

## What is a patient story?

A patient story is a personal recollection about someone's personal experience with a rare disease. Patient stories help those who are currently searching for answers as well as healthcare professionals who want to improve their knowledge and services in order to help future patients.

## What is the goal of writing a patient story?

The main goal of writing a patient story is to raise awareness about a disease. With rare diseases in particular, patient stories are so important because they allow people to connect and analyze other people's experiences compared to their own. By sharing their patient story, people may be able to find answers about themselves or connect to other patients, caregivers, and supporters going through the same things.

## How to write a patient story?

Try to target **the five W's** and **one H**

### Who

Who is this story about?

Who first noticed something unusual?

### What

- What rare disease do you have?
- What was the diagnostic journey like?
- What was your healthcare experience like?
- What does the future of this disease look like?
- What advice would you give to others?
- What resources would you have wished there were when you went through your diagnostic journey?

### Where

- Where did you receive treatment?•Where did you go for more information?

### When

- When did symptoms start to appear?

### Why

- Why is it important to raise awareness about this rare disease?
- Why are you sharing your personal story?

### How

- How did things change after diagnosis?
- How can others help or get help?

## Tips:

- Stories should be about 500 to 2000 words
- Bring in your own personality to the story – don't be afraid to use humor
- Try to explain things in a way that anyone can understand with any level of prior knowledge
- Try to include information that was key to finding a diagnosis or about your experience
- Your story can include some kind of turning point (whether it be a development, diagnosis, treatment, or self-perspective) and how life has been since that