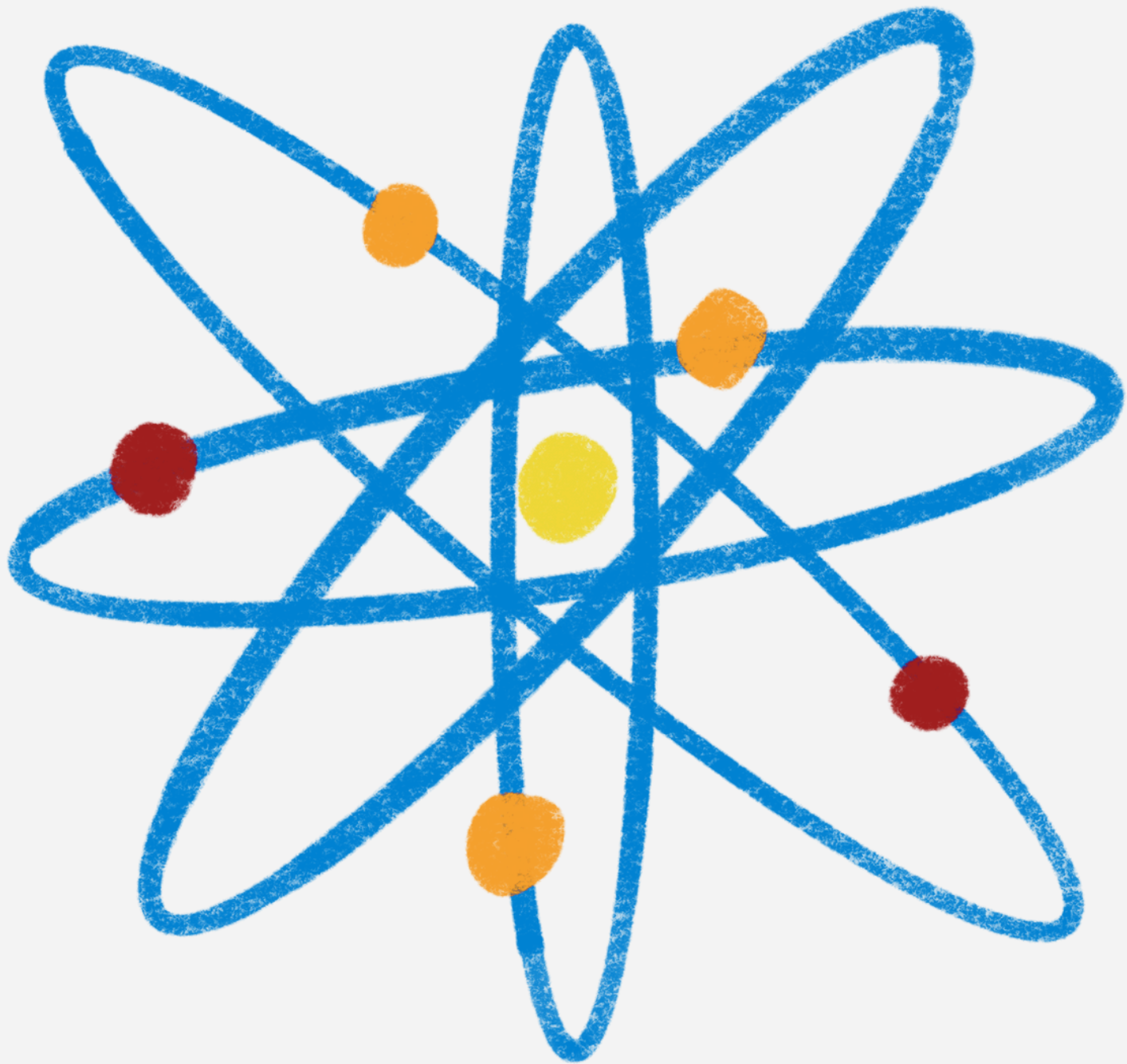


# WHAT IS THE PATIENT- SCIENCE MODEL?



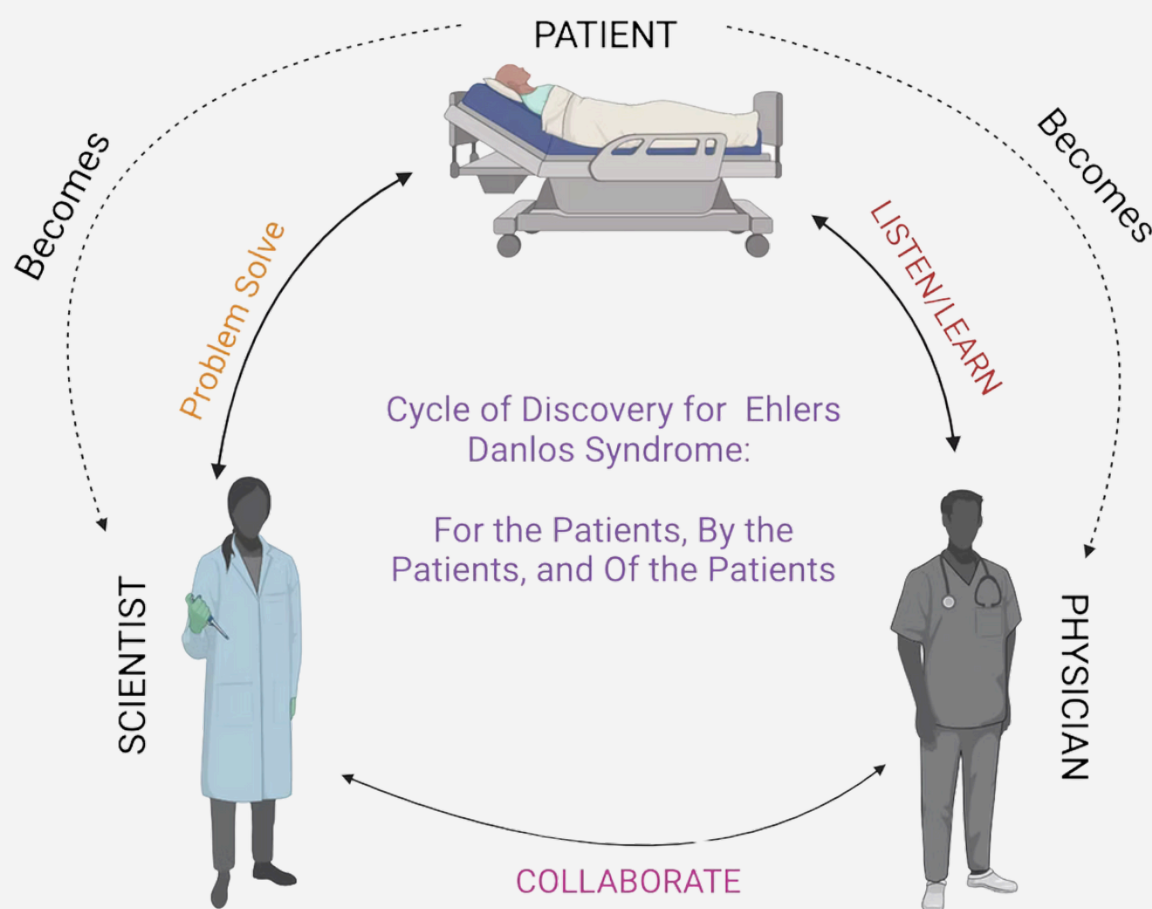
At the Norris Lab, we recognize patients as the true experts. Their lived experiences shape critical research questions, and with the right scientific tools, they have the power to drive meaningful discoveries. That's why we're pioneering a patient-scientist model —where patients don't just participate in research, they lead it. By integrating patient perspectives at every stage, we're making science more relevant, compassionate, and transformative.

# WHY PATIENT-SCIENCE MATTERS IN EDS RESEARCH

Most medical schools spend less than an hour on Ehlers-Danlos Syndrome, despite its prevalence.


Many healthcare providers lack adequate training or understanding of EDS, leading to missed or delayed diagnoses.

Studies show an average 14-year diagnostic delay for EDS patients, along with significant financial burdens.




Patients with EDS who enter research spaces help shape meaningful and relevant questions, guided by their lived experiences and a deep desire for answers. Creating inclusive scientific environments, especially for researchers with chronic illnesses and disabilities, is essential to driving research that reflects the real needs of patients and communities, with the potential to translate into better care and improved health outcomes.

By fostering accessible research environments, challenging assumptions about patients' capabilities, and integrating patient perspectives from the start, patient-scientists gain both the tools and empowerment needed to drive meaningful discoveries. In our experience, many go on to pursue advanced degrees in research or healthcare, contributing directly to the understanding and care of EDS and its comorbidities.



*Connecting to something bigger than myself to help future generations with EDS, gives me hope and purpose. And that is what the Norris Lab enables through this unforgettable internship. Beautiful things can come out of tough situations and this opportunity has been absolutely beautiful. The impact of this internship doesn't stop when it's over. Right now, you see a bunch of excited and energized students inspired that we had great mentors and exciting data. What you may not see is the confidence that each of us has internalized, and the cascading effect that this program has enabled.*

-Sydney Severance



*As someone who has hypermobile Ehlers-Danlos Syndrome, I struggled with the lack of representation of chronically ill and disabled individuals in research. I often discouraged myself from pursuing certain career paths and opportunities due to this, but the Norris Lab showed me that there are people just like me who have the kind of careers that I dream of.*

-Arianna Meurlott

