

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)
