

### ***Alliance for Lupus Research (ALR)***

The mission of the Alliance for Lupus Research (ALR) is to find better treatments and ultimately prevent and cure lupus, a debilitating autoimmune disease, by supporting medical research. The ALR was founded in 1999 by Robert Wood Johnson IV, a member of the Johnson & Johnson family, after his daughter was diagnosed with the disease. Over the years the ALR has become the largest private funder of lupus research in the world.

In 2002 the ALR kicked off its signature national fundraising program, Walk with Us to Cure Lupus (ALR Walk). To date, ALR Walk raised over \$28 million to support the most aggressive and innovative lupus research the scientific community has to offer. Today, tens of thousands of volunteers from across the country have joined this grassroots effort. These dedicated individuals share their stories and their spirit, while raising awareness of the ALR mission.

### **Facts about the ALR**

- ALR has given more money to lupus research than any non-governmental agency in the world. **To date, the ALR has committed \$100-million to lupus research.**
- The ALR Board of Directors funds all administrative and fundraising costs, **100% of all donations raised goes directly to support lupus research programs.** The ALR uses a strategic business model in fundraising and employs a “venture capitalist” approach to fund innovative projects for rapid results.
- ALR-funded researchers are held to the highest standards: NIH-style peer-review to guarantee best projects are funded; stringent benchmarks, collaborative work and two year funding horizon to guarantee quick return on investment.
- Since 1999, the progress is clear: from no new treatments in decades to several drugs in clinical trials. The ALR has been directly supportive of many of the agents currently in clinical trials.
- The ALR successfully initiated and organized the effort to include lupus as a disease eligible for funding under the Department of Defense (DOD) Peer Reviewed Medical Research Program (PRMRP). To date, lupus has continued to be one of the few diseases to have medical research funded by the DOD.
- In 2008, the ALR-funded International SLE Genetics Consortium (SLEGEN) announced their discovery of multiple genes linked to lupus. This historic finding is the first time direct genetic links have been associated with lupus.
- Looking back over the last 15 years, the ALR is proud of the many thousands of people across the country that have joined our quest for a cure by donating their time, voices, or dollars.
- In addition to our signature research grant mechanisms, the ALR has partnerships with several groups and organizations to work collaboratively in finding a cure across varied research models and methodologies. These include initiatives with the NIH/NIAMS, the Lupus Research Institute, and the Lupus Foundation of America among others.

## ***Prevent. Treat. Cure.***

### **Facts about Lupus**

#### ***What is Lupus?***

- Lupus is a chronic autoimmune disease in which a person's immune system mistakenly attacks healthy tissue, cells and organs.
- Symptoms are unpredictable and can range from extreme fatigue, skin rashes, severe joint inflammation and muscle pain to organ failure and even death.

- Lupus is not a rare disease, it is estimated 1.5 million Americans suffer from lupus – more people than suffer from diseases such as leukemia, muscular dystrophy, multiple sclerosis or cystic fibrosis.
- The exact cause of lupus is unknown; however, research suggests it is caused by a combination of genetic and environmental factors (e.g., infection, sunlight, stress) that trigger the disease in susceptible individuals.

### ***Who is most often affected?***

#### **Women**

- Of the estimated 16,000 Americans who develop lupus each year, more than 90 percent are women in their child bearing years between the ages of 15 and 45.
- Women who have lupus and become pregnant are more likely to develop preeclampsia, a serious condition that causes high blood pressure and problems with the kidneys and other organs.
- Women who have lupus have are at greater risk of developing other diseases; osteoporosis, type 2 diabetes and are 50 times more likely of having a heart attack than women of a similar age.

#### **African Americans**

- African American women are three times more likely to get lupus than Caucasian women.
- Studies have shown that African Americans develop lupus earlier in life and have more symptoms, most prevalently seizure, strokes and kidney disease.
- African-Americans are more likely to suffer premature death from lupus.

#### **Latinos**

- Latinos tend to have the most aggressive disease activity and are prone to develop heart disease, kidney damage and die earlier in life from complications of lupus.
- Most Latinos that suffer from lupus develop it at a younger age and when diagnosed are already dealing with ancillary health issues as a result of the disease.
- Many times because of language barriers it is difficult to spread the message of what the warning signs of lupus are within Latino communities.

**More information about the ALR and lupus can be found by visiting [www.alr.org](http://www.alr.org).  
*Prevent. Treat. Cure.***