



The Alström Syndrome Registry...

- Will expand on previous information collected.
- Will identify symptoms we haven't associated with Alström Syndrome before.
- Will increase interest in research for Alström Syndrome.
- Will find the best way to identify and locate undiagnosed people.
- Will reach out and gather data from minority communities and other identified communities that have not been fully represented in the past.



Drop by drop we will form a lake!

What is the Alström Syndrome Registry?

- A patient-centered survey that collects health data directly from people living with Alström Syndrome.
- A first-ever secure way to connect patients and families to research scientists.
- A highly secure web portal.

What is CENA?

CENA (Community Engaged Network for All) is a partnership with Genetic Alliance, University of California, and nine other disease advocacy organizations serving different conditions.

What kind of information will be collected?

The Alström Syndrome Registry will collect general health information and Alström-specific medical information. Survey respondents will be asked to complete, at their own pace, simple and short surveys over the course of a year. Participants/patients will select and manage their own privacy preferences, and respond to a self-reported questionnaire about how their lives are affected by Alström Syndrome (whether as a caregiver or patient). The Alström Syndrome Registry will also ask questions of patients and caregivers that will provide a background of what it is like to live with Alström-- questions that address the lived experience of Alström Syndrome, including life skills and quality of life issues.

The Alström Syndrome Registry

Connect families with each other and researchers



Share the information you want others to know



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The Alström Syndrome Registry

The ASI Alström Syndrome Registry, the first ever participant-powered registry, provides people with Alström Syndrome the opportunity to structure the record of their individual experiences with Alström. It empowers participants to use this information as a way to become more proactive in improving the quality of their lives.

Participants will be asked to answer questions about their medical history, diagnosis, symptoms, and overall well being.



The Alström Syndrome Registry is also focused on engendering interest in research on Alström Syndrome. Data you choose to provide will create an overview of what typical issues are from

a patient perspective. It also allows you to make a selection that allows different levels of contact by researchers.

The highly secure survey located on our web site, www.alstrom.org, will allow participants to educate themselves about what others are experiencing by comparing symptoms and available treatments for disease management. It will also allow medical researchers to obtain the data they need to conduct important research on Alström Syndrome.

Helping ASI, other families, and researchers by sharing...

When you participate in the Alström Syndrome Registry, you are providing information that will help you to advocate for yourself and foster interest in research.

Your data will be protected by an Institutional Review Board (IRB) to assure that researchers requesting access for projects are "Scientific", "Ethical", and "Regulatory".

Patients are at the center!

YOU are in control! You set your own sharing levels, who has access to your data, and for what purpose. You can share as much of your health information as you want, when you want, and with whom you want.

The Alström Syndrome Registry will enable you to share your story and information that is important to you, as well as medical history, all of which will empower potential researchers to better understand Alström Syndrome, discover relevant interventions, and one day find a cure!

Collecting information from individuals with Alström Syndrome about their health and their lifestyle will help advance overall well-being for everyone. It is important that we gather lived experience, clinical, and health information from as many individuals as possible. Since we are RARE, numbers count!



If you participate in the Alström Syndrome Registry, you may choose to be informed, to be contacted, and to participate in new therapeutic trials that may be developed in the future.

The information we provide can be a vital force in helping to advance research!

How do I participate?



A link to the highly secure ASI Registry can be found on the ASI website, www.alstrom.org

How do I control who can see my data?

Choosing your settings is very easy! We have provided you with some encouragement from individuals within ASI who can guide you in understanding your choices. You will find videos of them on the website and clear choices within the actual survey.

You set your own sharing, privacy, and data access preferences using a safe and secure technology, What you make available is determined by you. We encourage you to share at the highest level with which you feel comfortable, and you will find information on our web site to help you to understand how.

