



# FAQs About JUMP (Journey to Understand MMA and PA)

#### What is JUMP?

The JUMP (Journey to Understand MMA and PA) Study is being conducted by HemoShear Therapeutics and AllStripes, a rare disease online research platform. JUMP is designed to accelerate understanding of the natural course of methylmalonic acidemia (MMA) and propionic acidemia (PA) disease and treatment for families, researchers, clinicians and industry.

The study will collect and provide patient medical record information from multiple institutions for families to access in one place at no cost. AllStripes will remove identifying information like name and address from your medical data and aggregate this data for the Hemoshear team to better understand the medical experience and progression of MMA and PA over time. In addition, academic researchers, healthcare practitioners and patient advocacy groups can apply to use the collective patient community data to answer specific research questions at no cost.

### How can my medical records advance research?

Your (or your loved one's) medical records contain clues that could help advance treatment research. They can be a rich source of knowledge about symptoms, progression and impact of your condition on patients and families. After AllStripes de-identifies the information in your records, by removing information like name and address, your medical journey can be combined with data from the rest of your community to help with a wide range of research efforts, including:

- Jumpstarting new research for MMA and PA
- Determining important symptoms to target
- Speeding up development of treatments by improving clinical study
- Making multiple research efforts possible at one time

You may also be asked to complete surveys within the AllStripes platform to answer specific research questions or provide more insights back to you and your community.

# Why do drug companies like HemoShear need to learn from patients' medical data?

MMA and PA are so rare that there is no well-established long-term data on the course of these diseases. HemoShear is collecting natural history data on MMA and PA because the company needs insight into the real world experience of many patients to better understand the disease and be able to scientifically demonstrate whether the potential new treatment they are developing is effective in improving outcomes. The de-identified MMA and PA patient data in the AllStripes platform may be used in the future by other companies who are developing new treatments.

# Will I have to pay a fee to join AllStripes, participate in the JUMP study and receive access to my health records?

No. AllStripes' commitment to patients and families is that there is never a cost to join research programs or use the platform.

#### How do I sign up for AllStripes and participate in JUMP?

You can join the AllStripes research programs to be a part of the JUMP study and future research from your own home.

- 1. Go to allstripes.com/mma or allstripes.com/ppa
- 2. Create your account Sign up, review the research consents and share the names of your health facilities (about 10-15 minutes). No appointments, no uploads.
- 3. Success you're helping JUMP-start research progress!

Through AllStripes, you will be able to easily access all medical records collected into your private and secure portal at no cost, and you also will receive research updates on the MMA and PA community.

# Who owns the information in the medical records that AllStripes collects for patients and families?

Patients own their own data, always. Patients who consent to research can opt out at any point. They may download their data to take with them or contribute to outside research.

If patients or caregivers consent to being involved in AllStripes' research, researchers will organize the de-identified data from their medical records, combine it with data of other individuals with the same condition, and analyze that data to generate insights and advance treatment research.

### How does AllStripes keep patients' data safe and confidential?

Only properly trained and authorized personnel will have access to patient medical information for processing purposes. AllStripes follows strict policies and procedures to ensure that patient information is protected. To view the full AllStripes Privacy Policy, visit https://www.allstripes.com/privacy.

Patients' secure accounts are not accessible to others, unless the patient chooses to share the account with caregivers or their doctors. If a patient (or their legally authorized representative) chooses to participate in AllStripes research through proper informed consent, AllStripes will only share deidentified data with qualified researchers.

#### What is HemoShear?

HemoShear Therapeutics, Inc. is a pharmaceutical company driven to apply scientific insights to develop medicines that improve the lives of patients with rare metabolic diseases. HemoShear has developed HST5040, an experimental drug treatment for methylmalonic acidemia (MMA) and propionic acidemia (PA). The company is currently conducting a clinical study called HERO (HEIp Reduce Organic Acids) to assess HST5040 in patients with MMA and PA aged 2 and older.

### What is AllStripes?

AllStripes is the leading research platform dedicated to rare disease. AllStripes is on a mission to unlock new treatments for people affected by rare disease, and is transforming how patients and families are involved in the research process. The platform makes it easy for participants to access their own medical records and contribute their de-identified information to advance new treatment research – all from home, at no cost.