

Press Release, Kick-Off project MinE

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Kick-Off project MinE: Large-scale, groundbreaking research into the genetic cause of ALS

Two men diagnosed with the fatal disease ALS (Amyotrophic Lateral Sclerosis), the [ALS Foundation of the Netherlands](#), and the [Netherlands ALS Center](#) have joined together to start *Project MinE*, a large-scale, groundbreaking research project into the genetic cause of ALS. Undertaken at the specialized [Netherlands ALS Center](#), the research of [Project MinE](#), whose name represents a fusion of the concept of “mining” with a reorganization of the letters to spell “in ME,” will literally dig deep into the DNA profiles of 15,000 ALS patients and several thousand healthy control specimens in order to come to better understanding of the genetic basis of the condition. More information about the cause for ALS will ultimately lead to effective treatments for this debilitating degenerative disease. However, such an ambitious research project comes with a significant price tag. That’s why the ALS Foundation of the Netherlands and the other founders are launching an international campaign to raise funds for this necessary study with the slogan “MinE: Make it yours!”

Unfortunately, because so little is known about the precise cause of ALS, an effective treatment has yet to be found. However, it has become increasingly clear that ALS does have a genetic basis. Taking advantage of new revolutionary technology to compare the genomes (full DNA profiles) of 15,000 ALS patients with thousands of healthy control profiles, the ultimate goal of [Project MinE](#) is to quickly and definitively find new treatments for this (now) terminal illness. By “mining” into this vast resource of genetic data, *Project MinE* is searching for a genetic clue that will lead to a cure—a ray of hope for those suffering from ALS.

At this time, because of the extensive number of DNA samples and full genetic profiles being analyzed, *Project MinE* is the largest genetic-based ALS research study in the world. As such, this research does come at a significant price. Although the cost to analyze a DNA sample has dropped in recent years, the funds necessary to support the project will be significant. The ALS Foundation of the

Netherlands has joined forces with two active and progressive ALS patients, Bernard Muller and Robbert Jan Stuit, to generate the financial resources necessary to make this project a success.

Robbert Jan, the married father of an infant son Alec, was diagnosed with ALS in 2011. “I’ve been on this journey for two years, and fully intend for ALS to be no more than a temporary bump in the road. This past year, along with the ALS Foundation of the Netherlands, we successfully secured 2.1 million euros for the first phase of the study: the analysis of the first 300 DNA profiles of ALS patients. *Project MinE* is now a reality.” This first phase of research is being conducted by scientists at the Netherlands ALS Center under the leadership of Professor Leonard van den Berg.

In order to collect the thousands of DNA samples needed for the second phase of the research study, Bernard, Robbert Jan, and the ALS Foundation of the Netherlands are kicking off an international fundraising campaign entitled “MinE: Make it yours!” Companies, individuals, and institutions from all over the world can actively support the second phase of *Project MinE* (www.projectmine.com) through their generous donations and sponsorship. “All donations to the project go directly towards the analysis of DNA samples. You can choose either to sponsor a small portion of a genetic profile or an entire genome,” says Bernard, who’s been living with ALS since 2010. “In this way, every cent contributes in a tangible way to the success of the project.

Our slogan says it all— [“MinE, make it Yours!”](#)