN define an atlas of Immunopathogenesis and specific signatures of oligoclonal CD8+ T cells	Yueran Li, BioMedSc, Hons (Australia)
6:47 PM-6:54 PM	Drug-specific exosomes and their miRNA contents in patients diagnosed with SJS/TEN exhibited cytotoxicity effects in keratinocytes	Nithikan Suthumchai, BSc Micro, PhD Candidate (Thailand)

7:15 PM – 7:30 PM Networking and Virtual Lounge Break

# Day 1 Webinar #6 - 7:30 PM - 9:00 PM (US Central Time)

#### 7:30 PM - 8:15 PM

# SESSION 1 (PART 1) Registries, Electronic Health Records, Networks and New Studies

Moderators: Bruce Carleton, BSc, PharmD, FCP, FISPE (Canada) and Elizabeth Phillips, MD (USA)

7:30 PM-7:45 PM	AUS-SCAR: Australasian registry of severe cutaneous adverse reactions	Jason Trubiano, MBBS, PhD (Australia)
7:45 PM-8:00 PM 8:00 PM-8:15 PM	Update on Asia and Southeast Asia Pharmacogenomics Q&A Discussion	Chonlaphat Sukasem, Bpharm, PhD (Thailand)

#### 8:15 PM - 9:00 PM

# **Session 6 (part 1) Innovation and Implementation**

Moderators: Simon A. Mallal, MBBS (USA) and Mayumi Ueta (Japan)

8:15 PM-8:30 PM	New approaches to defining immunopathogenesis of SJS/TEN	Shuen-Iu Hung, PhD (Taiwan)
8:30 PM-8:45 PM	SJS/TEN - Implementing new treatment into the clinic	WenHung Chung, MD, PhD (Taiwan)
8:45 PM-9:00 PM	Q&A Discussion	The state of the s

# End of Day 1

# Sunday, August 29, 2021 (Day 2)

7:00 AM - 9:00 AM

Arrivals, Virtual Lounge Networking, Poster viewing

### **Day 2 Webinar #1 - 9:00 AM - 11:30 AM** (US Central Time)

9:00 AM – 9:15 AM

**Welcome** and Introductions

Elizabeth Phillips, MD, Sherrie Divito, MD, PhD and Charles Bouchard, MD, MA

9:15 AM - 9:45 AM

SJS/TEN - The End of One Era and the Beginning of Another: A Tribute to Jean-

Claude Roujeau

Speaker: Professor Maja Mockenhaupt, MD, PhD (Germany)

9:45 AM - 11:30 AM

# SESSION 1 (PART 2) Registries, Electronic Health Records, Networks and New Studies

Moderators: Professor Sir Munir Pirmohamed, MB ChB (Hons), PhD, FRCP, FRCP(E), FBPhS, FFPM, FMedSci, and Bruce Carleton, BSc, PharmD, FCP, FISPE

9:45 AM-10:00 AM	RegiSCAR - an update	Maja Mockenhaupt, MD, PhD (Germany)
10:00 AM-10:15 AM	AfriSCAR - an update	Jonny Peter, MB ChB, PhD (South Africa)
10:15 AM-10:25 AM	Medical Dermatology Society Research - an update	Daniela Kroshinsky, MD (USA)

10:25 AM-10:35 AM	Society of Dermatology Hospitalists Research - an update	Robert Micheletti, MD (USA)
10:35 AM-10:50 AM	Utilizing the EHR data for SJS/TEN Research: Updates from Partners-SCAR	<u>Li Zhou</u> , PhD (USA)
10:50 AM-11:10 AM	SJS Survivor Study and NATIENS	Elizabeth Phillips, MD (USA)
11:10 AM-11:30 AM	Q&A Discussion	

11:30 AM – 11:45 AM Virtual Lounge Networking / Poster Viewing

# **Day 2 Webinar #2 - 11:45 AM - 1:00 PM** (US Central Time)

11:45 AM – 12: 15 PM

**Report back from the workshops Part 1: Pharmacogenomics Workshop** 

Moderators: Bruce Carleton, BSc, PharmD, FCP, FISPE and Kathy Chang, PhD

12:15 PM - 1:00 PM

SESSION 2: SJS/TEN as an Immunotherapy Toxicity and Other Manifestations

Moderators: Annie Dewan, MD and Ben Kaffenberger, MD

12:15 PM-12:30 PM	Newly described toxicities and management of ICI toxicity	Alina Markova, MD (USA)
12:30 PM-12:45 PM	Stevens Johnson Syndrome, Toxic Epidermal Necrolysis, and Drug Induced	<u>Jay Hoofnagle</u> , MD, NIDDK (USA)
12:45 PM-1:00 PM	Liver Injury  Q&A Discussion	(001)
12.43 1 M-1.00 1 M	QXA Discussion	

# **Day 2 Webinar #3 - 1:00 PM - 2:30 PM** (US Central Time)

1:00 PM - 1:30 PM

SESSION 3: Working Lunch:

How to get published (an editor's view and interactive discussion)

Moderators: Jonathan Peter MB ChB, PhD (South Africa) and Sherrie Divito, MD, PhD (USA)

Speaker: Kanade Shinkae, MD, PhD (Editor, JAMA Dermatology) (USA)

#### 1:30 PM - 2:30 PM

Session 4: Long-term Sequelae of SJS/TEN

Moderators: Roni Dodiuk-Gad, MD (Israel) and Maja Mockenhaupt, MD, PhD (Germany)

1:30 PM-1:45 PM	Impact of SJS/TEN on Psychosocial function	Kemberlee Bonnett, MA and David Schlundt, PhD (USA)
1:45 PM-2:00 PM	Recognition of long-term complications of SJS/TEN: what are we missing	Ranks Lehloenya, MMChB, FC Derm (South Africa)
2:00 PM-2:15 PM	Prevention of SJS/TEN Eye morbidity and long-term management	Haji Saeed, MD (USA)
2:15 PM – 2:30 PM	Q&A Discussion	

#### 2:30 PM - 2:45 PM

Virtual Lounge Networking / Poster Viewing

# **Day 2 Webinar #4 - 2:45 PM - 4:15 PM** (US Central Time)

**2:45 PM – 4:15 PM** (\*\*Concurrent session\*\*)

**Session 5a:** Updates for Patients and Clinicians

Moderators: Jeff Shupp, MD, Tom Beachkofsky, MD and Haji Saeed, MD

2:45 PM-3:00 PM	What is new in Burn Care of SJS/TEN?	Arthur Sanford, MD (USA)
3:00 PM-3:15 PM	What is new in Eye Care of SJS/TEN?	James Chodosh, MD (USA)
3:15 PM-3:30 PM	Genitourinary issues for women with SJS/TEN, Report of 10 years review	Esther Fuchs, MD (USA)
3:30 PM-3:45 PM	Unusual Presentations of SJS/TEN and Mimickers	Helena Pasieka, MD, PhD (USA)
3:45 PM-4:15 PM	Panel Discussion Q&A	All speakers and moderators

# Day 2 Webinar #5 - 2:45 PM - 4:15 PM (US Central Time)

**2:45 PM – 4:15 PM** (\*\*Concurrent session\*\*)

**Session 5b: Moving the Field Forward** 

Moderators: David Ostrov, PhD, Sherrie Divito, MD, PhD and Teresa Bellón, PhD

2:45 PM-3:00 PM	Using single-cell approaches to define personalized treatment	Chris Nagao, MD, PhD, NIAMS (USA)
3:00 PM-3:15 PM	Developing Immunological Tools for Discovery of T-cell Epitopes	Stephen Elledge, PhD (USA)
3:15 PM-3:30 PM	The role of epigenomics in skin health and inflammation	Elena Ezhkova, PhD (USA)
3:30 PM-3:45 PM	The roles of novel GPCRs in adverse drug reactions	XinZhong Dong, PhD (USA)
3:45 PM-4:15 PM	Q&A Discussion	

# **Day 2 Webinar #6 - 4:15 PM - 5:15 PM** (US Central Time)

4:15 PM - 5:15 PM

Session 6: Part 2: Regulation, Innovation and Implementation Moderators: Melissa Reyes, MD, MPH, DTMH and Jennifer Goldman, MD

4:15 PM-4:30 PM	Stevens-Johnson Syndrome and Toxic Epidermal Necrolysis: FDA Regulatory Science and Action	Michael Phan, PharmD, US FDA (USA)
4:30 PM-4:45 PM	Improving SJS/TEN Assessment with Photography and Artificial Intelligence	Eric Tkaczyk, MD, PhD (USA)
4:45 PM-5:00 PM	Cell death pathways and novel therapeutics	Riichiro Abe, MD, PhD (Japan)
5:00 PM-5:15 PM	Q&A Discussion	A CONTRACTOR

# Day 2 Webinar #7 - 5:15 PM - 6:15 PM (US Central Time)

5:15 PM - 5:45 PM

Report Back from the Workshops: Part 2 SJS Survivor, Family and Community Workshop

Jean McCawley (USA) and Sonia Whyte-Croasdaile (Canada)

5:45 PM - 6:15 PM

Session 7: Questions, Next Steps and Priorities

Elizabeth J. Phillips, MD, Sherrie Divito MD, PhD and Charles Bouchard, MD, MA

# End of Day 2

# Biographies - Meeting Chairs



Elizabeth Phillips, MD, FIDSA, FAAAAI

Professor of Medicine, Pathology, Microbiology Professor of Pharmacology John A. Oates Chair in Clinical Research Center for Drug Safety and Immunology Vanderbilt University Medical Center

Dr. Phillips is a world leader in translational approaches to drug hypersensitivity and has pioneered the discovery and implementation of immunogenomic predictors, immunopathogenesis and novel technologies into clinical practice. She has led clinical and research programs in SJS/TEN across different medical systems for over 25 years. She is PI on NIH funded research to define genetic and other markers to lead to prediction and prevention earlier diagnosis and to define the most effective treatment. She is Co-Chair of SJSTEN 2021 and also chaired the 2019 and 2017 meetings.



Sherrie Divito, MD, PhD

Assistant Professor
Department of Dermatology
Harvard Medical School
Brigham and Women's Hospital
Dana Farber Cancer Institute
Boston Children's Hospital

Dr. Divito is a dermatologist and immunologist specializing in complex medical dermatology with expertise in the areas of severe cutaneous adverse drug reactions and graft-versus-host disease. She is principal investigator of an immuno-dermatology research laboratory studying the immunopathogenesis of T cell mediated drug reactions and GVHD. Her lab's efforts span bedside to bench and back again with the direct goal of improving patient care. Their work is highly translational, incorporating prospective and retrospective human studies and novel humanized mouse models of disease. They utilize both innovative and traditional laboratory techniques in their research and are highly collaborative with clinicians and

investigators across multiple disciplines. Dr. Divito is the recipient of a prestigious Early Independence Award from the NIH Office of the Director and was named a Future Leader by the European Society for Dermatological Research. She is currently PI on two NIH grants. Clinically, she attends on the inpatient dermatology consult service and in a specialized embedded oncodermatology clinic. She is particularly passionate about training and mentoring young researchers and physician-scientists.



Charles S. Bouchard, MD, MA
Professor and Chairman,
Department of Ophthalmology
Loyola University Medical Center

Charles S. Bouchard is the John P. Mulcahy Professor and Chairman of the Department of Ophthalmology at Loyola University Medical Center where he has been on the staff since 1990 and Chairman since 2003. He received a Master's Degree in physiology from Boston University School of Medicine and an MD degree from Northwestern University. Dr. Bouchard completed his residency training in ophthalmology at George Washington University Medical Center. He continued his subspecialty training in corneal and external diseases, completing a fellowship at Georgetown University Center for Sight. 2004-2005. He has served as President of the Chicago Ophthalmological Society and as member of the Board of Directors for the Illinois Society for the Prevention of Blindness for 15 years. He has received the Honor Award and Senior Honor Awards form the American Academy of Ophthalmology and the Annual Illinois Eye Bank Service Recognition Award in 2014. He has written more than 170 scientific papers, abstracts and book chapters and has presented numerous lectures regionally and internationally on a wide variety of diseases of the cornea and ocular surface. His has a special interest in Stevens Johnson syndrome, ocular graft vs host disease and Sjogren syndrome. He has recently developed an interest in the ocular manifestations of obstructive sleep apnea; a disease that effects more than 25% of the adult population in the US yet is undiagnosed in 80%.

# Biographies - Academic Faculty



#### Riichiro Abe, MD, PhD

Professor and Chair, Division of Dermatology Niigata University Graduate School of Medical and Dental Sciences

Dr. Abe received an M.D. degree in 1994 and a Ph.D. degree in 2001 from Hokkaido University, Sapporo, Japan. He was a postdoctoral fellow at the Picower Institute for Medical Research, New York, from 1998 to 2000. Since September 2015, he has been a Professor at Niigata University. In addition, he has been the Editor-in-Chief of Journal of Dermatological Sciences since 2018. His interests are in adverse drug reactions, skin regenerative medicine and skin oncology.



# Thomas M. Beachkofsky, MD, FAAD

Lt Col, USAF, MC, FS Chief, MacDill Dermatology Clinic & Laser Center Assistant Professor of Dermatology, Uniformed Services University

Dr. Beachkofsky is a board-certified Dermatologist with expertise and interest in adverse drug/vaccine reactions including SJS/TEN. He received his undergraduate degree from the United States Air Force Academy in Colorado Springs, CO; his medical degree from the Uniformed Services University of the Health Sciences in Bethesda, MD; and completed his dermatology residency training at the San Antonio Uniformed Services

Health Education Consortium (SAUSHEC) in San Antonio, TX. His current research and clinical interest include genomic/transcriptomic evaluation of adverse drug reactions and the use of medical lasers for scar therapy including rehabilitation and repair. He currently resides in Tampa, FL and is serving on Active Duty in the United States Air Force at MacDill Air Force Base.



#### Patrice Becker, MD

Section Chief, A<mark>llergy, Asthma and</mark> Airway Biology Branch
Division of Allergy, Immunology and Transplantation, NIAID/NIH

Dr. Becker received her M.D. from the New York State program at Sackler School of Medicine, Tel Aviv University. She completed an internship and residency in internal medicine at the University of Maryland Medical Center, followed by postdoctoral clinical and research training in pulmonary disease and critical care medicine at Johns Hopkins University School of Medicine. She spent 18 years as a faculty member in the Division of Pulmonary and Critical Care Medicine at Johns Hopkins, where her

academic research focused on exploring mechanisms of acute and chronic lung injury and remodeling. She then spent nine years working at small-mid size biopharmaceutical companies, overseeing clinical and translational programs evaluating anti-inflammatory and immune-modulatory drugs as therapies for autoimmune and rare diseases across multiple therapeutic areas. Dr. Becker joined the Allergy, Asthma, and Airway Biology Branch at the NIH/NIAID in August 2019, as chief of the Asthma and Airway Biology Section.



### Teresa Bellón, PhD

Director of the Drug Hypersensitivity Laboratory at Hospital La Paz Health Research Institute (idiPAZ) Madrid, Spain

Dr. Teresa Bellon obtained her bachelor degree in Universidad Complutense de Madrid and studied myeloid cells as a graduate student in the Spanish Research Council to obtain her PhD in 1993. She then moved to Jefferson Cancer Institute (Philadelphia, USA) to work on myeloid cell-specific transcription factors. In 1996 she joined the laboratory of Dr M López-Botet at the Immunology Department of Hospital de la Princesa (Madrid, Spain) to study cell surface receptors related to human NK and

CTL activity. In 2001 she obtained a position as a researcher in Hospital La Paz. Since then she has been focused in severe cutaneous drug reactions (SCARs), with special interest in diagnostic tools for the identification of culprit drugs, and in the involvement of cytotoxic lymphocytes as effector cells in toxic epidermal necrolysis. She is member of PIELenRed (a Spanish group for the study of SCARs) and of RegiSCAR since 2011.



Kemberlee Bonnet, MA

Qualitative Research, Vanderbilt University

Kemberlee Bonnet is a social scientist and research coordinator for the Qualitative Research Core at Vanderbilt University. She is experienced in community-based recruitment, focus group development and facilitation, conducting one-on-one and group interviews, and qualitative data analysis. Kemberlee's background is in social psychology and litigation psychology. She completed her graduate training at San Francisco State University and at Kokushikan University in Tokyo.



#### Isabelle Boothman, BA

PhD Candidate, Royal College of Surgeons in Ireland

Isabelle is a PhD student working in RCSI Dublin as part of the Science Foundation Ireland FutureNeuro Research Centre, and the Genomics Data Science Centre for Research Training. She graduated from Trinity College Dublin in 2019 with a B.A. (Mod.) in Genetics. Isabelle's research aims to find out how genetic differences affect a person's response to drug treatments, and to identify genetic predictors of severe cutaneous adverse drug reactions to anti-seizure medicines. Hopefully this research can lead to improved drug treatments for people with epilepsy.



#### Bruce Carleton, BSc, PharmD, FCP, FISPE

Professor and Chair, Division of Translational Therapeutics
Department of Pediatrics
Faculty of Medicine
University of British Columbia

Dr. Carleton is a Senior Clinician Scientist at the BC Children's Hospital Research Institute and runs the Canadian Pharmacogenomics Network for Drug Safety, a pan-Canadian and International Network devote to the study of the pharmacogenomic basis of serious adverse effects.

He holds faculty appointments at UBC in the Department of Medical Genetics, School of Population and Public Health, Centre for Health Services and Policy Research and the Faculty of Pharmaceutical Sciences. He is also an adjunct professor at the School of Health Information Science at University of Victoria. Dr. Carleton has served on the national Canadian Drug Expert Advisory Committee since its inception and serves the US Government as a Special Government Employee to advise the Advisory Committee for Pharmaceuticals and Clinical Pharmacology of the FDA. A key element of Dr. Carleton's research is the creation of tools to make drug therapy more optimal and safe for all patients. Another key priority is the communication of results to clinicians, patients, healthcare administrators, and government staff who also hold responsibilities to improve patient care.



# Gianpiero Cavalleri, PhD

Professor, Human Genetics Royal College of Surgeons in Ireland

Dr. Cavalleri completed his PhD studies in genetics at University College London in 2005. After a brief Postdoctoral position at Duke University, he joined RCSI in 2006. His work is focused on the genetics of epilepsy predisposition and treatment. Prof. Cavalleri has contributed to several clinically relevant discoveries that have impacted the care of epilepsy, including the discovery of HLA-A\*3101 as a predictor of severe skin reactions attributable to carbamazepine.



# Wan-Chun Chang, PhD

Postdoctoral Research Fellow, Division of Translational Therapeutics, Department of Pediatrics, Faculty of Medicine, University of British Columbia and BC Children's Hospital Research Institute

Dr. Wan-Chun (Kathy) Chang is a Postdoctoral Research Fellow in the Division of Translational Therapeutics, Department of Pediatrics, Faculty of Medicine at the University of British Columbia and British Columbia Children's Hospital Research Institute, Vancouver, Canada. The focus of her doctoral studies was on the pharmacogenomics of antiepileptic druginduced severe cutaneous adverse reactions (SCAR), including Stevens-

Johnson syndrome (SJS) and toxic epidermal necrolysis (TEN). Currently, she is working with Dr. Bruce Carleton and the Canadian Pharmacogenomics Network for Drug Safety (CPNDS) on both the pharmacogenomics and immunogenesis of drug-induced cutaneous adverse reactions in patients with different ancestries. She is also working on the development of pre-prescription screening tools to prevent the occurrence of cutaneous adverse drug reactions and on the prediction of therapeutic outcomes, with the ultimate goal of providing effective precision medicine.



## James Chodosh, MD, MPH

Edith Ives Cogan Professor of Ophthalmology Mass. Eye and Ear - Harvard Medical School

Dr. Chodosh serves as Vice Chair for Education, Director of Diversity and Inclusion, Associate Director of the Cornea and Refractive Surgery Service, Associate Director of the Infectious Disease Institute, Director of Boston Keratoprosthesis, and Director of the Ocular Burn Service at Mass. Eye and Ear, an HMS affiliate. He is also a member of the HMS PhD Program in Virology. He completed his residency in Ophthalmology at Baylor College

of Medicine, clinical fellowship in Corneal Diseases at the Bascom Palmer Eye Institute, postdoctoral research fellowship in Virology & Molecular Biology and Infectious Diseases at St. Jude Children's Research Hospital, and Masters of Public Health degree at the University of Oklahoma. He is a recipient of the Alcon Research Institute Award, and four awards from Research to Prevent Blindness. He served as Chair of the Anterior Eye Disease NIH Study Section, on the National Advisory Eye Council for the NIH, and is currently Chair of the FDA Dermatologic and Ophthalmic Drugs Advisory Committee. Dr. Chodosh has published over 350 peer reviewed papers and book chapters, and was co-Editor-in-Chief of the British Journal of Ophthalmology. He has personally trained over 60 clinical cornea fellows. He is internationally known and respected for his work on viral genomics and pathogenesis, and his basic research program has been continuously funded by the NIH since 1996. He is the senior author for the American Academy of Ophthalmology web pages on COVID- 19, which have garnered over 1.5 million views. His primary clinical interests include infectious eye disease, ocular chemical injury, Stevens Johnson syndrome, and the restoration of seemingly hopeless cases of corneal blindness with the Boston keratoprosthesis.



### Wen-Hung Chung, MD, PhD

Director, Dermatology and Drug Hypersensitivity clinical and research center, Taipei/Linkou Chang Gung Memorial Hospital

Dr. Chung is a physician of dermatology and a specialist of the field in severe cutaneous adverse drug reactions (SCARs) and immunologic disorders. He currently serves as director of department of dermatology and drug hypersensitivity clinical and research center at Taipei/Linkou Chang Gung Memorial Hospital. Dr. Chung has devoted himself into the investigation of SCARs for over two decades and his devotion and findings

have great impact in clinic. Dr. Chung have identified genetic biomarkers for SCARs (Nature 2004, PNAS 2005, JAMA 2014, JACI 2021). He also discovered granulysin as the major mediator for the extensive keratinocyte death in SJS/TEN (Nature Medicine 2008). Since these contributions, Dr. Chung had received awards, including 2009 the 47th Ten Outstanding Young Persons in Taiwan, 2011 the International League of Dermatological Societies Young Dermatologist International Achievement Award, 2014 outstanding research award of Ministry of Science and Technology, and 2018 the 15th National Innovation Award.



#### Dr. Ricardo Cibotti, PhD

Program Director, Skin Immunology and Diseases, Skin Mic<mark>robiome</mark>
Program

National Institute of Arthritis and Musculoskeletal and Skin Diseases

Dr. Ricardo Cibotti is the Program Director of the Skin Immunology and Diseases Program at the NIAMS. He has been trained at the NCI as a T cell immunologist.



#### Anna Dewan, MD

Assistant Professor, Dermatology
Director, Inpatient Dermatology
Director, Dermatology Residency Program
Vanderbilt University Medical Center

Dr. Anna Dewan grew up in Chicago and attended Northwestern University for her undergraduate studies. She earned her medical degree from Yale School of Medicine, where she also completed a Doris Duke Clinical Research Fellowship. She completed dermatology residency including a chief resident year at Vanderbilt University Medical Center. After a

fellowship in Complex Medical Dermatology at Brigham and Woman's Hospital in Boston, Dr. Dewan returned to Vanderbilt as Director of Inpatient Dermatology. She is also the Program Director of the Dermatology Residency Program. Her clinical practice focuses on inpatient dermatology, complex medical dermatology, and supportive oncodermatology.



#### Roni Dodiuk-Gad, MD

Vice-Head, Dermatology Department, Emek Medical Center, Israel. Clinical Assistant Professor, Bruce Rappaport Faculty of Medicine, Technion - Institute of Technology, Israel.

Assistant Professor- status only, Department of Medicine, University of Toronto, Canada.

Dr. Roni Dodiuk-Gad is a Clinical Assistant Professor in the Ruth and Bruce Rappaport Faculty of Medicine at the Technion, Israel and an Assistant Professor, status-only appointment, in the Department of Medicine at the University of Toronto, Canada. She is the initiator and head

of both "International Telehealth Rounds in Dermatology (ITRD)", delivered under the auspices of the Canada International Scientific Exchange Program (CISEPO) and the global platform "International Dermatologists Fighting Coronavirus Together". Dr. Dodiuk-Gad is a global opinion leader in Dermatology, specifically on the topics of adverse cutaneous drug reactions and Darier disease. She mentors students and residents both in Israel and Canada and leads several research teams focusing specifically on these topics. Dr. Dodiuk-Gad has received various national and international research grants and honors.



### Arturo Dominguez, MD, PhD

Associate Professor, Departments of Dermatology and Internal Medicine, UT Southwestern Medical Center

Dr. Dominguez specializes in complex medical dermatology, autoimmune blistering diseases, teledermatology, and hospital dermatology. Dr. Dominguez is a proud *fronterizo* and was born on the U.S.-Mexico border in El Paso, TX and lived much of his childhood in Ciudad Juarez, Mexico. He earned his undergraduate degree at Princeton University and his medical degree at UT Southwestern. He completed an internal medicine residency at the University of

Washington School of Medicine and then a dermatology residency at UT Southwestern. He takes part in UT Southwestern-based clinical trials to evaluate diseases such as severe cutaneous drug reactions and autoimmune blistering diseases such as pemphigus vulgaris. Dr. Dominguez attends on the internal medicine teaching service at Parkland Hospital and is active in residency education in that department.



### Xinzhong Dong, PhD

Professor, Department of Neuroscience, Johns Hopkins University School of Medicine

Dr. Xinzhong Dong completed the Ph.D. program in the Department of Biological Chemistry at UCLA and received his postdoc training at Caltech. He started his own lab at Johns Hopkins University School of Medicine in 2004. His laboratory has taken a multidisciplinary approach to understand the cellular and molecular mechanisms of different types of somatosensations including pain and itch, which are initiated and mediated by primary sensory neurons in dorsal root ganglia (DRG). They identified

a large family of G protein-coupled receptors in mice called Mrgprs. Many of these receptors are exclusively expressed in distinct subsets of DRG neurons and function as novel itch receptors mediating non-histaminergic itch. More recently, his lab has found other Mrgprs are specifically expressed in immune cells including mast cells, neutrophils, basophils, and dendritic cells mediating innate immune responses and contributing to drug toxicity such as anaphylactic reactions and SJS.



# Stephen Elledge, PhD

Gregor Mendel Professor of Genetics and Medicine, Harvar<mark>d Medical</mark> School

Brigham and Women's Hospital, Division of Genetics Howard Hughes Medical Institute Investigator

Dr. Elledge received his B.S. in chemistry from the University of Illinois and his Ph.D. in biology from the Massachusetts Institute of Technology. He began his laboratory at the Baylor College of Medicine in Houston and moved in 2003 to the Brigham and Women's Hospital and Harvard Medical School Department of Genetics. He is a member of the National Academy

of Sciences, National Academy of Medicine, and American Academy of Arts and Sciences. His many awards include the Dickson Prize (2010), Lewis S. Rosenstiel Award for Distinguished Work in the Basic Medical Sciences (2013), Gairdner Foundation International Award (2013), Albert Lasker Basic Medical Research Award (2015), Breakthrough Prize in Life Sciences (2017) and Gruber Prize in Genetics (2017). Dr. Elledge's research interests center on the study of proteins that sense and respond to DNA damage, and regulate the cell division cycle and cancer. He has uncovered what is now known as the DNA Damage Response. Along with Dr. Wade Harper, he discovered the two largest families of E3 ubiquitin ligases: the cullin-RING ligases (CRL), starting with the Skp1-Cul1-F-box sub-family, and the RING domain ligases. More recently Dr. Elledge has developed a suite of immunological methods, such as T-Scan and VirScan, that allows the genome-wide identification of epitopes recognized by B and T cells.



#### Elena Ezhkova, PhD

Professor, Department of Cell, Developmental, and Regenerative Biology
Department of Dermatology
Black Family Stem Cell Institute
Mount Sinai School of Medicine

Dr. Ezhkova's laboratory implements an array of powerful cellular and high-throughput molecular biology tools to dissect how epigenetic gene regulators play a role in cell fate determination, homeostasis, and regeneration of the skin. Identification of these molecular mechanisms aids in expanding our understanding of skin development, homeostasis, and the

progression of various tissue disorders, including cancer



#### Esther Fuchs, MD

Assistant Professor, Department of OBGYN, University of Washington

Dr. Fuchs is a board certified Obstetrician Gynecologist, trained in Obstetrics and Gynecology in Switzerland prior to completing residency training in the USA. Within the UW Department of OBGYN, she joined the division at Harborview Medical Center which is one of the largest Trauma and Burn Centers in the USA. She evaluated vulvovaginal care received by SJS/TENS patients with the goal of optimization of care. Other interests are resident education especially in vulvovaginal and cervical dysplasia, pelvic ultrasound, minimal invasive surgery, pelvic pain,

abnormal uterine bleeding, and immigrant health. Dr. Fuchs won several teaching awards and worked in different countries.



# Jennifer Goldman, MD, MS

Associate Professor of Pediatrics
Director, Drug Safety Service
Medical Director, Antimicrobial Stewardship Program
Divisions Pediatric Infectious Diseases and Clinical Pharmacology
Children's Mercy Kansas City

Dr. Goldman is currently an Associate Professor of Pediatrics at the University of Missouri – Kansas City with appointments in the Divisions of Pediatric Infectious Diseases and Clinical Pharmacology at Children's Mercy Kansas City. She serves as the medical director of both the

Antimicrobial Stewardship Program and Drug Safety Service at Children's Mercy. Her clinical and research efforts are centered around individualizing antimicrobial treatment in children to avoid the unintended consequences of anti-infectives. She is investigating potential biomarkers that may predict and prevent severe adverse drug reactions. She works with an amazing team to identify underreported adverse drug reactions, determine the epidemiology of these reactions, and investigate the biochemical and genetic factors associated with reaction risk. Her research is supported by the National Institutes of Health. She currently serves as the Pediatric Health Organization Representative on the Pediatric Advisory Committee for the Food and Drug Administration.



#### Christian Grimstein, PhD

Team Lead, Division of Translational and Precision Medicine, Office of Clinical Pharmacology, U.S. Food and Drug Administration

Dr. Grimstein received his Ph.D. in Pharmaceutics from the University of Florida/USA (2008). His expertise is in clinical pharmacology and public health genomics, specifically as related to precision medicine strategies in drug development and utilization. At the FDA, he reviews investigational and new drug applications, contributes to regulatory policy development, and conducts research that supports FDA's core public health mission.



# Jay Hoofnagle, MD

Director, Liver Disease Research Branch, NIDDK

Dr. Jay Hoofnagle is the Director of the Liver Disease Research Branch in the Division of Digestive Diseases and Nutrition of NIDDK of the National Institutes of Health (NIH). Dr. Hoofnagle is a hepatologist and gastroenterologist who had done laboratory and clinical research on liver diseases for the last 50 years, initially at the Food and Drug Administration in hepatitis B and subsequently at the NIH in hepatitis B, C and D, autoimmune liver diseases, nonalcoholic steatohepatitis, and drug-induce liver injury. He has published more than 400 original articles on liver

disease. He is a former president of the American Association for the Study of Liver Disease and is the current editor-writer for the NIH-sponsored LiverTox website that provides clinical and research information on drug-induced liver disease.



# Shuen-lu Hung, PhD

Professor, Director, Cancer vaccine and immune cell therapy Center, Chang Gung Memorial Hospital, Linkou Branch, Taiwan

Dr. Hung has been working in the field of translational immunogenomics for more than 20 years, and making important contribution to the discovery of biomarkers and pathomechanism of drug hypersensitivity. Her work focused on the severe cutaneous adverse reactions (SCAR), including Stevens-Johnson syndrome (SJS), toxic epidermal necrolysis (TEN) and drug reaction with eosinophilia and systemic symptoms (DRESS). She led team to identify the genetic predisposition of different drug-induced SCAR,

and discover the biomarker granulysin and T cell receptor (TCR) in SJS/TEN. Furthermore, Dr. Hung extended her work to the functional studies on the molecular interaction of HLA, neoantigens, and T cell receptors in the immune synapse. The studies of Dr. Hung do not only have important impact on SJS/TEN, but also be successfully translated to the clinic applications.



# Ben Kaffenberger, MD, MS

Associate Professor, Ohio State University, Wexner Medical Center, Division of Dermatology

Dr. Kaffenberger graduated from Ohio State University College of Medicine and completed his residency at Ohio State. His clinical interests are in hospital based dermatology, autoimmune skin disease, graft-versus-host disease, and drug reactions. He has research interests in hospital dermatology outcomes, imaging techniques and analysis in dermatology, teledermatology/patient access to dermatology, and clinical trials. His

research has been funded by the National Psoriasis Foundation, American Acne and Rosacea Society, Dermatology Foundation, National Rosacea Society, the Ohio Department of Medicaid, and the NIH. In his spare time, he enjoys music, being outdoors, fishing, home improvement, cross-country skiing, and spending time with his wife and four children.



### Daniela Kroshinsky, MD

Director of Inpatient Dermatology and Director of Pediatric Dermatology
Massachusetts General Hospital
Associate Professor of Dermatology, Harvard Medical School

Dr. Kroshinsky graduated *summa cum laude* from Northwestern University Honors Program in Medical Education, where she received her Medical Degree and was inducted to the Alpha Omega Alpha Honor Society. She received her Masters of Public Health from the Harvard School of Public Health. She completed her internship at Yale-New Haven Hospital where she received the Preliminary Intern of the Year award and her residency

training at SUNY Downstate University where she served as Chief Resident. Dr. Kroshinsky is a board-certified dermatologist at the Massachusetts General Hospital and MassGeneral Hospital *for* Children where she serves as the Director of Inpatient Dermatology and the Director of Pediatric Dermatology. She specializes in complex medical dermatology in the outpatient and hospital setting. She is an Associate Professor of Dermatology at Harvard Medical School where she greatly enjoys teaching. She is past-President of the Medical Dermatology Society and President-elect of the Society of Dermatology Hospitalists. She is an active researcher and has been awarded the several research grants, resulting in the authorship of over 140 peer reviewed medical publications and invitations to speak nationally and internationally on her findings.



#### Rannakoe Lehloenya, MMChB, FC Derm

Consultant Dermatologist, University of Cape Town and Groote Schuur Hospital

Dr. Rannakoe Lehloenya is a Dermatologist and an Associate Professor of Medicine at the University of Cape Town and Groote Schuur Hospital. His main research interest is cutaneous adverse drug reactions, a subject on which he has published extensively. He is currently involved in multiple local and international studies on the subject. His other significant interests are tattoos, hyperpigmentation in a dark skin and anthropology of human attractiveness, the latter a subject on which he is currently writing a book.



#### Simon Mallal, MBBS

Director, Center for Translational Immunology and Infectious Disease Vanderbilt University Medical Center

Dr. Mallal completed his training in Internal Medicine and Clinical Immunology and Allergy training in Pathology in Western Australia before undertaking a post-doctoral fellowship in Infectious Diseases at Johns Hopkins Medical School. He has undertaken clinical practice management altering research throughout his career that has informed and directed his basic science research. This has had impacts over time in the domains of: reproductive endocrinology (1978 – 82), genetic disease association studies

(1987 – present), immune restoration disease in HIV (1994 onwards), improved efficacy of antiretroviral therapy (1988 onwards), mitochondrial toxicity and metabolic complications of antiretroviral therapy (1997 on), use of pharmacogenetic tests to avoid drug hypersensitivity (2002 on) and HIV and Hepatitis C adaptation to HLA restricted immune responses to support vaccine immunogen design and potential eradication approaches. He is best known for championing the discovery and successful translation of HLA-B\*5701 screening to prevent abacavir hypersensitivity for which he shared the William J. Darby Award for Translational Research that Changed the Practice of Medicine with Dr. Elizabeth Phillips. The impact on clinical and healthcare practice and policy in these domains has been important, as has the development of new multidisciplinary capacity and approaches to translational medicine. This culminated in the establishment of a purpose-built translational medicine Institute in Western Australia and centers at Vanderbilt that he leads. He has authored over 300 articles and book chapters and given over 250 presentations at international scientific meetings. He received the Western Australian Premiers Science Award in 2006.



#### Alina Markova, MD

Director of Inpatient Consultative Dermatology; Assistant Attending Physician, Dermatology Service, Memorial Sloan Kettering Cancer Center

Assistant Professor of <mark>Dermatol</mark>ogy, Weill Cornell Medical Coll<mark>ege</mark>

At Memorial Sloan Kettering Cancer Center, I have the privilege of leading the inpatient dermatology consultative service, co-directing the multi-disciplinary graft-versus-host disease clinic, and serve as the dermatologic leader of the MSKCC Transplantation and Cellular Therapies (TCT) Toxicities Working Group at a high-volume academic oncology hospital

with an extensive clinical trial program. My outpatient clinical practice in addition to my inpatient consultative time is devoted to patients affected by severe drug eruptions and toxicities to hematologic cancer therapies. My clinical research aims to systemically characterize such reactions, analyze etiology and therapeutic approaches in order to provide evidence-based improvements in the care provided by dermatologists and oncologists to patients with and survivors of cancer. My long-term research and clinical goals include improving our understanding and management of severe dermatologic adverse events in patients with cancer in order to optimize clinical outcomes and quality of life of cancer survivors.



Robert G. Micheletti, MD

Associate Professor of Dermatology and Medicine Perelman School of Medicine, University of Pennsylvania

Robert Micheletti, MD is a graduate of Stanford University and Duke University School of Medicine. He completed a combined residency in internal medicine and dermatology at the University of Pennsylvania, where he is now Associate Professor of Dermatology and Medicine. He is the Chief of Hospital Dermatology at Penn as well as Chief of Dermatology at Pennsylvania Hospital. He also directs the Cutaneous Vasculitis Clinic in the Penn Vasculitis Center. He has clinical and research focuses in vasculitis, severe drug reactions, autoimmune blistering diseases,

hidradenitis suppurativa, and other areas of complex medical dermatology.



SJS/TEN 2021 - Meeting Program

# Maja Mockenhaupt, MD, PhD

Professor of Dermatology, Medical Center and Medical Faculty -University of Freiburg, Germany Managing Senior Physician (Vice Head) of the Dept. of Dermatology, Medical Center - University of Freiburg, Germany

Dr. Mockenhaupt started her work on severe cutaneous adverse reactions 1990 as a research fellow at the Department of Dermatology, University of Freiburg, Germany. She was/is involved in various epidemiologic studies in this field, e.g. SCAR and EuroSCAR, both large scale case-control

studies, as well as the ongoing RegiSCAR-project and the German Registry of severe skin reactions. After her PhD in 2007 she received a personal grant for clinical research by Else Kroener-Fresenius-Foundation. She had her training as a dermatologist at the same department and passed her board examination in 1996. She has since worked in different clinical units of the department, including operative and conservative dermatology in the inpatient and outpatient setting, day clinic and allergy department. She serves as a senior dermatologist with teaching obligations and managing senior physician (vice head) of the department of dermatology. She also holds the position of a professor at the medical faculty of the university.



# Keisuke Nagao, MD, PhD

Senior Investigator, Dermatology Branch, NIAMS, National Institutes of Health

Dr. Nagao is a Dermatologist with long standing interest in skin immunity and immunological diseases. His research program aims at understanding interactions that take place between skin structures and immune cells that shape skin immunity and mediate host-microbial symbiosis.

Dr. Nagao graduated from Keio University School of Medicine (Tokyo, Japan) in 1994, where he received his dermatological training. He obtained his Ph.D. on Microbiology in 2005. After completion of his postdoctoral

fellowship at the Dermatology Branch, National Cancer Institute (NCI), he returned to Keio University in 2008 and led independent research programs and headed the Allergy and Drug Hypersensitivity Clinic. He returned to the NIH in 2014.



Allison Norton, MD

Pediatric Allergy Immunology Assistant Professor, Vanderbilt University

I am board-certified in pediatric allergy-immunology and have over 10 years of experience caring for children and families with chronic asthma, allergic disease, immunodeficiency, and drug allergy at Vanderbilt Children's Hospital. While I see patients of all types of allergic and immunologic conditions, since 2015, I have focused my clinical and research efforts in drug allergy. These efforts have resulted in a strong referral center at Vanderbilt University for children with drug and vaccine

allergies. I have evaluated and treated hundreds of patients with concerns ranging from mild to severe drug allergy and have created outpatient protocols for skin testing and de-labeling.



#### David Ostrov, PhD

Associate Professor, Department of Pathology, Immunology and Laboratory Medicine, University of Florida College of Medicine

Dr. Ostrov received his PhD in 1995 working with Pat Concannon at the University of Washington in Seattle. He worked as a postdoctoral fellow with National Academy of Science member Stan Nathenson until joining the University of Florida College of Medicine as a faculty member in 2002. He is currently a member of the Department of Pathology, Immunology and Laboratory Medicine.



#### Amy Palubinsky, PhD

Postdoctoral Fellow, Vanderbilt University Medical Center

Dr. Palubinsky received her PhD in Neuroscience from Vanderbilt University Medical Center in 2020. She is currently working as a Postdoctoral Fellow in Infectious Disease focusing on identifying the genetic and cellular mechanisms that drive HLA-mediated adverse drug reactions. A main area of interest is the further development of TScan technology for the discovery of epitopes that activate T cells harboring specific / dominant T cell receptors.



### Helena Pasieka, MD, PhD

Assistant Professor of Dermatology & Medicine, Uniformed Services
University, Bethesda, Maryland & Department of Dermatology MedStar
Washington Hospital Center/Georgetown University

Hi, I'm Dr. Pasieka! I'm both an internist and dermatologist, with a background in hospital medicine and complex medical dermatology. My interests lie in severe and life-threatening desquamating diseases of the skin, primarily as it pertains to severe adverse cutaneous reactions to drugs. I love my work because I get to see the impact of evaluation by dermatologists on the hospitalized patient, and the role of novel

multidisciplinary teams for the treatment of severe skin diseases. I enjoy partnering with other researchers in burn surgery, gynecology, ophthalmology, psychiatry and other specialties to provide the best care for SJS/TEN. I also wear the hat of principal investigator or co-investigator on several university and departmentally funded projects and am developing a translational research lab to better understand the genetic and molecular underpinnings of severe drug reactions. I'm looking forward to meeting you all and sharing ideas and learning with and from you!



#### Johnathan Peter, MB ChB, MMed, FCP (SA), PhD

Division of Allergy and Clinical Immunology, University of Cape Town Allergy and Immunology Unit, University of Cape Town Lung Institute

A/Prof Jonny Peter is a physician, specialised in internal medicine at the University of Cape Town, South Africa. In February 2016, Jonathan was registered with the HPCSA as the first adult allergologist in South Africa, and is Head of the Division of Allergology and Clinical Immunology at Groote Schuur Hospital, University of Cape Town and the Allergy and Immunology unit, UCT Lung Institute. Current clinical and research interests include: i) immune-mediated adverse drug reactions ii) urticaria

and angioedema, as well as the intersection between COVID19 and immunogenomic pathways associated with Angioedema. Jonny Peter is a founding member of the AFRISCAR network. Jonny has over 100 publications in high impact factor journals, and H-index of 38. His research work is supported by international and local grant funding from the NIH, EDCTP, SA NRF and MRC.



#### Michael Phan, PharmD

Food and Drug Administration/Center for Drug Evaluation and Research/Office of Surveillance and Epidemiology/Department of Pharmacovigilance-I ORISE Fellow Chapman University School of Pharmacy Adjunct Faculty

Michael Phan graduated with a doctorate in pharmacy from Chapman University's School of Pharmacy in 2018. After graduating, he completed an academic fellowship in pediatric research at CHOC Children's Hospital in Orange County, California. He then joined the US Food and Drug Administration as an Oak Ridge Institute for Science and Education

(ORISE) Fellow, where he currently researches post-market safety surveillance trends within the Office of Surveillance and Epidemiology. Throughout his time as a researcher, he has successfully published eight manuscripts in academic peer-reviewed medical journals and has more publications in the pipeline. He also has published content in other sources of scientific media and has been awarded a grant for his research at CHOC Children's Hospital. In addition to his full time duties as an ORISE fellow, he is an adjunct faculty member at Chapman University.

Professor Sir Munir Pirmohamed, MB ChB (Hons), PhD, FRCP, FRCP(E), FBPhS, FFPM, FMedSci

David Weatherall Chair of Medicine and NHS Chair of Pharmacogenetics

Affiliation University of Liverpool, Director, MRC Centre for Drug Safety Science and Wolfson Centre for Personalised Medicine

Sir Munir Pirmohamed is a consultant Physician at Royal Liverpool University Hospital. He also holds the only NHS Chair of Pharmacogenetics in the UK and is Director of SJS/TEN 2021 – Meeting Program

the M.R.C. Centre for Drug Safety Sciences, and Director of the Wolfson Centre for Personalised Medicine, and President of BPS. He was awarded a Knights Bachelor in the Queen's Birthday Honours list in 2015. He is also an inaugural NIHR Senior Investigator, and Fellow of the Academy of Medical Sciences in the UK. He is also Chair of the Commission on Human Medicines. He is also a member of the MRC Governing Council and a non-executive director of NHS England/Improvement and Director of HDR North. His research focuses on personalised medicine in order to optimize drug efficacy and minimize toxicity, move discoveries from the lab to the clinic, and from clinic to application.



# Melissa Reyes, MD, MPH, DTMH

Medical Regulatory Officer, Center of Drug Evaluation and Research, US FDA

Lieutenant Commander Melissa serves as a Commissioned Corps Officer in the United States Public Health Service, working for the Food and Drug Administration as a regulatory physician. She is boarded in dermatology and pediatric dermatology and provides subject matter expertise related to adverse drug reactions of the skin. Her interests including ensuring that safe and effective drugs are available for patients with dermatologic conditions and that healthcare providers have evidence-based, up-to-date drug

information to facilitate the care of patients.



# Hajirah Saeed, MD, MPH

Assistant Professor of Ophthalmology, Mass. Eye and Ear/Boston Children's, Harvard Medical School Director, Cornea Fellowship, Harvard Medical School

Hajirah (Haji) Saeed is a faculty member on the cornea service at Massachusetts Eye and Ear, Harvard Medical School. Her clinical interests and expertise revolve around the practice of ocular surface disease and pediatric cornea. She is an expert on ocular disease in SJS/TEN and her research focuses on the ocular morbidity and mortality of SJS/TEN as well

as genetic risk factors that increase patients' risk for developing this blinding disease. Dr. Saeed has been recognized as an international expert on SJS/TEN and has given numerous national and international talks on the subject. Her goal is to reduce the morbidity and mortality of SJS/TEN by early identification of atrisk individuals.



#### Arthur Sanford, MD, FACS

Associate Professor, Trauma, Surgical Critical Care and Burns, Loyola University Medical Center

Dr. Sanford is Originally from Southern California, and he obtained his BS in Biology from USC and MD from Creighton University School of Medicine. He did general Surgery training at Los Angeles County + USC Medical Center as well as his first Burn Fellowship. He subsequently did a Pediatric Burn Fellowship at the Shriner Hospital for Children in Galveston, Texas where he stayed on faculty for ten years before accepting his current

position with the Loyola University Burn Unit where he has been for the past 12 years. His expertise of acute care of burns and SJS/TENS exceeds 20 years, with both academic teaching positions, numerous publications and the fostering of productive and collaborative relationships with both dermatologists and ophthalmologists.



#### David Schlundt, PhD

Associate Professor, Department of Psychology, Vanderbilt University

Dr. Schlundt has 40 years of research experience, and has authored or coauthored over 230 papers in peer reviewed journals. He is trained as a clinical health psychologist and has been studying the assessment and modification of health behaviors for the past 35 years, has 25 years of experience with health disparities, and 21 years with community-based participatory research. He directs the qualitative research core for the Vanderbilt Institute of Medicine and Public Health. The qualitative core supports investigators doing qualitative and mixed methods studies. He

works with the Community Outreach Core of the Meharry Medical, Vanderbilt, Tennessee State University Cancer Partnership (MVTCP). He is an investigator with the Southern Community Cohort Study. He has been part of the Vanderbilt University Diabetes center since 1985 and has extensive experience using qualitative and quantitative methods for research on health.



# **Daniel Schneider**, PsyD

Clinical Psychologist, MedStar Washington Hospital Center Assistant Professor of Psychiatry & Surgery Georgetown University School of Medicine

Dr. Schneider specializes in addressing psychosocial factors within the scope of integrative care on the burn surgical team's pre- and post-operative patients with major, surgical, skin conditions which include burn injury (inflicted heat and cold injuries), amputations, necrotizing acute soft tissue infections (NASTI), hidradenitis (HS), stevens johnson syndrome (SJS), and toxic epidermal necrolysis (TEN). He is a key contributor on the Burn

Team facilitating innovative strategies for the integration of medical and behavioral health with an emphasis

on the biopsychosocial model of treatment for individuals served. He provides early assessment and interventions to individuals and their families on the inpatient ICU and step-down burn service units at MWHC in addition to the burn outpatient clinic. Dr. Schneider uses psychoeducation, cognitive behavioral therapy, acceptance & commitment therapy, mindfulness-based techniques, crisis interventions, grief counseling, individual and group therapy modalities, stress management, and relaxation training to treat individuals coping with a medical trauma.



#### Neil Shear, MD, FRCPC, FACP, FCDA

Professor Emeritus, University of Toronto
Dermatology; Internal Medicine, Clinical Pharmacology & Toxicology

Dr. Shear's primary academic research is in Drug Safety, including basic mechanisms that lead to increased risk for drug-induced harm. His practice is considered advanced medical dermatology. Diseases of focus are atopic dermatitis, psoriasis, auto-immune blistering disease, drug-induced diseases, hidradenitis suppurativa, cutaneous lymphomas and auto-immune skin disease. Shear trained in Engineering Science (University of Toronto), Medicine (McMaster), Internal Medicine (FRCPC), Dermatology

(University of Toronto; FRCPC) and Clinical Pharmacology (Hospital for Sick Children, Toronto). Professor Shear was the Head of Clinical Pharmacology at the University of Toronto for 9 years, and the Head of Dermatology at the University for the 16 years following. Past positions include President of the Canadian Dermatology Association, President of the Canadian Society of Clinical Pharmacology, President of the Canadian Professors of Dermatology, President of the Canadian Dermatology Foundation and Head of Dermatology at University of Toronto. He has received two Presidential Citations from the American Academy of Dermatology. And he has been an honoured as a visiting professor over 50 times. Shear was made an honorary member of the Société Française de Dermatologie (2017) and the Scottish Dermatological Society, recipient of the Lifetime Achievement Award of the Ontario Medical Association, and many teaching awards. Dr. Shear has been an author of over 60 text book chapters, Editor of Litt's Drug Eruption Manual, as well as over 400 peer-reviewed publications. Shear has had the pleasure of mentoring 40 postgraduate fellows from Canada and abroad; as well as a large number of dermatologists and clinical pharmacologists in Canada.



#### Kanade Shinkai, MD PhD

Professor of Dermatology, University of California San Francisco

Dr. Shinkai specializes in medical dermatology and inpatient dermatology consults. She is passionate about medical education and has recently served as residency program director at UCSF; she now serves as vice-chair for education for the department. She has served as the current editor-in-chief of *JAMA Dermatology* since July 2018.



# Jeffrey Shupp, MD, FACS

Chief of Burn Surgery, MedStar Health/Georgetown University
Burn Center Director--MedStar Washington Hospital Center
Professor of Surgery, Plastic and Reconstructive Surgery, Biochemistry,
and Molecular & Cellular Biology
Georgetown University School of Medicine

Jeffrey W. Shupp is an acute care surgeon at MedStar Health. He is the Director of the Burn Center at MedStar Washington Hospital Center. He is also the lead investigator at the Firefighters' Burn and Surgical Research Laboratory and the Director of Burn Research at MedStar Health Research

Institute. Dr. Shupp is a Professor of Surgery, Plastic and Reconstructive Surgery, Biochemistry, and Molecular & Cellular Biology at Georgetown University School of Medicine. Given his regular collaboration with various entities in the Department of Defense and his frequent training of military medical students residents, and fellows he holds and adjunct Professorship in Surgery at the Uniformed Services University of the Health Sciences. Dr. Shupp specializes in treating acutely injured patients, trauma to the skin, including electrical and chemical injuries, complex wounds, and other skin disorders that result in skin loss, such as toxic epidermal necrolysis and Stevens-Johnson syndrome. Dr. Shupp's research interests include polytrauma, surgical infections, wound healing, biophotonics, burn pathophysiology, host response to injury, coagulopathy, TBI, combined radiation exposure, (endogenous and exogenous) cutaneous desquamating conditions and abnormal wound healing such as hypertrophic scar.



# Chonlaphat Sukasem, BPharm, PhD

Head, Division of Pharmacogenomics and Personalized Medicine, Department of Pathology, Faculty of Medicine Ramathibodi Hospital, Mahidol University, Bangkok, Thailand

Prof. Sukasem is the Founder member and appointed Secretariat of Biosafety Association of Thailand. Dr. Sukasem also serves as Chief of Laboratory for Pharmacogenomics, Somdech Phra Debaratana Medical Center (SDMC) since 2011. He has a background in pharmacological science and pharmacogenomics. Professor Sukasem has also published more than 130 peer-reviewed papers in the field of pharmacogenomics. His

research has focused on pharmacogenomics and personalized medicine, clinical pharmacology and drug safety. His work has seen him at the forefront of translational pharmacogenomics researches into clinical practices including pharmacogenetic testing, TPMT enzyme activity and therapeutic drug monitoring for the precision medicine. He has contributed the international guidelines of The Clinical Pharmacogenetics Implementation Consortium for (1) HLA Genotype and Use of Carbamazepine and Oxcarbazepine and (2) CYP2B6 and Efavirenz-containing Antiretroviral Therapy.



Jhih-Yu Syu, MPharm

Technical Specialist, Taiwan FDA

Jhih-Yu Syu joined Taiwan Food and Drug Administration (TFDA) in 2012. She has been working in the Division of Medicinal Products, TFDA for nearly 9 years. During her work in TFDA, she had experiences in several areas, including reviewing new drug and biological product applications, post-marketing changes, and involving in the regulatory related issues. Since July 2019, she serves as the Technical Specialist in the Section of

Drug Safety and Evaluation. She is currently responsible for medicinal products safety surveillance, assessment, and drug injury relief.



# Eric Tkaczyk, MD, PhD, FAAD

Dermatology Service and Research Service, Tennessee Va<mark>lley Healthcare</mark> System, Department of Veterans Affairs

Vanderbilt Dermatology Translational Research Clinic (VDTRC.org), Department of Dermatology, Vanderbilt University Medical Center

Dr. Tkaczyk is a physician-scientist with research interests in biophotonics for diagnosis and treatment of skin diseases. He is a graduate of the MD/PhD at the University of Michigan, with PhD in electrical engineering from the Center for Ultrafast Optical Science (CUOS). At CUOS, he overlapped with his academic grandfather Gerard Mourou, the 2018 Nobel

Laureate who founded the lab. Dr. Tkaczyk's post-doctoral training in medical device design at the University of Tartu was supported by Fulbright and Whitaker awards. This work culminated with a prize awarded by the US Ambassador to Estonia and the Estonian Speaker of Parliament at the 2011 Estonian-American Innovation Award ceremony. In 2016, he completed dermatology residency training at Vanderbilt University Medical Center, where he is Assistant Professor of Dermatology and Biomedical Engineering. He is also an attending dermatologist at the VA Medical Center. As founding Director of the Vanderbilt Dermatology Translational Research Clinic, he lectures internationally on dermatologic imaging technologies, which is his research focus.



# Jason Trubiano, MBBS, PhD

Deputy Director, Department of Infectious Diseases, Austin Health (Melbourne, Australia)

Director of Drug and Antibiotic Allergy Service, Austin Health (Melbourne, Australia)

Research Fellow, University of Melbourne

Dr. Trubiano is an Infectious Diseases Physician and NHMRC Research Fellow in Melbourne, Australia. Dr Trubiano is the Director of Antimicrobial Stewardship (Austin Health) and Head of the Centre for Antibiotic Allergy and Research. A/Prof Trubiano is a University of

Melbourne Clinical Associate Professor. In 2017, he was awarded an NHMRC-supported PhD in antibiotic

allergy testing in Antimicrobial Stewardship, and in 2020 completed a post-doctoral fellowship with the National Centre for Infections in Cancer exploring antibiotic allergy in immunocompromised hosts. His primary research remains in translational antibiotic allergy diagnostics, point-of-care tools and health services penicillin allergy testing programs. He is the clinical research lead for the Australasian Registry of Severe Cutaneous Adverse Reactions (AUS-SCAR), has over 130 publications in peer-reviewed journals and his work in the development of antibiotic allergy assessment tools, clinical prediction rules and whole-of-hospital allergy programs have been published in leading journals and cited in international guidelines and policy.



# Mayumi Ueta, MD, PhD

Associate Professor, Department of Ophthalmology, Kyoto Prefectural University of Medicine, Kyoto, Japan

We are investigating the pathogenesis and genetic predisposition of SJS/TEN with severe ocular complication. Regarding genetic predisposition, we are conducting international collaborative research with Korea, Brazil, India, Taiwan, Thailand, the UK, the US.



# Simona Volpi, PharmD, PhD

Program Director, Division of Genomic Medicine (DGM), National Human Genome Research Institute (NHGRI) National Institute of Health (NIH)

Dr. Volpi joined the Division of Genomic Medicine at the National Human Genome Research Institute (NHGRI) as a Program Director in 2010. She is responsible for managing a portfolio of extramural grants and contracts related to the newly established Implementing Genomics in Practice (IGNITE) Pragmatic Clinical Trials Network (PTN) (IGNITE-PNT) program. Dr. Volpi is also the Co-Lead of the Scientific Program Analysts

program at NHGRI. Her research interest includes pharmacogenomics, promoting access to genomic medicine and clinical evidence base for, and demonstrating effectiveness of, genomic medicine.

Upon her arrival in the United States in 1999, Dr. Volpi was a postdoctoral fellow in the Developmental Endocrinology Branch at the intramural program in National Institute of Child Health and Human Development (NICHD) where she studied the hypothalamic-pituitary-adrenal axis response under physical-psychological stress. Five years later, Dr. Volpi left the National Institutes of Health (NIH) and joined Vanda Pharmaceuticals as the Associate Director for Pharmacogenomics. She was responsible for managing a team of scientists focused in the genetic and genomic research areas of schizophrenia, depression, and sleep disorders. Dr. Volpi completed her pharmacy residency training and received her Pharmacy Degree in 1999 at the University of Milan, Italy. She also received her Ph.D. degree in endocrinology and metabolism from the University of Milan in 2005.



Li Zhou, MD, PhD, FACMI, FAMIA

Associate Professor of Medicine, Harvard Medical School

Division of General Internal Medicine and Primary Care, Brigham and
Women's Hospital

Dr. Li Zhou is an Associate Professor of Medicine at Harvard Medical School and Lead Investigator at the Brigham and Women's Hospital. She earned her PhD in Biomedical Informatics from Columbia University and then served as a Medical Informatician at Massachusetts General Brigham for over ten years. Her research has focused on temporal reasoning, natural language processing (NLP), machine learning and clinical decision support.

Dr. Zhou directs the MTERMS Lab at BWH and her team have applied informatics methods to diverse clinical domains. She has served as PI on numerous research projects, including an NIH/NIAID R01 that aims to leverage advanced informatics and longitudinal EHR data to identify severe cutaneous adverse reactions (SCAR) cases (including SJS/TEN) to study genetic and epidemiological risk factors for SCAR. She is an Associate Editor for International Journal of Medical Informatics and serves on the AMIA Board of Directors.

# Biographies — SJS Community



#### Alicia Bianco Amaral

SJS/TENS Survivor Stage 4 Metastatic Melanoma Lung Cancer Survivor

Alicia Bianco Amaral is a SJS / TEN survivor since 1989. After successful treatment with Immunotherapy, she also is a survivor of Stage 4 Metastatic Melanoma Lung Cancer for over 6 years and counting! Alicia does public speaking on her journey of self-awareness, codependency, personal healing and spiritual growth.

Alicia is the author of *The Miracle of Me – A memoir based on surviving and living with Stevens-Johnson Syndrome/TEN*. Her mission was to bring awareness to this horrific reaction/disease by sharing her experiences with the hope it could possibly help even if only one person then her pain and suffering, along with those who lost their life, would not have been in vain.

Alicia is the proud mother of 3 successful children and "MiMi" to 2 beautiful grandchildren. She enjoys hiking, yoga, creative expression and spending lots of time with family and friends.



## Wanpen Anderson Paul Anderson

Paul is a US Air Force Vietnam veteran and is retired from the United States Postal Service. Wanpen, a native of Thailand and US citizen is a retired accountant from the University of Illinois. They have been married for 45 years and have 2 children, Tim, age 30 and Angela. Angela died December 28, 2015 of SJS/TEN at the age of 22. Paul and Wanpen initiated the SJS/TEN Research Fund in Memory of Angela Anderson at Vanderbilt University Medical Center in 2016 with a \$22,000 check from donations received from Angela's funeral and visitation. They have since raised over

\$100,000 for the fund. They continue to raise awareness and fundraise for SJS/TEN research.



#### **Louis Chaix**

My name is Louis Chaix, I am 23 years old, and I am from Nantes, France. In 2004, when I was 6 years old, I was diagnosed with TEN (80% of my body was affected), I was transferred by helicopter to a burnt unit in Paris because the first hospital I was at had no idea on what was happening to me. Today I play Ice Hockey at Missouri State University while studying exercise & movement science. 17 years after surviving TEN I decided that it was time for me to be a part of something greater than myself, which is why I have decided to rollerblade from Los Angeles to New York City in order to raise awareness and funds for research for SJS/TEN. Tag along and

follow the 10forTEN journey as our goal is to give hope one stride at a time.



# **Nicole Chapman**

I am Nicole Chapman. I live in Klamath Falls, Oregon with my parents. I came down with SJS/TENS at the age of 6. I have had around 39 surgeries. I have put on a car show for the past 11 years to help spread awareness. My family and I started SJS Awareness Oregon in 2017. https://www.sjsawarenessoregon.org/. I am active in my community trying to spread awareness about SJS, we also promote the awareness and importance of Air Link, which is our local life flight program. In the future I'd like to see the doctors being able to diagnose SJS/TENS in a timely matter.



# **Angie Lowe**

Angie Lowe is a librarian, Medical Office Assistant, Skate Canada Official and mother to two wonderful boys.

In 2015, Sulfasalazine, due to suspected psoriatic arthritis caused Angie's SJS. Symptoms included a skin rash in conjunction with blisters, mucosal involvement including nose, mouth, throat and genital ulcers and ocular involvement leading to an emergency dual-amniotic membrane transplant. After attending the SJS Information Sharing Session at Sunnybrook Hospital in 2017 and the 2019 SJS/TEN Conference in Vancouver, Angie wanted to help bridge the gap between knowledge for patients, family and the medical field, by creating a virtual hub called S.T.I.A.: SJS/TEN

International Alliance. The hub will direct and connect people to new and already in place resources, studies, trials and information. Given numerous doctors do not have knowledge with the disease and therefore can not guide their patients; many are misdiagnosed or left with unanswered questions during the acute phase and at discharge. There is hope the online hub will include a section for patients, survivors and family to access a virtual Q&A or virtual appointments by SJS/TEN experienced doctors. This resource is still in its infancy but will be complete shortly at www.stia.ca



### Jean McCawley

Jean McCawley is the founder of the Stevens-Johnson Syndrome Foundation. She founded the SJS Foundation in 1995, after her 11-month-old daughter, Julie, was diagnosed with SJS/TEN. She spent 27 days in the burn unit by her daughter's side and has never left her side since. McCawley wanted to create a foundation to provide people with information on SJS and a community for those affected by SJS so that no one has to go through SJS alone like her and her daughter. The foundation started out of McCawley's living room and was initially called the Julie Foundation in honor of her daughter. Since starting the foundation, McCawley has helped

thousands of SJS patients and families get the information and support they need. When McCawley is not working on the foundation, she enjoys spending time with her two daughters, son-in-law and two-year-old grandson.



# Julie McCawley

Julie McCawley is the founder of the Stevens-Johnson Syndrome Kids Support Group. She founded the SJS Kids Group in 2008 when she was 15 years old to create a space for children diagnosed with SJS to share their experiences. McCawley was diagnosed with SJS/TEN at 11 months old and spent 27 days in the burn unit. She suffered burns on over 80% of her body, is blind in her right eye and has low vision in her left eye, among many other side effects. McCawley was the inspiration for the founding of the Stevens-Johnson Syndrome Foundation by her mother, Jean. She earned her B.A. from the Metropolitan State University of Denver and is

now an elementary school teacher, mother and wife. In her free time; McCawley loves reading to, singing and playing with her two-year-old son, who she adores.



# **Katie Niemeyer**

Katie Niemeyer is a survivor of SJS/TEN as a teenager and now works as a certified nurse anesthetist, entrepreneur, mother, and philanthropist to promote SJS/TEN awareness and research (Figure 11, C). Left with chronic eye irritation that hindered her training as a distance runner, Katie created a high-performance wristband, Handana, to keep sweat from burning her already sensitive eyes. Handana was the first runner up in the 2015 Under Armour Future Show. Katie has donated proceeds from her business endeavors to supporting research in the treatment of acute and chronic SJS/TEN eye disease and established the Katie Niemeyer Research Fund at

the Massachusetts Eye and Ear clinic. Katie is also the founding member of the SJ Syndrome of Texas (www.sjsyndrome.com) and frequently shares her story with health care and general audiences around the country to educate and inspire hope within and outside the SJS/TEN community. These stories underscore major threats associated with SJS/TEN, a disease that (1) affects previously healthy individuals in an unpredictable manner in the absence of validated screening mechanisms, (2) is characterized by sequelae

that are numerous, severe, and lifelong, (3) lacks highly specific diagnostic modalities that often results in delayed recognition of acute disease, and (4) in its severest form, moves quickly and with high mortality.



## Sonia Whyte-Croasdaile

My professional career includes over 25 years as a Nurse and a Registered Social Worker. I am also a trained Relaxation and Life Coach. Like many professionals, I aspire to maintain my professional career until retirement, but eleven years ago, I battled SJS/TEN which completely transformed and rearranged my life.

After my discharge from hospital, I became a stranger to my own body. I was and still remain mentally, physically and emotionally different. My body was painfully falling apart, and there were no community resources available to assist me. I felt as if I was sent home to die, and so with the

support of family and friends Stevens Johnson Syndrome Canada (www.sjscanada.org) was formed. Through our mission we aim to promote health by providing people suffering from SJS/TEN as well as their families and caregivers with access to related counselling, support groups and information programs.

