

Transcript: Introduction

Keeya: My name is Keeya Steel and I am the creator of Hell's Bells and Mast Cells. After more than 29 years of symptoms and medical appointments, I was finally diagnosed with mast cell activation syndrome, dysautonomia and Ehlers-Danlos syndrome. At the time, there was little to no information online. So I created Hell's Bells and Mast Cells, a blog and collection of memes to raise awareness about invisible, chronic, and complex disease through humor. Since then, I have used my professional training in communications and advocacy to collaborate with healthcare professionals and other patient leaders to provide resources for people with complex disease.

Linda: My name is Dr. Linda Bluestein. I am a complex disease doctor and I specialize in chronic pain. I've worked in a variety of healthcare settings, including private practice and multidisciplinary clinics. I also am a complex disease patient. I know what it's like to have multi-system disease and need lots of care from specialists.

Keeya: I wanted to create this course because doctors are trained how to be doctors, but no one trains patients how to be effective patients. In this course, you'll learn how to prepare for your appointments, connect with your doctors and advocate for your body while we address the challenges of complex disease like low energy, brain fog, anxiety, bad past experiences, long wait times, symptoms all over your body and symptoms that are hard to measure and invisible. I understand what it's like when it's so hard just to show up for that appointment, let alone advocate for your body. We want to improve your medical experiences and save you time, energy, and money.

Linda: I want to be able to spend more time during the visit, developing a comprehensive treatment plan and be able to more efficiently get a clear picture of what's going on with the patient. Patients are generally not very aware of the constraints that are placed on doctors. There are a lot of administrative burdens, regulations, policies, and things that influence how we're able to deliver care. By giving you a behind the scenes look at these things, I feel that we can give you a better idea as to what's going on and help you create a better doctor/patient relationship.

Keeya: This course contains six modules.

Linda: Each module contains a video, a transcript and additional resources. You can watch and re-watch the videos at any time. We know this is a lot of information and it will take time to develop the skills taught in this course. Go at your own pace and implement the changes that you learn when you go to your next upcoming appointments. And keep in mind that small incremental changes can have a very big impact.

Keeya: You are your body's best advocate and we are so excited to offer you this course, providing tools and resources to help you become a more effective patient and have more positive medical experiences to get the care that your body deserves.