The Alliance for Lupus Research (ALR) was founded in 1999 by Robert Wood Johnson IV, a member of the Johnson & Johnson family and owner of the NY Jets, after his daughter was diagnosed with lupus.

The ALR is the largest private funder of lupus research in the world - $100M.
The Mission of the ALR is to prevent, treat and cure Systemic Lupus Erythematosus (SLE) by supporting biomedical research.
Lupus...The Unfortunate Truths

• Lupus is a chronic, potentially fatal, autoimmune disease

• Rather than protect against infection, the immune system of lupus patients attacks their own tissues and organs — kidneys, brain, heart, lungs, blood, skin and joints

• Lupus has no known cause
1.5 MILLION AMERICANS HAVE LUPUS

NINE OUT OF 10 ARE WOMEN

x3 AFRICAN-AMERICAN WOMEN ARE 3 TIMES MORE AT RISK

LUPUS HAS NO CURE
Whether it's your mother, your brother, or your coworker's cousin... someone you know has lupus.
The Need For Better Treatments

• Only one new drug (Benlysta) has been approved for treatment in the last 54 years.

• Today’s treatments offer lupus patients only temporary relief — and cause significant, dangerous or debilitating side effects.
Repositioning What’s Already Approved

• ALR commissioned review of all FDA approved medicines for 6,800 indications

• Identified 157 drug candidates and complementary therapies that could be efficacious in lupus

• Vetted/reviewed the scientific evidence and identified high priority candidates
Clinical Trial Industry Discussions

- Janssen – Stelara
- Kadmon - KADO25 ROCK II Inhibitor
- Pfizer – various
- Bristol Myers Squibb - various
- Aker BioMarine – Krill Oil (Omega 3)
- University of VA – Mindfulness practices
Lupus Clinical Investigators Network (LuCIN)

• **Goal:** To create a cohesive, interactive group of academic lupus investigators to carry out small, focused, proof of concept trials in a comprehensive and expeditious manner

• Identify 50-60 academic centers of excellence in the US and Canada to conduct ALR and Industry Sponsored Clinical Trials

• ALR to provide a financial incentive to support institutional infrastructure to carry out the planned clinical trials

• Site feasibility and verification process to begin 3Q2015

• First clinical trial planned for 4Q2015
Enrollment in Lupus Clinical Trials

Challenges to Overcome

- Lupus studies carried out globally often do not follow best practices in lupus diagnosis and study recruitment, which can produce suboptimal results
- Difficult to recruit African American patients
- Build patient TRUST
Patient Advocates for Lupus Studies (PALS)

- ALR will attempt to breakdown patient-centric barriers to enrollment in lupus clinical trials through a planned, organized learning experience focused on:
  - Increasing knowledge of disease
  - Increasing knowledge regarding the benefits of clinical research
  - Being an active member of the healthcare team
  - Being an active advocate and resource for patients
The Alliance for Lupus Research (ALR) seeks to improve its efforts to reach out to people in the major cultural heritage groups most affected by lupus with messages of hope about lupus research, the tools to understand more about the signs of the disease, and engagement with individuals in fundraising efforts to make a difference.
Thank you!

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