

LIFE

They are us

A new arts festival seeks to raise awareness about people living with rare diseases and disabilities, **Cheng Yuezhu** reports.



“This platform will provide effective channels and a real drive for integration and equal artistic expression of different groups.”

Ge Huichao, founder and curator of the Beijing festival

A diverse ensemble of different ages, genders and degrees of physical mobility tell similar stories through the play, *Rare Hug*.

“I look different from everyone else. I sit in a wheelchair, measuring the floor with my hands. But I’m just like everyone else. I need to go to work in order to do what I like,” a member of the group says onstage, during a recent performance of the stage production that seeks to highlight the lives of people with rare diseases.

“While I look just like everyone else, I am a myasthenia gravis patient,” says another member.

The neuromuscular disease leads to muscle weakness. The symptoms include drooping eyelids, a tendency to fall, and a lack of balance and physical strength.

“It can be life-threatening,” the person adds.

Each story is about a real experience. The play’s performers are either patients with rare diseases or are from families in which other members have them.

Rare Hug reveals such struggles. It features performers from the Illness Challenge Foundation, a Chinese nonprofit in Beijing.

The play was staged as part of the 2019 Luminous Festival held in Beijing from Oct 13 to 20, as the first edition of an annual event to promote inclusive arts.

“At this year’s Rare Disease Day event (in February), we talked about creating a play to express ourselves through art so that the public can truly feel that patients with rare diseases actually live among them and to help them understand our life experiences through stories,” says Pan Longfei, one of the actors and a patient with Kallmann syndrome, a condition characterized by delayed or absent puberty and an impaired sense of smell.

A dozen patients with rare diseases volunteered to perform in the play. Directors Chen Meiping and Liang Wanyun helped turn their life experiences into a stage production.

Another performance at the Beijing festival related to the lives of people with rare diseases or disabilities was presented by Dancing Wheels, a dance company in the United States that has facilitated collaborations between dancers with and without disabilities since its founding in 1980.

The company’s founder and president, Mary Verdi-Fletcher, is the first professional dancer who uses a wheelchair in the US. She was born with spina bifida, a type of neural-tube defect. Doctors said she could not even grow up, let alone become a dancer. However, her family refused to give up and brought her up with faith and perseverance.

“My mother was a dancer. My father was a musician. So, I always loved the idea of dancing. I worked with a non-disabled partner, and we started to dance,” Verdi-Fletcher says.

Her appearance on *Dance Fever*, a US music-variety show, in 1980, won her a standing ovation and made history. “Before you know it, we had audiences that wanted to come and see, and then we built a company from there.”

She is working to raise public awareness through performances and education, including dancing in Beijing’s Luminous Festival.

“We love to be able to go into other countries and be able to not only dance but to give the example about what’s possible. So, I think that it opens people’s minds, broadens their vision of accessibility, of dance, of inclusion,” she adds.

The festival also hosted the China-UK Disability Arts Forum, an



Top: Members of Dancing Wheels, a dance company in the United States, perform at the 2019 Luminous Festival in Beijing.

Above: Performers stage *Rare Hug*, a play featuring real experiences of patients with rare diseases. PHOTOS PROVIDED TO CHINA DAILY

exhibition by students with disabilities, and art-therapy workshops.

Founder and curator of the Beijing festival, Ge Huichao, started out as a modern-dance producer. During a trip to New York in 2016, she was exposed to performances

includes age, gender and social minorities,” Ge says. “This platform will provide effective channels and a real drive for the integration and equal artistic expression of different groups.”

Upholding the concept of symbiosis, the festival’s forums and workshops take in almost the same number of participants with and without disabilities, Ge says.

“Inclusion and communication are very important.”

The China-UK Disability Arts Forum, a major section of the festival, is supported by the British Council, with “inclusion” as a focus area for its activities this year, as it marks the 40th anniversary of its presence in China. Four British and four Chinese experts spoke at the forum, and art and charity organizations were invited to exchange ideas on inclusive arts and disability awareness.

“We hope to invite troupes from more countries to perform in next year’s festival. We devoted a lot of time to hosting this year’s festival, and hopefully we will have more funding and possibilities next year,” Ge says.

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The event is organized by the China Ballroom Dance Federation and Siming district government. PROVIDED TO CHINA DAILY

By YUAN SHENGGAO

More than 5,000 ballroom dancers from countries and regions involved in the Belt and Road Initiative twirled and shimmed on the dance floors of Siming district in Xiamen on Nov 1, hoping to be crowned winner in a vast array of categories.

The three-day 2019 CBDF “the Belt and Road” World Open Ballroom Championships was organized by the China Ballroom Dance Federation and Siming district government, which aspire for it to become a world-class event.

Wang Yonggang, vice-president and secretary-general of the CBDF, said he hoped the event can better promote ballroom dancing and provide a platform to train troupes of dancers.

Competitors, guests and judges came from countries and regions involved in the BRI, as a part of efforts to promote the development of BRI culture and art.

“Siming district attaches great importance to promoting its local cultural brands. A year on, we’ve come here again. The competition has attracted dancers from more than 20 countries and regions. In addition to the competition, they also felt the city’s charm and beauty,” Wang said.

He said the success of the first competition last year caused great sensation in dancing circles. In the first half of 2019, a series of ballroom dance activities were held in the district, including a ballroom dance training camp for Chinese and foreign college students and an elite salon for talent, which is making Siming a popular



Dancers sashay to Siming for BRI ballroom event



From left: Young dance partners strut their stuff in front of judges during the competition. Professional dancers embrace mid-performance. Latin dancers strike a pose during the event. LIN YUYANG / FOR CHINA DAILY

destination for ballroom enthusiasts.

Yao Yuping, deputy director of Siming district, said the event is a heavy-weight brand for the district’s “sports fashion season” this year, and he hoped to build it into a key platform to gather dancers, guests and judges from BRI countries and regions as a

window for cultural and sports exchanges in Xiamen.

The event invited many famous international judges, including Rob in Short, honorary president of the World Dance Council and Jelena Samuilova, president of the Latvian Professional Dance Sport Federation.

“I am honored and delighted to attend the 2019 CBDF Championships in Xiamen. I believe that this important event will receive large entries and all competitors will try their best to give excellent performances,” Short said.

This competition is the only inter-

national ballroom competition in China that takes BRI as the theme.

One of the highlights of the competition was a dance-off among seven countries: Russia, Ukraine, Poland, Italy, Latvia, Lithuania and China. Dancers speaking different languages and from different cultur-

al backgrounds put the achievements of the BRI on full show.

Stanislav Popov, honorary vice-president of the World Dance Council from Russia, led the Russian team and won first place with 101 points. This was his second visit to Xiamen.

“Last year, we earned second place, this year we won the championship. Thanks to the competition, I got the chance to know China and Xiamen,” Popov said.

Marcel De Rijk, president of the International Dance Asia Association and vice-president of the Euro Asian Dance Council, was appointed as the lead judge of the competition. He said the young dancers showed tremendous potential.

World professional modern dance champions Domen Krapez and Natasha Karabey from Germany and world Latin dance champions Nikita Brovko and Olga Urumova from Russia also performed, proving a popular draw at the event.

Gu Kunxuan, a dancer from China said: “The development of Xiamen ballroom dancing is getting better and I feel the progress every time I take part in a competition like this.”

During the event, the first Euro-Asian Ballroom Dance Championship was held in Xiamen.

The competition is an important part of what Siming district calls its “sports fashion season”.

Guo Yinfang, deputy director of Siming cultural and tourism bureau said: “Siming district’s sports fashion season this year will last for 100 days, starting from October and ending in January in 2020. We hope to promote our culture, sports and tourism while hosting more than 20 events.”