## Potential Prompts for Alport Odyssey

- If you are a person who has lived with an Alport diagnosis for more than 5 years, write a letter or a poem to your younger self about what you would like to tell them during the time they were receiving that diagnosis and first learning about Alport syndrome.
- If you are a person who recently received a diagnosis, write about what you want your future to look like, or explore your thoughts on challenges you might face or hopes you might have.
- If you are a person who experiences Alport-related hearing loss, reflect on what that experience is like for you. What is your relationship with hearing aids?
- If you are a transplant recipient, reflect on what receiving a transplant means to you or express how you feel about your donor.
- How has Alport syndrome impacted your identity?
- Write a letter to your body. What would you say to it as it experiences fear, uncertainty, and anxiety?
- What have you endured, survived, and conquered in your life in relation to your Alport syndrome? What have those experiences taught you about survival, change, and traumatic experiences?
- Write down your current emotional, physical, and mental needs. How can you find ways to fulfill them during the day?
- Picture yourself surrounded by joy. What is joy? What is its shape, color, sound, or texture? Picture yourself being encompassed by it and held up in its arms. How do you feel? How does this help to provide support for your body and mind?
- What is your first memory related to Alport syndrome?
- What is the most supported you have felt during your Alport journey?
- What would you like people to know about living with chronic illness or Alport syndrome specifically?
- Write a letter to Alport syndrome.
- A self-portrait.
- A prompt for writing a poem by Joseph Fasano:

## My Poem (Title)

My name is (name).

Today I feel like a/an (adjective) (noun).

(verb)ing the (noun).

Sometimes I am a/an (noun).

Sometimes I am a/an (noun).

But always I am (adjective).

I ask the world, "(question)?"

And the answer is

a/an (repeat your words from line 2).