UGM Hospital Presents Seminar on Duchenne Muscular Dystrophy (DMD)

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“The life expectancy of patients with Duchenne Muscular Dystrophy only reaches the second decade,” stated Prof. Dr. dr. Elisabeth Siti Herini, Sp.A(K), Director of Medical Services of UGM Hospital.

This was stated in a press conference entitled “Seminar on DMD Genetic Disorder” on Saturday (9/8) at the Auditorium of UGM Hospital. The seminar was held by the hospital in collaboration with Genetic working group of UGM Faculty of Medicine, Public Health, and Nursing. The goal was to educate families of patients with DMD on the latest diagnosis and therapy.

Herini said the seminar was also held to commemorate the Duchenne Awareness Day. “Therefore, the disease that we highlight here is DMD.”

DMD, she added, is a muscular dystrophy caused by a genetic mutation that mainly affects young boys. The patients generally experience muscle weakness that begins with difficulty in walking and standing.

“Once it reaches the internal organs such as respiratory and heart, that is when the last phase of DMD, death, arrives.”

Dr. Gunardi, Ph.D., Sp.BA., Chairman of the working group, mentioned DMD patients are normal at birth. The symptoms start appearing at the age of 4 or 5. Once they are 8 or 9 years old, their condition deteriorates and they will usually need wheelchairs for mobility.

“However, in some cases, symptoms appear before three years of age, indicated by the baby’s difficulty to start crawling or walking,” he explained.

Gunardi further explained this disease mainly affects males because the gene that carries a DMD-causing mutation is located on the X chromosome, which only presents in males. Meanwhile, females will only be the carriers.

“Actually, females can manifest a similar disease called Becker Muscular Dystrophy (BMD). The difference is that BMD patients do not have a specific lifespan compared to DMD.”

He admitted there is no cure for DM to this date, but there are available treatments to inhibit the progression.

“Especially in Indonesia, steroid therapy is most commonly performed for DMD patients.”

However, Gunardi argued, this therapy is ineffective in inhibiting the DMD muscle degeneration process. Therefore, Gunardi pointed out that the seminar attempted to introduce a gene therapy that directly targets the root of DMD.

He explained the gene therapy is currently trending in Europe. It can extend the patient’s life expectancy by a decade. Additionally, it can also inhibit DMD, thus postponing the need to use a wheelchair to the teen years.

Muhammad Fahmi Husaen, Diploma student of Computer and Information System UGM who suffers from DMD, expressed his gratitude for the seminar. “Although I cannot fully recover, this seminar encourages me,” he said.

Fahmi has been diagnosed with DMD since 8 months old. This, however, does not discourage him in pursuing education. In fact, he has won a number of competitions since junior high school.

His latest achievement is in the last week's National Scientific Week 2018. Along with his two partners, he earned two gold medals in creation category for presentation and poster. The innovation presented is the Shoes to Prevent Ankle Contracture for people with paralysis. "This was also initiated by my personal experience as a DMD patient," he explained.

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