OUTLINE

AMERICAN AUTOIMMUNE RELATED DISEASES ASSOCIATION’S
NATIONAL AUTOIMMUNE DISEASE AWARENESS MONTH
WASHINGTON, DC ACTIVITIES

Event #1: “The State of Autoimmune Disease: A National Summit”
#AARDA #autoimmune

Monday, March 23, 2015 @
The National Press Club
9:00 a.m. – 4:00 p.m.

Venue/Room
Holeman Lounge

Invited Audience:
Patients
National Coalition of Patient Groups reps
Autoimmune Partnership Council reps
Researchers – Academic, Government and Private Sector
Media (Washington, D.C.-based Local and National Print and Broadcast Outlets)

Format:
9:00 – 9:30 a.m.
Reception/sign-in
Coffee/Tea Service
Reel of 30, 60 and 90-second patient testimonials plays on screens in room (TBD).

9:30 – 9:35 a.m.
Welcome
Virginia T. Ladd
Executive Director, AARDA

9:35 – 9:45 a.m.
Opening Speaker
Dr. Noel Rose (CONFIRMED)
Director, Center for Autoimmune Disease Research, Johns Hopkins University

9:45 – 10:30 a.m.
Panel #1 – Autoimmune Disease Research: A View from Academia, Government and Private Sectors
Introduction/Q-and-A Facilitator:
Dr. Noel Rose (CONFIRMED)
Panelists (each speaker has 8 minutes to present: group Q&A 10 minutes)
Andrew Lichtman, Harvard University, “State of Autoimmune Research: Academia” (INVITED)
Robert Carter, NIH/NIAMS, “State of Autoimmune Research: Government” (CONFIRMED – ask to speak about new NIAMS study Gene Regulatory Elements and Autoimmune Disease)
PhRMA rep, “The Pipeline”
10:30 – 10:45 a.m.
Unveiling Autoimmune and Fatigue Survey Results
Virginia T. Ladd

10:45 – 11:30 a.m.
Panel #2 – Autoimmune Disease and Fatigue: What’s the Connection?
   Introduction/Moderator/Q-and-A Facilitator:
   Virginia T. Ladd – leads facilitated discussion amongst panelists.
Panelists:
   Tracy Evans, Patient (CONFIRMED)
   Patient #2 – DC Area
   Dr. Anne Davidson, Feinstein Institute for Medical Research (INVITED)

11:30 a.m. – 12:15 p.m.
Panel #3 – Autoimmunity and the Environment
   Introduction/Overview and Q-and-A Facilitator:
   Fred Miller, NIEHS (CONFIRMED)
Panelists: (each speaker has 7 minutes to present; group Q&A 10 minutes)
   Dan Littman, NYU Langone Medical Center – “Microbiome” (INVITED)
   Dr. Noel Rose, “Infection as an Environmental Trigger for Autoimmune Disease” (CONFIRMED)
   Jennifer Nyland, University of South Carolina “Mercury and Heavy Metals as a Trigger” (INVITED)

12:15 - 12:30 p.m.
Break - Reel of 30, 60 and 90-second patient testimonials plays on screens in room (TBD).

12:30 – 1:00 p.m.
LUNCH - Reel of 30, 60 and 90-second patient testimonials plays on screens in room (TBD).

1:00 – 1:30 p.m.
Keynote Speaker – Meghan O’Rourke, journalist, author, poet and autoimmune disease patient (CONFIRMED)

1:30 – 1:45 p.m.
Break - Reel of 30, 60 and 90-second patient testimonials plays on screens in room (TBD).

1:45 – 2:30 p.m.
Panel #4 – Top Autoimmune Advocacy Issues for 2015
   Introduction/Moderator/Q-and-A Facilitator:
   Stephanie Hales, Policy Overview – leads facilitated discussion amongst panelists; introduces AARDA’s new white paper on Biosimilars. (CONFIRMED)
Panelists:
   Biosimilars – Naming/Notification – Dr. David Charles, Alliance for Patient Access (INVITED)
   Biosimilars – State Issues – Michael Reilly, Alliance for Safe Biological Medicines (CONFIRMED)
   Access to Medicine = Adam Cooper, American College of Rheumatology/CAT (INVITED)
   Legislative Representative - Rep. Anna Eshoo (INVITED)
2:30 – 3:15 p.m.
Panel #5 – Patient Perspective: Getting an Autoimmune Disease Diagnosis
   Introduction/Moderator/Q-and-A Facilitator:
   Steve Taylor, Sjogren’s Syndrome Foundation (CONFIRMED)
   Panelists:
   Rich Hodge – “Medical School Autoimmune Education” (CONFIRMED)
   Sjogren’s Syndrome Foundation Patient/“I Look Better Than I Feel” (S. Taylor to provide patient)
   Patient/Diagnosis Story – Pemphigus Foundation (INVITED)
   Dr. Abid Khan, MidMichigan Health, University of Michigan Health System “Need for an Autoimmune Diagnostic Triage Clinic” (CONFIRMED)

3:15 – 3:25 p.m.
Panel #6 – Autoimmune Disease Patient Registry

   Speaker
   Virginia Ladd
   Overview – The need and what it will do/provide for the research community
   Purpose - What is it?
   Why is it needed?
   Where are we now?
   How many NCAPG groups have signed on?

   NOTE TO CDF SUPPORTERS: Celiac Disease Foundation is the first group to sign on to the Autoimmune Disease Patient Registry project. 42,000 records have been loaded to a secure celiac disease patient registry database that will be managed by CDF.

3:25 – 4:00 p.m.
Panel #7 – Capstone/Keynote Speaker
   Introduction and Wrap-up – 10 minutes
   Dr. Noel Rose - recap some key messages from daylong panels and announce that a highlights report will be prepared, published and available online in the next few weeks.

   Keynote Closing Speaker: Kellie Martin, “The Pajama Dance” (Videotaped Message)

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