

Research Directions in Genetically-Mediated Stevens-Johnson Syndrome/Toxic Epidermal Necrolysis

March 3-4, 2015

NIH Building 31 Conference Center (6th floor of 31C)

NIH Main Campus, Bethesda MD

Meeting Objectives:

1. Review current state of knowledge of surveillance, pathogenesis, and treatment of Stevens-Johnson Syndrome/Toxic Epidermal Necrolysis (SJS/TEN)
2. Examine role of genomics and pharmacogenomics in etiology, treatment, and eradication of preventable causes of drug-induced SJS/TEN
3. Identify gaps, unmet needs, and priorities for future research to eliminate genetically mediated SJS/TEN globally

Day 1: Tuesday, March 3rd

Location: NIH Building 31 Conference Center 6C Room 10

8:00 AM	Registration	
Session 1: State of the Science (20' talks, 10' discussion)		Moderator: Ricardo Cibotti
8:30 AM	Welcome, Introduction and Goals	Teri Manolio
9:00 AM	Clinical syndromes, epidemiology, genomics, diagnosis and treatment	Neil Shear
9:30 AM	Basic science of pathogenesis, functional genomics and mechanisms	Wen-Hung Chung
10:00 AM	Defining and prioritizing unmet research needs for a rare but deadly disease	Elizabeth Phillips
10:30 AM	Discussion	All
11:00 AM	<i>Break</i>	
Session 2: International Experience Part 1 (10' talks, 5' discussion)		Moderator: Steven Katz
11:30 AM	Europe	Maja Mockenhaupt
11:45 AM	Taiwan	Shuen-lu Hung
12:00 AM	iSAEC	Munir Pirmohamed
12:15 PM	Thailand	Wasun Chantratita
12:30 PM	<i>Break (pick up food for working lunch)</i>	
1:00 PM	Discussion	All
Session 3: Challenges in Case Finding and Surveillance (20' talks, 10' discussion)		Moderator: Dan Roden
1:30 PM	Pharmacovigilance for SJS/TEN in the US	Lois La Grenade
2:00 PM	Potential for electronic phenotyping	Josh Denny
2:30 PM	Pharmacovigilance in Thailand	Wimon Suwankeasawong
3:00 PM	Discussion	All
3:30 PM	<i>Break (move to break out group rooms)</i>	

Workshop Planning Group Members: Mark Avigan (FDA), Ricardo Cibotti (NIAMS/NIH), Robert Davis (U Tennessee), Josh Denny (Vanderbilt), Carolyn Hutter (NHGRI/NIH), Lois La Grenade (FDA), Teri Manolio (NHGRI/NIH), Neil Shear (U Toronto), Lisa Wheatley (NIAID/NIH)

Session 4: Working Groups		
4:00 PM-5:45PM	Group 1: Basic research gaps and opportunities: mechanisms, risk alleles, other biomarkers, animal models (6C Room 10)	Lauren Trepanier Wen-Hung Chung
	Group 2: Clinical implementation gaps and opportunities: PGx Screening, CPIC guidelines, and global eradication, recurrence prevention, cost effectiveness (6C Room 7)	Howard McLeod Surakameth Mahasirimongkol
	Group 3: Pharmacosurveillance gaps and opportunities: phenotype definitions, EMRs, resource needs (6C Room 9)	Robert Davis Simone Pinheiro

Day 2: Wednesday, March 4th

Location: NIH Building 31 Conference Center Room 6C Room 6

Session 5: International Experience Part 2 (10' talks, 5' discussion)		Moderator: Juan Lertora
8:30 AM	Recap	Neil Shear
8:45 AM	Singapore	Cynthia Sung
9:00 AM	Indonesia	Rika Yuliwulandari
9:15 AM	United States	Steven Leeder
9:30 AM	Discussion	All
10:00 AM	<i>Break</i>	
Session 6: Special Topics (15' talks, 5' discussion)		Moderator: Michael Lee
10:30 AM	Regulatory consideration of pharmacogenomics data in labeling	Mike Pacanowski
10:50 AM	Identifying causal variation in studies of disease associations with MHC genes	Mary Carrington
11:10 AM	Drug-induced liver injury and cross-reactivity across drugs/organs	Jay Hoofnagle
11:30 AM	Health economics, policy implementation, and cost-effectiveness research	Dave Veenstra
11:50 PM	Discussion	All
12:10 PM	<i>Break (pick up food for working lunch)</i>	
Session 7: Report of Working Groups (15' talks, 15' discussion)		Moderator: Carolyn Hutter
12:45 PM	Basic Research working group report	Lauren Trepanier Wen-Hung Chung
1:00 PM	Discussion of basic research opportunities	All
1:15 PM	Clinical Implementation working group report	Howard McLeod Surakameth Mahasirimongkol
1:30 PM	Discussion of clinical implementation research opportunities	All
1:45 PM	Pharmacosurveillance working group report	Robert Davis Simone Pinheiro
2:00 PM	Discussion of pharmacosurveillance research opportunities	All
Session 8: Wrap-up and Next Steps		Moderator: Santa Tumminia
2:15 PM	Discussion of Next Steps	Teri Manolio
3:00 PM	Adjourn	