



# Rare Find

Chicago Cubs star Derrek Lee and Boston Celtics CEO/co-owner Wyc Grousbeck have teamed up with vision researchers at the University of Iowa. Their mission: to find every person in the country affected by Leber's Congenital Amaurosis (LCA).

They call their effort "Project 3000" because a central part of their plan is to find every man, woman and child affected with LCA in the United States – an estimated 3000 people. LCA is a rare inherited eye disease that appears at birth or in the first few months of life, typically characterized by nystagmus, sluggish or no pupillary responses, and severe vision loss or blindness.

"Given the rarity of this disease, we are looking for a very small needle in a very large haystack," said Edwin M. Stone, M.D. PhD. Stone is Director of the Carver Family Center for Macular Degeneration at the University of Iowa and a Howard Hughes Medical Institute (HHMI) investigator. "VSP network doctors can play a critical role in helping us track down people affected by LCA."

According to Stone, ten genes have been linked to LCA so far. He estimates that at least six other genes will be discovered. "The first step on the road to treatment and a cure is to find the genes. As more people affected by LCA are identified, we will be able to find those genes."

"I hope VSP doctors understand how important they are to the success of Project 3000," Derrek Lee said. "They are the first line in diagnosing vision problems and in many cases, they are the first to detect symptoms of eye diseases that could be genetically based. Without their help, we simply won't be able to find the people affected by LCA."

Project 3000 will offer the located LCA patients state-of-the-art genetic testing. The John and Marcia Carver Nonprofit Genetic Testing Laboratory at the University of Iowa will host the patients. Philanthropic donations will help offset costs for affected individuals without health insurance.

A baseball star. A basketball CEO. Different men, different sports. Common cause: each has a child with Leber's Congenital Amaurosis (LCA).

## PROJECT 3000 HAS FIVE MAJOR GOALS

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### PROVIDE HOPE.

Many individuals affected with Leber's Congenital Amaurosis have heard "there is nothing that can be done to improve/restore their vision." Project 3000 intends to make it clear that there is a lot that the 3000 individuals with LCA can do as a group to help combat this disease.

### 2 PROVIDE ACCURATE INFORMATION.

By collecting some basic clinical information from thousands of people affected with LCA, doctors will be able to learn how each genetic subtype of LCA behaves over time. They will use this information to give newly diagnosed individuals and their families more accurate information about what to expect.

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### 3 FIND THE REMAINING GENES.

The genes responsible for about one third of LCA cases are yet to be discovered. Scientists believe that by gathering samples from the hundreds of individuals affected by LCA whose genes have not yet been discovered, they will be much more likely to find all of the remaining ones.

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### 4 FIND CURES.

Trials of new treatments for LCA will require access to individuals affected with specific genetic subtypes of LCA. Even the most common genetic types of LCA occur in less than 300 people in the United States. Project 3000 seeks to identify as many individuals as possible with each genetic subtype so that clinical trials will never be slowed by a lack of affected individuals.

### 5 MAKE GENETIC TESTING THE STANDARD OF CARE FOR LCA.

Many insurance companies are currently unfamiliar with the value of genetic testing for LCA. By encouraging thousands of individuals with LCA to seek payment for their nonprofit genetic tests, Project 3000 intends to demonstrate the value of such testing to doctors and insurance companies across the country.

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# YOUR HELP COUNTS

## MAKE PROJECT 3000 A SUCCESS! TELL YOUR PATIENTS WITH LCA ABOUT THE PROJECT.

Go to [www.carverlab.org](http://www.carverlab.org) and click on the Project 3000 link for information you can share with your patients.

## CONNECTING PATIENTS TO THE REGISTRY

If you know of individuals affected by LCA, or their families, please direct them to the Carver Lab, Project 3000 website where they can sign up to learn more about Project 3000, and/or enroll in the Project 3000 Registry. If your patient does not have web access, they can call 1-866-495-CURE (2873), to learn more about Project 3000 and/or to enroll in the Registry.

