

OPINION

The Okanagan Sunday, March 21, 2010

DOWN SYNDROME

Changing face of reality

March 21 is Down syndrome day and it was picked for a good reason. Down syndrome is caused by the presence of all or part or an extra 21st chromosome.

It was named by British physician John Langdon Down, who described it in 1866.

There are combinations of typical traits that are associated with Down syndrome.

Down syndrome was described as Trisomy chromosome 21 in 1959 by Jermome Lejeune. In the 1800s and early 1900s, many parents would never have met their child with Down syndrome as was common in those days, children born with a "difference" were taken away at birth or institutionalized.

That apparently was not outrageous in the 1800s and well into 1900s. I hate to think what happened before that with these children.

Down syndrome is not a disease, nor can one catch it from someone who possesses it. In itself, it is not considered a medical condition.

Although Down syndrome may present some typical characteristics and potential limitations, it also offers some incredible insight into a straightforward and simpler world as evidenced by many of our friends and our own daughter.

Interestingly, many common physical features of Down syndrome may also appear in people with a standard set of chromosomes. A few examples would be an unusually round face, small chin, larger tongue or almond shaped eyes.

Although there are some conflicting references, approximately one in 800-1,000 births in Canada have Down syndrome.

The incidence has not shown to increase or decrease, although some sources state that as mothers age, the likelihood increases. Therefore, with the current trend of many people becoming parents later than a few decades ago, chromosomal challenges tend to increase.

I was 29 and my husband 34 when our third child was born with Down syndrome, so draw your own conclusions.

Down syndrome occurs without prejudice



ALLISON
MCNEILL

Whose Challenge Is It Anyway?

QUICKFACTS

Upcoming events dealing with Down syndrome.

Kelowna Self Advocates monthly meeting, 11:30 a.m.-1 p.m., April 13 at Parkinson Recreation Centre. Email: info@misscommunicating.com.

Community workshop of RDSP, March 25, April 14 and May 12 at B.C. Coalition of people with Disabilities. Email: sam@bddpd.bc.ca.

Spring Fling Dance family fundraiser for Self Advocates, May 17 at Parkinson Rec Centre. \$5 person. Email: info@misscommunicating.com.

we believe it was actually destiny.

When I was pregnant in 1988, it was not standard in B.C. to prescreen pregnant moms under 30 to find the presence of any chromosomal issues.

Parents may now choose to have a screening during pregnancy, which may show the presence of Down syndrome.

There are many methods, including non-invasive methods such as a special blood testing or ultrasound. Your physician will be able to help you with the best options for you.

I can see what life is like for our 21-year-old

or no information about Down syndrome available to them when I was born. My parents always treated me as an equal within the family.

"I have one older sister and one younger brother; the only one with a disability. I was blessed by growing up in a family that had an aunt who was a speech therapist and mother who was a teacher. I learned a lot from my own experiences as well."

He now lives independently in Kelowna with his wife of several years. Both work for Kelowna organizations and are self sufficient.

There is a local support group for families who have had or adopted a child with Down syndrome, KSFC-Down Syndrome Family Connection.

Its goal is to help families understand and interpret the massive amount of Down syndrome information coming their way, to connect them to other like-minded families and individuals and to provide a host services.

They are associated with the Central Okanagan Child Development Association, which delivers an array of services to help children (primarily under five) and their families.

The DSFC society is celebrating Down syndrome day today by hoping to share information.

The society wants to help our community understand and welcome as equal contributors all people, including those with Down syndrome.

They feel it important to connect to our community so that myths are corrected.

Most people tend to have some misconceptions before becoming part of the Down syndrome world; ill informed about exactly what Down syndrome is and how it occurs.

Another reason the DSFC feels our community should understand Down syndrome is that their children are growing up in our community, attending our schools, playing in our parks, swimming in our pools and skiing on our ski hills.

The DSFC has monthly meetings welcoming parents, children and family members to

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Down syndrome occurs without prejudice in all human populations, on all continent's cultures, and analogous effects have been found in other species.

Genetic history or pure chance? Sometimes a person with Down syndrome is created like any other child, rather than being due to something in one of the parents genetic history.

Some parents choose to go on to have more children after they have a child with Down syndrome, as we did, and we were offered genetic counselling.

After genetic counselling, we were told our daughter was born with Down syndrome not due to either of us having a genetic history;

ing or ultrasound. Your physician will be able to help you with the best options for you.

I can see what life is like for our 21-year-old daughter with Down syndrome and frankly it is pretty typical.

We can see how it is for some friends who have smaller children or grandchildren and again in those cases, it is a pretty typical lifestyle.

I wondered what it was like to have been brought up before 1988, so I spoke with a friend who has Down syndrome. I wanted to get insight into what it would be like to be an adult with Down syndrome in 2010 in Kelowna.

He was born in 1975 in a small B.C. town and had some interesting insights.

"According to my parents, there was little

ing in our parks, swimming in our pools and skiing on our ski hills.

The DSFC has monthly meetings welcoming parents, children and family members to engage in play, discussion, education and community advocacy.

For more information on Down syndrome or to contact their group, email DSFC@shaw.ca.

For more on World Down Syndrome Day, check www.world.downsyndromeday.org.

The Canadian Down Syndrome Society can be found at www.cdss.ca.

Allison McNeill is stepmom to two, a mom to four, one with a developmental disability, and Kelowna's Women of the Year. She has a communications company and can be reached at info@misscommunicating.com.

LETTERS

Planning lessons from south of the border

I just came back from an 8,000 kilometre tour of western United States and saw well planned, beautiful cities that Kelowna can learn from.

In Carmel by the Sea, Santa Barbara and Carlsbad, Calif., everything is done to enhance heritage and ensure open views and space along the ocean for maximum public enjoyment.

Development is kept well back from the beaches. To encourage people to visit downtown, parking is free. Although, Santa Barbara and Carlsbad have populations similar in size to Kelowna, as I strolled their downtown streets I felt I was in a small town.

The atmosphere was peaceful and relaxing. The abundant beautiful flowers and trees along the streets with views of the ocean waves were awe inspiring.

Surprisingly, Carmel, Carlsbad and Santa

Barbara, don't have tall buildings on the waterfront or downtown.

I asked a woman in charge of Carlsbad's tourist information why there was an absence of tall buildings.

She replied, "The citizens strongly don't want highrises because they destroy the quality, beauty and uniqueness of a city."

I felt good having seen beautiful cities where citizens protect their priceless natural assets and heritage.

However, my enthusiasm disappeared upon arriving home to backward planned Kelowna and reading the misleading article written by former mayors Walt Gray and Jim Stuart.

Their combined 19 years of being mayors have left a trail of highrise destruction along the public's precious sandy waterfront land now intrusively privatized for The Grand hotel and highrises, which community-mind-

ed pioneer Stanley Simpson would never tolerate.

In all my travels, I have never seen such fanaticism and fetish for highrises as in Kelowna. Here, in highrise haven, the blind belief is that highrises will solve all city problems by placing them near the lake on unstable sand.

Yet, people don't come downtown to see highrises. They come to see the waterfront treasures of nature, heritage and seek the feeling of a small town. This is what gives a city character, class and vibrancy.

Before making a bad, irreparable mistake with the proposed CD-21 plan, Mayor Sharon Shepherd and council should go to Carmel, Carlsbad, and Santa Barbara to learn how these superior, beautiful cities are planned.

**Robert Cichocinski
Kelowna**

City spends too much money on soothsayers

I was a proud Canadian, excited and teary, as every Canadian from coast to coast ought to have been, watching Alexandre Bilodeau receiving his Olympic gold medal, the first on home soil.

I understand why for many Kelowna people, the Battle of the Plains of Abraham lives on.

Here is a French Canadian winning for Canada and I am tempted to respond to Mischa Popoff's column about the metric versus the Imperial system of measurement, and to Pat Bulmer's editorial about French Canadians.

As if that was not enough within a week, now we have the Chamber of Commerce orchestra in full swing, giving free concert to whoever wants to listen to "Me, Me."

Former mayors Walter Gray and Jim Stuart are now at the foot of the Forum in Rome, belting: "Friends, Kelownians, citizens, lend us your ears. We are not here to bury Kelowna,

but we are here to praise it."

As if that was not enough, Barry LaPointe is flying high on the CD zone proposal. It is all poetry in motion. I am now wondering if Andre Blanche didn't write the music.

I am as mad as hell and I can't take it anymore with the chamber's camel dung. Here is a group of self-servers who screwed up traffic on Highway 97 by locating the bridge in the same location when Walter Grey was mayor.

Now, they are about to head to the cemetery, but they would first stop at the mortuary, and get a chorus to screw up downtown Kelowna further. Frankly, I am not sure who runs the city. I know what the chamber's song says.

Now, let us put things in perspective. Does downtown bring more people and business that Wal-Mart, Costco, Superstore and others do far away from downtown?

I do not think so. What do we have down-

town? We have lawyers and financial institutions — enough to make anyone hit the road — a handful of stores, and restaurants.

Bernard Avenue is not Wall Street. Would anyone of sound mind deliberately screw the shoreline of Kelowna and counting council to hammer the last nail?

If the answer is in the affirmative, we need a pastor to do the blessing or to give the last rites to our great city.

Perhaps we need a consultant to tell the city whether we are at a crossroads. The city is, after all, willing to fork out \$45,000 to hire a consultant to investigate if Kelowna would have enough sand and gravel for the next 100 years.

Council and bureaucrats cannot tell us what is going to happen in the next 100 days, so why want to spend tax money on soothsayers.

**Mo Rajab
Kelowna**