



## The Autoimmune Research Network

The Autoimmune Research Network (ARNet) is a program run by the American Autoimmune Related Diseases Association, Inc. (AARDA), in collaboration with many members of the National Coalition of Autoimmune Patient Groups (NCAPG.) This research network empowers patients by facilitating their participation in research on autoimmune diseases by collecting patient information. Information shared with ARNet will be stored securely. Only the anonymized data will be made available for researchers to query. This registry will be of great help to researchers and clinical trials.

### How it works

Patients will go to the ARNet website to enter information about their disease(s).

If at any time in the future a researcher is interested in enlisting a participant in a research study, the researcher will contact ARNet. AARDA or the participating group will then seek permission from the patient before sharing the patients information.

Personal information will never be shared with the researcher without the patients permission.

As autoimmune diseases can cluster in individuals and in families, this information can be vital in understanding autoimmunity and possible future breakthroughs.

### Gathering data

The more data collected, the stronger and more reliable the information will be for researchers to study.

For this reason, it is important to have as many participants as possible included in the Autoimmune Research Network (ARNet).

NCAPG members and other interested parties who want to join ARNet are welcome to create their own webpage on their own website to encourage participation.

### Using the data

The data collected will be stored securely through Global Vision Technologies.

When researchers want access to the information, they will contact ARNet. From that point, AARDA or the participating group will work with the researchers to provide them with the data, regardless of which organization the patients went through to submit their data.

The information will be used to gather patient experiences and help with autoimmune research.

Researchers and companies may make a contribution to the charity for access to the information.

Find ARNet at [www.aarda.org](http://www.aarda.org)

*"ARNet seeks to fill in some of those research gaps and foster projects that uncover knowledge to benefit all autoimmune diseases and assist with clinical trials."*

-Virginia Ladd, Executive Director, AARDA

### CONTACT INFO

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