

# Adrenal Disease Registry

ADULTS AND CHILDREN



## Do You Have an Adrenal Disease? JOIN US

### Purpose:

- Understand how adrenal diseases impact individuals—quality of life, complications and health status
- Assess the effectiveness of current treatments
- Identify common causes and risk factors for adrenal diseases
- Understand the Natural History of Adrenal Diseases – how they occur and progress over time
- Potentially participate in new treatment trials (optional)

### Several ways to join

1. To link: <https://bit.ly/MyAIRegistryAdults>  
<https://bit.ly/MyAIRegistryPediatrics>
2. Through NADF website: <https://www.nadf.us/>
3. Contact us by phone (847) 726-9010) or email [adrenal@njhealth.org](mailto:adrenal@njhealth.org) for more information and assistance
4. Mail attached form for enrollment packet



**NADF**  
NATIONAL ADRENAL DISEASES FOUNDATION

The National Adrenal Diseases Foundation  
P.O. Box 95149  
Newton, MA 02495 USA

## Who should enroll in the registry?

- Anyone who has been diagnosed with an adrenal disease (particularly those with reduced adrenal function or adrenal insufficiency)
- Including but not limited to persons with: autoimmune adrenal insufficiency, pituitary diseases, Cushing’s disease, adrenal cancer, post-surgical adrenalectomy, congenital adrenal hyperplasia (CAH)
- “At risk” people — have a family history of adrenal disease or current autoimmune disease
- People on high-dose “steroids”

## What is involved in participating?

*No fees or cost to enroll*

1. Review the study information and consent
2. Sign the consent to participate in the research
3. Complete the data entry forms
4. Provide medical records to confirm diagnosis of disease category
5. Provide semi-annual updates regarding your health and any new illnesses
6. Tell us about any hospitalization or crisis

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*Your information is protected by a Certificate of Confidentiality from the National Institutes of Health. The study has been reviewed and approved by the BRANY Institutional Review Board.*

The Principal Investigator for the Registry is Elizabeth Regan MD, PhD at National Jewish Health, Denver CO



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[www.nadf.us](http://www.nadf.us)

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## Receive an Enrollment Package by Mail

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Email: \_\_\_\_\_ Phone Number (optional) \_\_\_\_\_

Mail it to:  
Adrenal Registry  
National Jewish Health K706  
1400 Jackson Street  
Denver, CO 80206