

The Alström Syndrome Registry

One of the most frightening things about discovering that you or someone in your family has Alström Syndrome is the mystery that surrounds it. The fact is that much has been learned about the disorder – what causes it, how its symptoms can be managed, and what to expect. But there is so much more to discover! These circumstances dictate the need to develop methods for using patient data and information regarding the lived experience of Alström Syndrome by those *actually living it* to determine the most appropriate ways to define and treat and monitor the disease. Therefore, *your* data is vital for research! *Your* contributions can help find a cure! The greater the participation, the greater the impact!

What is the Alström Syndrome Registry?



The Alström Syndrome Registry (ASR), powered by a cutting edge survey tool called Platform for Engaging Everyone Responsibly (PEER), is a comprehensive registry that details the clinical phenotypes and psychosocial aspects of Alström Syndrome. The registry will be used by research scientists, physicians, individuals, and families affected by the syndrome. The overall goal is to increase available knowledge about Alström Syndrome while encouraging research and providing patients and caregivers with the tools to maximize self-management and quality of life.

What kind of information will be collected?

The Alström Syndrome Registry will collect basic demographic and general health information as well as Alström-specific medical details. The intention is to further refine the clinical characteristics and natural history of organ-specific diseases in Alström Syndrome while encouraging early identification and diagnosis and intervention that can moderate the progression of the disease phenotypes and improve the longevity and quality of life for patients. Participants, whether as a care giver or affected individual, will manage their own privacy preferences and respond to a questionnaire about how their lives are affected by Alström Syndrome. You will be asked to share information that is important to you, such as your medical history, your symptoms, and your feelings - in other words, the lived experience of an individual with Alström Syndrome.



Who is the Alström Syndrome Registry for?



The Alström Syndrome Registry is intended for everyone impacted by Alström Syndrome, not just the person with the diagnosis. Caregivers and family members, including those who have lost loved ones, are invited and encouraged to complete the survey. All can help ignite the interest of potential researchers in understanding the condition and developing relevant interventions that advance the well-being of all. Those who may wish to examine the ASR data include patients, parents, care-givers, physicians and researchers, especially those who may eventually provide therapeutic interventions while striving to find a cure!

Share as much or as little as you like - YOU will make the decisions!



Remember, the Registry portal is secure. Simply share *as much* or *as little* information as you wish *when you want* and *with whom you want*. World-wide and world-class researchers will then be able to access the Alström Syndrome Registry to understand the Syndrome, develop new treatments, and conduct further studies. Importantly, participants can give permission for researchers to contact them, or not. The ASR also provides an opportunity for all stakeholders to compare symptoms and strategies for better disease management and a better quality of life.

How to participate:

Find the secure portal on the ASI Web Page or at www.alstrom.org/registry as well as links to the *Alström Syndrome Registry Flyer*, *Alström Syndrome Registry Brochure* and a *Webinar* featuring Sharon Terry, President and CEO of Genetic Alliance, gives a CENA overview and Alström Syndrome Registry preview.

Use the information when and how YOU please to help the cause!