Research Directions in Genetically Mediated SJS/TEN

March 3-4, 2015
National Institutes of Health Campus
Bethesda, Maryland

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Joint Effort and Collaborative Funding

- Food and Drug Administration (FDA)
- National Center for Advancing Translational Sciences (NCATS)
- National Institute of Allergy and Infectious Diseases (NIAID)
- National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS)
- National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)
- National Institute of Neurologic Disorders and Stroke (NINDS)
- National Human Genome Research Institute (NHGRI)
Research Directions in Genetically-Mediated SJS/TEN

• How did we get here?
• What are our goals?
• Where do we go from here?
• How do we get there?
• Where are the bathrooms....
Global leaders in Genomic Medicine 2014

National Academy of Sciences Bldg
2101 Constitution Avenue, NW
Washington, D.C.
NHGRI’s Genomic Medicine Meetings

Genomic Medicine Centers Meeting VI: Global Leaders in Genomic Medicine

On January 8-9, 2014, the National Human Genome Research Institute (NHGRI), sponsored its sixth Genomic Medicine Centers meeting - Genomic Medicine Centers Meeting VI: Global Leaders in Genomic Medicine - at the National Academy of Sciences Building in Washington, D.C. Geoffrey Ginsburg, M.D., Ph.D., Duke University, and Teri Manolio, M.D., Ph.D., NHGRI, co-chaired the meeting.

The goals of the meeting were to:

- Identify areas of active translational and implementation research, potential common strategies, and opportunities for collaborative efforts.
- Identify common barriers to implementation of genomics in healthcare and a policy agenda relevant to advances in the field.
- Identify nations with unique capabilities (such as national healthcare systems) that may allow rapid implementation and measures of key outcomes.
- Discuss opportunities (such as national healthcare system) that may allow rapid implementation and measures of key outcomes.

View meeting videos and slides from: January 8  January 9

http://www.genome.gov/27549225
50 International Genomic Medicine Leaders
25 Countries

Courtesy, G Ginsburg, Duke U
Stevens Johnson Syndrome/Toxic Epidermal Necrolysis
Carbamazepine and SJS/TEN: Allele Frequency of HLA-B*15:02

Courtesy W Chantratita, Ramathibodi Hospital
Suggestion: According to update information, this person has HLA-B*1502 which has a high risk to develop a severe skin disorder (SJS/TEN), if he takes carbamazepine or drug structurally similar.

Need more information: please contact our PGx laboratory. Tel 02-200-4330-3…

Courtesy W Chantratita
Workshop on Research Directions - Objectives

1. Review current state of knowledge of surveillance, pathogenesis, and treatment

2. Examine role of genomics and PGx in etiology, treatment, and eradication of preventable cases

3. Identify gaps, unmet needs, and priorities for future research to eliminate SJS/TEN globally

Planning Group

Mark Avigan, FDA
Ricardo Cibotti, NIAMS
Robert Davis, U Tenn
Josh Denny, Vanderbilt
Carolyn Hutter, NHGRI
Lois La Grenade, FDA
Neil Shear, U Toronto
Lisa Wheatley, NIAID
Agenda Review

Tuesday, March 3rd 8:30 AM - 5:45 PM

8:30  Session 1: State of the Science

11:30  Session 2: International Experience Part 1

  *Includes working lunch*

1:30  Session 3: Challenges in Case Finding and Surveillance

4:00  Session 4: Working Groups

  *Working group and room assignments are in your packet*
Agenda Review, Day 2

Wednesday, March 4th 8:30 AM - 3:00 PM

8:30  Session 5: International Experience Part 2

10:30 Session 6: Special Topics

Includes working lunch

12:45 Session 7: Report of Working Groups

2:15  Session 8: Wrap-up and Next Steps

3PM  Adjourn, return to hotel or to airports
The workshop is being broadcast live, and will be video archived.

A link to the video is available at: https://www.genome.gov/27560487

Please use microphones.
• We apologize that government regulations prohibit us from paying for meals
• There is a cafeteria on the first floor
• If you ordered lunch on line, it will be delivered to the meeting room each day
• We hope you can join us for dinner tonight at Bistro Provence!
  – Sign up at registration table by end of 1st break
  – Map in your packet
Logistical Support

• Registration Desk
  – Jennifer Adona and Joshua Shapiro from Capital Consulting Corporation
  – Assistance with logistical questions
  – Assistance logging onto NIH guest network
  – Taxi arrangements

• Shuttle
  – Shuttle to hotel from B2 level at 6:00 PM
  – Shuttle will pick up at hotel at 7:15 AM
Thank You!

* On both the Planning Committee and the Working Group
Objectives of GMVI: Global Leaders in Genomic Medicine

- Identify areas of active translation and implementation
- Prioritize common barriers to implementation in healthcare
- Frame a policy agenda to advance the field
- Highlight nations with unique capabilities
- Discuss opportunities for international collaborations