

難治性血管奇形の啓発や患者支援続ける

みらいプラネットが総会



「カラフレ」がコンサートを行った

駅南町のいちほなで13日、NPO法人「みらいプラネット」(山口県難治性血管奇形相互支援会、新橋町)の通常総会と交流会が開かれた。来賓として榎屋敬悟衆議院議員や江島潔参議院議員らを迎え、会場には約60人が集まった。同法人は、一部が難病指定されている難治性血管奇形の患者を支援し、治療法研究のため国への要望などを行っている。また、病気が広く知られていないために「自分の病気が何かわからない」と

あいさつする有富理事長



という人がいたり、患者が差別や偏見を受けることもあり、周知を目指す啓発活動にも取り組む。有富理事長はあいさつで、来場者や支援者らへの謝意を示した上で「次世代に向けて、笑顔いっぱい社会にしていきたい。少しずつでも一生懸命活動を進めていく」と述べた。交流会においては、同法人のテーマソング「みんな友達じゃけえ」を歌う地域アイドル「カラフレ」の4人が登場。元氣

いっぱいコンサートを行った。また、周南市の9歳の双子キッズモデル「マイトム」がダンスを披露。「マイトム」の児島舞華さんと冬夢くんは、同法人が制作した啓発用の学習教材DVD「咲き誇れ、強く-Irrepla ceable-」に出演した縁もあり交流会に登場した。このDVDは、難治性血管奇形の患者だけでなく、

障害者や母子家庭といった社会的弱者への偏見や差別をなくそうと同法人が制作。昨年度は県教育委員会に贈呈し、県内各小中学校や公立図書館に配布された。また、塩崎恭久厚生労働大臣にも贈呈。全国へ向けた配布も進めている。今年度も、同法人は宇部市のフロンティア大学で次世代教育講演や、愛情防府フリーマーケットへの参加といった啓発、患者支援などの活動に取り組んでいく。(杉田雄)

ほうふ日報

平成29年5月18日

難病への差別解消に

支援団体、県にDVD寄贈

山口県の難病患者支援団体「みらいプラネット」(有富健代表)は6月13日、沖縄県教育庁に平敷昭人教育長を訪ね、難病理解をテーマにしたDVD「咲き誇れ、強く—Irreplaceable—」600本とDVDの原作本60冊

を寄贈した。写真。DVDと原作本は県教委を通して、県内の小中学校や高校などに配布される。

DVDは難病患者への無理解や先入観による差別などの二次被害をなくしようと同団体が制作した。山口県職員の有富代表が「難治性



血管奇形」という難病にかけ、差別を受けた経験な

どを基にドラマ仕立てで構成している。

同団体はこれまでDVDを小中学校で活用してもらおうと山口県、東京都、佐賀県のほか、厚生労働省にも寄贈しており、11月には秋田県にも寄贈する。有富代表は「亀のような歩みだ

が、全国47都道府県に届けたい」と意気込む。

手交式で有富代表はDVDを通して「子どもたち(に)優しい心を持った大人になってほしい」と呼び掛けた。平敷教育長は「人権教育などに活用していきたい」と応じた。

琉球新報

平成29年7月7日

Drama tackles bullying of disease sufferers

By Yohei Takei
Yomiuri Shimbun Staff Writer

A nonprofit organization and a university movie-making group have produced a DVD drama calling for an end to discrimination and prejudice against people with a serious vascular disease.

Mirai Planet is an NPO in Yamaguchi Prefecture established by people with intractable vascular malformation (see ②), an ailment whose cause is unknown.

It plans to distribute free copies of the DVD mainly to elementary and junior high schools around the country.

About 30 minutes long, the drama is titled "Sakihokore, Tsuyoku (Bloom in glory, strongly) Irreplaceable." The main character is a girl with intractable vascular malformation who also suffers emotionally because many of the people around her do not understand her situation.

However, the school nurse and others support the girl. After she enters high school a specialist correctly diagnoses her illness, and she finally takes a more forward-looking attitude toward life.

The story is based on the experiences of Tsuyoshi Aridomi, the head of the NPO and an employee of the Yamaguchi prefectural government.

In 2001, Aridomi developed symptoms including backaches, numb-



A young girl played by Ayano Ito leaves a classroom due to her poor health and the insensitive words of her classmates.

Courtesy of Mirai Planet

ness in his left leg and swelling. Doctors were puzzled as to why this was happening and he was repeatedly hospitalized.

The pain was not the only problem. Aridomi said he also suffered psychologically due to a lack of understanding from people around him and "power harassment."

One of his colleagues complained, "He refuses to work by pretending to be sick," while another said, "I can't

trust you with any job."

In 2010, nine years after the onset of the illness, Aridomi finally received a correct diagnosis. He later established Mirai Planet to seek out fellow patients who had the same intractable disease but did not know it.

The NPO works to improve medical systems and government assistance for people with the condition.

Aridomi thought, "I want to make the world a place where not only people

with intractable diseases but all socially vulnerable people, including disabled people and crime victims, are free from prejudice or discrimination."

In spring 2015, he got the idea of producing the drama.

Mirai Planet procured ¥2.5 million, partly through the Red Feather Community Chest fund drive, and asked university movie-making groups to cooperate in shooting the film. A University of Tokyo group called Eiga

Seisaku Spika 1895 agreed to help out. Members of the Spika group usually produce movies for their own genera-

Kasumi Ishikawa, a table tennis player who won a bronze medal at the Rio de Janeiro Olympic Games; and Shoko Haida, a former singer in NHK music programs for children.

The movie was completed in March this year.

In May, copies of the DVD were distributed to elementary and junior high schools in Yamaguchi Prefecture. The NPO says the movie is used in school classes and company job training sessions.

Through Mirai Planet, Aridomi published his autobiography, "Makerumonoka!" (You won't beat me), and used the royalties to help finance production of the DVD. He aims to produce 50,000 copies and deliver them to elementary and junior high schools around the nation, as well as to public libraries.

"I hope lots of children will watch the drama and be encouraged not to engage in prejudice and discrimination," Aridomi said.

For inquiries in Japanese, call or fax (0835)22-3112 at Mirai Planet's secretariat, or email: info@ygm-support.org

"I want all socially vulnerable people to be free from prejudice"

— Tsuyoshi Aridomi, the head of Mirai Planet

tion, purely for entertainment.

Ayano Ito, 22, a Spika representative at that time, said: "It was our first time to produce a movie that a wide range of generations would find easy to understand, but we accepted the request because we wanted to use our knowledge and experience to help others."

Shooting began in August last year with Ito serving as director, scriptwriter and lead actress. Other participants included elementary school students in Yamaguchi Prefecture; Cara Fure, a local pop group in Yamaguchi city; and professional actors and actresses including Maiko Kawakami and Daijiro Harada.

The DVD also contains video clips in which about 140 people share comforting messages.

They include Health, Labor and Welfare Minister Yasuhisa Shiozaki;

Intractable vascular malformation

The cause of this ailment, which makes blood vessels inside the body become entangled, is unknown. Malformations can appear not only on the arms and legs, but on other parts of the body as well. There is no cure at the present time. The number of patients in Japan is estimated at 10,000. Some types of the disease are designated by the government as intractable.