

# Living with Arginase 1 Deficiency (ARG1-D)



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A resource for caregivers,  
patients, and families

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**ARG1-D**

# What is ARG1-D?

Arginase 1 Deficiency, also called ARG1-D, is an inherited metabolic disorder that can affect children, teens, and adults. A type of urea cycle disorder, ARG1-D is characterized by high levels of plasma arginine and may significantly impact health over time.

## Living with ARG1-D



ARG1-D provides challenges for patients and caregivers, including:

- Muscle tightness, affecting the ability to walk
- Problems with concentration and language skills
- Difficulty performing daily activities
- Worsening symptoms and complications as time passes

Because of the difficulties in performing simple everyday tasks, people with ARG1-D can struggle to care for themselves and may require a caregiver. As the condition progresses, some people with ARG1-D may even become unable to speak or read.

This guide, along with your healthcare team, the ARG1-D Community and the resources on ARG1Dinfo.com can help provide additional information.

# Facts about ARG1-D



ARG1-D is a rare disease that is estimated to occur in 1 of every 300,000 to 1 million people



It is caused by the body's inability to break down arginine in the urea cycle



Arginine builds up in the body, impacting the ability to do basic tasks in everyday life

## Symptoms usually appear



between  
**2 and 4**  
years of age



and can progress  
into adulthood



In some cases, symptoms can appear after puberty

# Signs and symptoms of ARG1-D can vary from patient to patient

Stumbling, toe-walking, seizures, and missed developmental milestones are some of the signs of ARG1-D.

## Signs and symptoms



# Managing ARG1-D

The current standard of care for ARG1-D includes:

- Reducing dietary protein like meat, eggs, cheese, beans, or legumes to help minimize arginine intake
- Essential amino acid supplements to add important nutrients to a restricted diet
- Other drugs to reduce the harmful effects of high levels of arginine in the body

The goal of management is to help reduce plasma arginine levels

**4-40 g/day\***  
ARG1-D patient  
daily protein intake

~25-60%  
LESS PROTEIN

## Clinic Notes and Recommendations:

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\*Protein intake amount varies by age and weight.

*Restricting diet and adding amino acid supplements are ways to help limit protein and lower arginine levels in people with ARG1-D.*

## ARG1-D care team

ARG1-D is typically managed by a team of specialists.

These healthcare providers each play a different role in diagnosing, understanding, and managing ARG1-D. Your care team may include some or all of these providers. You may need other specialists as well.



### Metabolic (Genetic) Specialist

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

Contact Info: \_\_\_\_\_

*If you'd like help finding the metabolic centers nearest you, visit [ARG1Dinfo.com](http://ARG1Dinfo.com)*



### Neurologist or Pediatric Neurologist

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

Contact Info: \_\_\_\_\_



### Primary Care Provider/Pediatrician

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

Contact Info: \_\_\_\_\_



### Dietitian

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

Contact Info: \_\_\_\_\_



### Physical Therapist and/or Movement Disorder Specialist

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

Contact Info: \_\_\_\_\_

## ARG1-D resources to help patients, caregivers, and families

These guides and resources are available in Spanish and English to help you understand and manage ARG1-D.



### Recipes

Quick and easy recipes that fit the dietary restrictions



### Photo Shopping List

An illustrated checklist to help you plan your next shopping trip



### Nutrition Label Guide

Tips to help you read labels and choose the right foods to meet nutritional goals



### Traditional Shopping List

A list of items, broken out by food groups, to help with your dietary plan

**Keep checking [ARG1Dinfo.com](http://ARG1Dinfo.com) to stay informed about new resources to help you and your family**

Early detection of ARG1-D is critical and can help your child get the treatment they need.

To learn more about no-cost testing sponsored by Aeglea, you and your doctor can visit [ThinkArginine.com](http://ThinkArginine.com).

***Find the metabolic center nearest you***

*Metabolic centers can be important for helping to diagnose and manage ARG1-D. For an easy way to find the metabolic centers nearest you, use the convenient finder tool at [ARG1Dinfo.com](http://ARG1Dinfo.com).*



# ARG1-D

## The ARG1-D community is here to help

While ARG1-D is a rare condition, patients and families don't have to face it alone.

### Join the community

It takes a community to support people living with ARG1-D. Visit [ARG1Dinfo.com](https://www.arg1dinfo.com) to learn more and to connect with these helpful organizations.



### Share your story

We love hearing from the ARG1-D community. Please reach out to us on [ARG1Dinfo.com](https://www.arg1dinfo.com) and share your experience living with or caring for someone with ARG1-D.



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