

Getting Started in Advocacy

➔ Advice and insights from the Autoantibody advocate community

Nearly 240 million people worldwide are living with an autoantibody disease,

which occurs when the body attacks its own cells, tissues and protein, and in pregnant individuals, maternal antibodies, or alloantibodies, can attack the organs and tissues of the fetus. While there are more than 80 varied allo- and autoantibody (AAb) diseases, those who are living with them share many experiences such as delays in diagnosis, feelings of grief and loss, and challenges navigating the unpredictability of symptoms and treatment cycles.

By advocating together, **people impacted by AAb disease are collectively driving greater awareness and sparking actionable movement around their diseases**, many of which are rare with significant unmet need.

“**To have other people sitting there saying that I understand what that is like and... I have that shared experience, it was profoundly emotional.**”

Ann Mallen, advocate for warm autoimmune hemolytic anemia (wAIHA) & lupus

“**By connecting with each other we can make the biggest impact.**”

Courtney Yeager, advocate for hemolytic disease of the fetus and newborn (HDFN)



The Path to Advocacy

Advice for those who want to start advocating

Share your own story

While it may be daunting at first, that is the simplest way to get started. Know that your story is worthy to be shared.

“I saw two options: I could either live with this or share my story, and I felt almost called to share my story.”

Audrey Getman, advocate for myasthenia gravis (MG)

Find a mentor

Through online or in-person resources, find someone in your disease space who has already become an advocate. They can guide you in the right direction based on personal experience.

“At first, I was on Twitter anonymously to talk about it with others. It took me a while to come into my own space.”

Michael Kuluva, advocate for rheumatoid arthritis (RA)

Get involved

Look into joining an advocacy organization for your specific disease or join groups/forums on social media to learn more from others about how they advocate. There are groups for every disease, no matter how rare.

“Go to any conference, if there isn't one for you, make your own group.”

Elisa Glass, advocate for idiopathic inflammatory myopathies (IIM)

Look into different mediums

Social media isn't the only way. Figure out what you're passionate about, such as policy work or clinical guidelines, and let it naturally translate into advocacy.

“The first step I took to advocating was writing an application to join a patient advisory group”

Rick Phillips, advocate for rheumatoid arthritis (RA)

Go at your own pace

Start slow, and know it may take time to find the right fit for you as an advocate. Try out different modes and find what works for you.

“I didn't realize I was advocating while I was doing it.”

Courtney Yeager, advocate for hemolytic disease of the fetus and newborn (HDFN)

Ask questions

Find a safe space to ask questions, whether it be about advocacy or about your own autoantibody disease. Asking questions will allow you to learn more about yourself and your personal journey, and can open you up to share your own experiences.

“We've all gone through similar emotions and experiences with doctors.”

Lisa Aube, advocate for fetal and neonatal alloimmune thrombocytopenia (FNAIT) & Sjögren's disease (SjD)

Shift your mindset

While there are so many benefits to patient advocacy, it can also be intimidating to get started. Let your “why” guide you and share in forums that fit your personal comfort-level.

“Instead of why me, reframe to why NOT me.”

Tasha White, advocate for myasthenia gravis (MG)

Every patient has the power to make a difference.

Whether it be through sharing your voice on social media, by informing clinical guidelines, or by participating with others through advocacy groups, learning how to tell your story, your way, will have impact.

“**There is a lot of value in educating people.**”

Ann Mallen, advocate for warm autoimmune hemolytic anemia (wAIHA) & lupus

For additional resources and information, **join the [HealthVoices \(@healthvoices\)](#) community on Instagram.**

HealthVoices is a multichannel program that illustrates Johnson & Johnson's commitment to educating and empowering online health advocates.

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