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"if we don't care , who will?"



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Dancing with Cystic Fibrosis

Good afternoon CF Association Members of CFW

Good day to all as we live in this very strange world, and I hope you and your families are well.

It is an exceptionally long time since I have meet with you and that is due to my own heath over the past 4 years and then of course the pandemic that has spread the world over the last near 2 years. Outside of those obstacles funding has been difficult to secure as we needed to pull back from plans which were in place to go into other countries to do our work. Although we have been quiet, we still have been active and working on other areas within countries where we had a footprint, and we will continue to operate that way until it is safe to travel.

There are a number of smaller pharma companies looking at what we do and how we can work together for mutual benefits, and I am pleased to say that we will put CFW into countries where help is desperately needed.

I receive many things across my desk, some we cannot see the benefits to the individuals or the organisation, then there are others that are new, different and could be exciting for the individual and could create awareness across continents and that is what I would like to outline and hopefully get your attention for people within your country to get involved. This is not looking at grabbing money from various countries but lifting interested individuals who are keen in that area of the arts.

CFW has been approached by an independent dance artist based in the United States—in Kansas City. The person who has a disability and has collaborated with dancers with diverse abilities and diagnosis including CF. Her name is Suzanne Ryanstrati and one of her former students inspired this program and is a teacher with the program when her health enables her to do so.

What is proposed to happen is teachers are found in each country, and there can be more than one teacher per country. So to let people within your own country know of this opportunity, this should go in your Newsletter or information going out by email, telling your members about the idea. The teacher would have their own space and the teacher would not be paid for their work unless that was an arrangement with the CF Association of the country or a sponsor. The students take lessons in their homes, which could include the kitchen, the garden, the living room etc.



The end goal would be to.

1. Raise awareness across continents which would be possible by participation of teaches and dancers in different countries.
2. Connect people of diverse geographic regions and cultures through dance (and CF but not the focus is not on therapy) which would be made possible if people in diverse regions took the same class.
3. Provide accessible dance class that is adapted to people with CF. This includes a teacher and a person being seated(or other) adaptations of the movement , supports breaks, understands the physical and psychological impacts of CF and accepts people as they are and what they need.

The hope is that the CF Associations in each country will communicate with their members, and we start having International dancing courses taking place. The first international teacher is in Ireland, they will start at the end of November 2021. Currently classes are offered in English, however some classes use French or Spanish, as the interest increases so will the languages increase.

I am going to give you Suzanne Ryanstrati's contact details as there are many questions I cannot answer. Emile Either dancingtogetherwithcf@gmail.com or go to **<https://www.ryanstrati.com/dancing-with-cystic-fibrosis>**

I feel anything we do to help people to communicate particularly now as so many people have been separated from their school groups, their families, their work groups and their social, sporting or art groups, this could be a first and early step to bring these groups back and expand.

I really recommend that you spread this information out to your communities as you never know what their or their children's interest may be. All the follow up could be done by the interested parties and who knows what this space will look like in 12 months' time.

Please follow through and communicate with Suzanne, there may be more interest than we know, and what a wonderful thing to do! It also tells the world something further about Cystic Fibrosis in all these different countries.

To become involved, send all your questions to Suzanne, her email addresses are above.

Take care, stay safe.

Yours in health.
Terry Stewart
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