

PRESS RELEASE

ALS Awareness Project Led by an ALS Patient
“I’M STILL”
A Painting Event Using an ALS Patient as the Model

Event Day: Wednesday, May 25, 2016 from 12:00 p.m. at Marunouchi (Chiyoda Ward)

[Tokyo—May 17, 2016]

The END ALS Association (Representative: Katsumasa Fujita, Headquarter: Setagaya Ward, Tokyo) will host “I’M STILL,” a painting event in which Masahiro “Hiro” Fujita, an ALS patient and founder of END ALS, will serve as the model. The aim of the event is to promote awareness and understanding of amyotrophic lateral sclerosis (ALS), a disease designated as “intractable” by the Japanese government.

Hiro has lived with ALS for 6 years (he is currently 36 years old). The ALS Ice Bucket Challenge which swept the world two years ago had done much to raise people’s awareness of the existence of ALS. However, there is still much more to be done to spread true understanding of the disease and its realities.

This event invites people of all ages to come paint Hiro and to see the “stillness” of his life, as ALS has taken movement away from him despite leaving intact his ability to think, sense, and feel. Hiro devised the event with the hopes that more people will come to understand the realities of the disease by directly seeing its effects. The ultimate goal is to urge stronger action in finding a cure for this devastating disease.

The inaugural hosting of “I’M STILL” will be at GOOD DESIGN Marunouchi, organized and operated by the Japan Institute of Design Promotion which has kindly offered their venue for this event.

Date/Time: Wednesday, May 25, 2016 from 12 p.m. to 5 p.m.

* The painting event with Hiro will be from 12 p.m. to 2 p.m. The gallery will exhibit the finished paintings from 2 p.m. to 5 p.m.

Venue: GOOD DESIGN Marunouchi (3-4-1, Marunouchi, Chiyoda-ku, Tokyo, Shin-Kokusai Bldg. 1F)

Participants: Approx. 25 people of all ages

Sample Image of the Event



Purpose of the “I’M STILL” Project: It has been four years since the END ALS Association was established, and two years since the ALS Ice Bucket Challenge, intended to raise awareness of ALS, swept the world in the summer of 2014. The Ice Bucket Challenge indeed helped to raise awareness of the existence of ALS, but today, most people remember the challenge, but not what the disease is about. In order to communicate that ALS is a disease that takes away one’s ability to move, Hiro wanted to use a method that had impact, but that didn’t seem like a lecture. That is how the project “I’M STILL” came to be born. In English, the word “still” has two meanings—one meaning “as yet” and the other meaning “motionless.” In the art world, “still life” is a painting of something that is inanimate. The naming of this event is intended as a wordplay of the END ALS slogan, “I’M STILL ALIVE” and Hiro describing his inability to move due to ALS as “I’M STILL.” The event aims to create social impact by intentionally taking an ironic approach of having an ALS patient serve as a painting model. Hiro will put his own body on display to illuminate the cruelty of the disease. Visitors to the gallery will be able to create a painting with Hiro as the subject and the finished works will cover the walls of the gallery. At the end of the event, all of the paintings will be donated to END ALS to be used as visuals for future advertising that will help to spread awareness of ALS. The hope is that “I’M STILL” will become a movement, where ALS patients all over the world will have themselves painted in a similar way, eventually turning into a big advertising for ALS awareness that will get us one step closer to putting an end to the disease.

About Masahiro “Hiro” Fujita: Hiro, currently age 36, was born in Tokyo in 1979. He is a planning director at the international advertising agency, McCann Erickson Japan. He joined McCann Erickson in April of 2004 and was assigned to the Strategic Planning Division, where he planned and developed PR/influencer marketing and brand communication strategies. He was diagnosed with ALS in November of 2010. He became wheelchair-bound the following March and was placed on an artificial respirator in January 2012. In January 2013, he received a tracheostomy and lost his voice to speak again. Since then, he continues to carry on his work at the ad agency and activities for END ALS using the Tobii eye-tracking system, which allows him to operate a computer with blinks and eye movement. His book, “99% Thank You: Things Even ALS Can’t Take Away,” was published in November 2013.

About ALS: Amyotrophic lateral sclerosis (ALS, also known as Lou Gehrig's disease) is an intractable disease characterized by the gradual weakening and atrophying of the muscles in the entire body, including that of the limbs, throat, tongue, and that required for breathing. Meanwhile, bodily sensation, such as cognitive function, vision, hearing, and functions of the internal organs, remain intact. With the advancement of symptoms, in most cases, eye movement eventually becomes the only means of communication. Some patients even lose this ability and enter a “total locked-in state” in which all muscle movement is completely lost.

About the END ALS Association: The END ALS Association is an advocacy organization founded by ALS patient and advertising planner Masahiro Fujita in September 2012. Its goals are to drive awareness and understanding of the current conditions surrounding ALS patients.

Mission

- (1) To work to establish a treatment for ALS
- (2) To call out for change in the government’s medical care policy so that ALS patients can remain a member of society

The END ALS Association

Representative: Katsumasa Fujita

Founder: Masahiro Fujita (Hiro)

Founding: September 3, 2012

<https://end-als.com/>

<https://www.facebook.com/endalswithhiro/>

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