DOWN SYNDROME DAY MARCH 21

Down Syndrome, Trees and Other Variations

by Tina Baldwin

“When you go out into the woods and you look at trees, you see all these different trees. And some of them are bent, some of them are straight, some of them are evergreens, and some of them are deciduous. And you look at the tree and you allow it. You appreciate it. You see why it is the way it is. You sort of understand that it didn’t get enough light, and so it turned where there was light. And you don’t get all emotional about it. You just allow it. You appreciate the tree.

"The minute you get near humans, you lose all that. And you are constantly saying ‘*You’re too this, or I’m too that*.’ Our judgmental mind comes in. And so I practice turning people into trees, and as the American spiritualist Ram Das says, “appreciating them just the way they are.”

Whenever you see a tree with Down syndrome appreciate it just the way it is. This appreciation has a long history of official recognition. In December 2011, the U.N. General Assembly declared that March 21st would be World Down Syndrome Day to celebrate the uniqueness of the triplication of the 21st chromosome that causes Down syndrome.

People with Down syndrome are part of our families and the love we share, part of the give and take of the full range of human activity, and they make contributions to the fabric of our life. They participate in religious activities, become artists, musicians and dancers, and enjoy sports and recreational activates just like people in the general population. Some attend college, others work and volunteer. Like each of us, like each tree out there, people with Down syndrome bring with them a richness, humor, and wisdom that adds to the lives of all they touch. I told my daughter that the world will celebrate Down Syndrome Day tomorrow, March 21 but that I celebrate her every day. To which, I was told “Of course, you do. You're my mother.” My daughter is one of the wisest people I know.

People with Down syndrome are making another tremendous contribution that few know about. They are genetically connected to Alzheimer's disease, which is the main medical problem and main cause of death in adults with Down syndrome. Consequently, the disease and this connection is being studied intensely. Down syndrome is now considered a genetically determined form of Alzheimer's disease. How is it possible to make this connection? Because people with Down syndrome are born with an extra or triplication of the 21st chromosome. This chromosome carries the gene which provides the genetic instructions for making a protein called amyloid precursor protein (APP) which is central to the study of Alzheimer’s disease. According to Juan Fortea, PhD, an international leader in the study of Down syndrome and Alzheimer’s, “people with Down syndrome are the best population to study for treatment and cure of all people with Alzheimer's because it is a pure form of the disease.”

This is hardly comforting, but Dr. Fortea stresses that the treatment possibilities for people with or without Down syndrome who have Alzheimer's dementia increases with research on people with Down syndrome. So those with Down syndrome are helping all people in profound ways, and similar to the overlooked trees in the forests that are helping all the other trees.

International networks and trial-ready cohorts have been built to perform observational studies and clinical trials. But how is Alzheimer's studied and diagnosed in people with Down syndrome? It's complicated because Down syndrome is associated with intellectual disability, as is detection of Alzheimer's disease. What you really need is a neuropsychologist trained to work with people with disabilities who can adapt neuropsych tests and interpret the results to the level of intellectual disability. These neuropsych evaluations are then useful to follow the patient over the years and develop longitudinal assessment and trajectory for an individual.

Mental health discrimination is a problem for many people with Down syndrome. According to Thomas F. Coleman, legal director of Spectrum Institute and co-chair of the Mental Health Project of Spectrum Institute, "It is disability discrimination under the Americans with Disabilities Act (ADA) for guardians, conservators, or other care providers to deprive people with Down syndrome and other developmental disabilities access to a full range of mental health therapy options that are available to the general population. Care providers who willfully or negligently deprive necessary health care services such as the test for APP levels to dependent adults in their custody or care commit dependent adult abuse."

We need to make the delivery of mental health services in each state compliant with the ADA. The Department of Justice (DOJ) brought suit against the State of Mississippi for this and the DOJ won. This is a civil right's precedent and a fiscal win for the all residents of Mississippi including people with Down syndrome.

I hope you will urge your legislators to begin the work of reforming the delivery of mental health services in your state--not only for people with Down syndrome but for everyone. I also hope with all my heart that on March 21st everyone will acknowledge the value of people with Down syndrome and appreciate them just the way they are—the same way we appreciate trees and all their many variations.

Tina Baldwin

Tina Baldwin is chair of the board of trustees of Spectrum Institute and director of the organization's Mental Health Project. Yesterday she held a "zoom party" to celebrate the 50th birthday of her daughter. Tina lives with her husband in Moscow, Idaho.

World Down Syndrome Day (WDSD), March 21, is a global awareness day which has been officially observed by the United Nations since 2012.