

OUR VOICE



QUARTERLY NEWSLETTER

JANUARY-MARCH, 2015



DOWN SYNDROME FAMILY NETWORK: Who are we?

The down syndrome family network is the first-ever non-profit advocacy group in the Caribbean focused solely on persons with Down syndrome. The group was founded in March 2011 by Fitzherbert Glen Niles along with members Margaret Timothy-Burgess, Gailann Le Bourne-Bain, Rhonda Sieunarine and Joanna Owen (all parents of children with Down syndrome). Our primary mission is to support families through advocacy, education and research in order for persons with Down syndrome to live as independently as possible and become included, valued, members of society.

Within the first four years of its existence, DSNF has grown from zero to more than 200 registered families and has become one of the most respected NGOs in Trinidad & Tobago. The Network has a registered office, an engaging Facebook page and a resource website, we are affiliated with all the major international advocacy groups, manage programmes and PR campaigns, are hosts to quarterly Family workshops, self-advocate training, annual conferences and the first ever annual Buddy Walk in the Caribbean.

DSFN'S MAIN EVENT

World Down Syndrome Day Conference 2015

March 21st, 2015 marked the 4th anniversary of United Nations sanctioned World Down Syndrome Day, this event has been celebrated by the international community since 2006. The theme for this year's event was "My Opportunities, My Choices"—Enjoying Full and Equal Rights and the Role of Families".

This fourth year coincided with the anniversary of the launch of the DSFN. The conference was held at the Hyatt Regency on March 20th in Trinidad and at the Magdalena Grand Beach Resort in Tobago on March 19th. Over the years, we have introduced some of the most dynamic professionals and Self-advocates to our audiences. The conference was open to persons of all abilities, their families, caregivers, educators and other professionals and all interested persons.

In attendance was His Excellency, President Anthony Carmona; from Canada, our Key Note Speaker and Self Advocate, Janet Charchuk along with her parents, Jackie and George Charchuk; from the United States, Guest Speakers, Tonia Ferguson, Director with the NDSC and Rob Snow, Founder of Stand Up for Downs.

Lots of Socks Campaign

DSFN invited everyone across the country to wear Lots Of Socks on March 21st to raise awareness on World Down Syndrome Day (WDSD). But Not Just Any Pair Socks...wear brightly coloured socks, long socks, printed socks, mismatched socks. Schools, corporations and individuals proudly wore their socks, however they chose to wear it so that persons would ask and be told about World Down Syndrome Day.



BUDDY WALK

Hundreds gathered for Down Syndrome Awareness

More than seven hundred persons gathered at Nelson Mandela Park on October 19th, 2014, in support of loved ones with Down syndrome. The masses gathered for the third annual Buddy Walk®—Themed "Your Voice... My Voice... One Voice." The awareness walk is one of over 250 Buddy Walks across the globe and is the only one in the Caribbean. The event included a one-mile walk around Nelson Mandela Park into the Queen's Park Oval for family activities, kids' play zone and the benefit concert. Top local Entertainers participated in the success of the show.



"It was awesome to see so many people come out to the Buddy Walk,"

Families of those with Down syndrome said they were extremely grateful for the event and for the organizers and sponsors who made it happen. "It was awesome to see so many people come out to the Buddy Walk," said Joymin Koon Koon. "It made me feel appreciated as a parent of a child with Down syndrome and happy to know that so many people are working with us to bring awareness of Down syndrome. The event was really inspiring." Mission accomplished! At the Buddy Walk, everyone walked together, participated in activities together and we all celebrated together. We experienced true integration... true inclusion!

DID YOU KNOW?

Myth: Most children with Down syndrome are born to older parents.

Truth: Most children with Down syndrome are born to women younger than 35 years old simply because younger women have more children. However, the incidence of births of children with Down syndrome increases with the age of the mother.

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DSFN: WHO ARE WE?

Board Of Directors



Fitzherbert Glen Niles

Glen is the Chairman and Founder of the DSFN and the parent of a son with Down syndrome. In 2014, Down Syndrome International of the United Kingdom presented him with the World Down Syndrome Day award in the voluntary and professional category, for his outstanding contribution of strengthening and enriching the lives of people with Down syndrome. He was also nominated and voted in as one of the representatives for persons with disabilities on the Civil Society Board. Glen is a Business and Security Analyst, and Fitness Consultant with close to thirty years of professional experience. He also sits on the Board of the YMCA and is the immediate past President.



Laura Cotton

With more than 15 years of experience with public relations and image development training Laura has been hands-on communicating nearly every type of challenge an organization could undergo. Today Laura serves as PR & Image Development Maven and full-time mentor at Pearl Strategies Ltd, in Trinidad & Tobago, her adopted home since 2006. Laura is also a full-time wife and parent, while she may be the boss at work, she has two bosses at home: three-year-old Adelaide and one-year-old Oliver. They demand cuddles and cupcakes, both of which she's happy to generously provide. Laura continues to serve as DSFN's main Senior Self-advocate Facilitator at our workshops—coaching, training and mentoring teens and young adults with Down syndrome.



Charlene Cudjoe

Charlene is a Marketing professional with extensive experience and management skills. She currently works in the Career Development Unit of the University of Trinidad and Tobago (UTT), assisting with marketing the university's programme offerings, as well as assisting students with resume writing, business etiquette and preparing them for the world of work via mock interviews. From time to time, Charlene serves as Coordinator for the DSFN's Family Workshops. Her desire is to see all persons with disabilities be included and treated with the care and respect they rightly deserve. Charlene also functions as volunteer and mentor at the "Be good Do good" foundation which helps children in orphanages across the country. Charlene is a graduate of Chartered Institute of Marketing in the UK.



Natalie Morales

Natalie currently works as a Communications Specialist at an international Company in the Energy sector, and serves as Communications Agent for the Network. She possesses extensive experience comprising over fourteen (14) years as a Radio Presenter. Her expertise in the area of communication extends to the banking sector, where she worked at the Training & Organizational Development Centre. While there, she performed a critical role in the research and development of the Bank's internal Newsletter. Also, several articles have been published in the form of prominent Human interests' features and other articles in a popular Caribbean lifestyle awareness magazine. As a reading tutor, Natalie thoroughly enjoys coaching her students in the effective use of reading strategies; working with children is her passion!



Joanna Owen

Joanna, is an Educator at the primary school level and a graduate of the University of the West Indies (UWI) with a BSc in Agriculture and from the University of Trinidad and Tobago (UTT) with a BSc in Special Needs Education. The birth of her daughter with Down syndrome 15 years ago fuelled her interest and enthusiasm to work closely with children of varying disabilities; to help them develop a sense of dignity, independence and equality. She also combined her former years of experience as a Manager in the Agricultural Industry, with her teaching knowledge and advocacy to efficiently execute her services as the Junior Self-advocate Workshop coordinator for the DSFN's Family Workshops. Her goal in the near future is to be instrumental in bringing at least three of the schools in Trinidad and Tobago to the level of fully inclusive educational facilities.

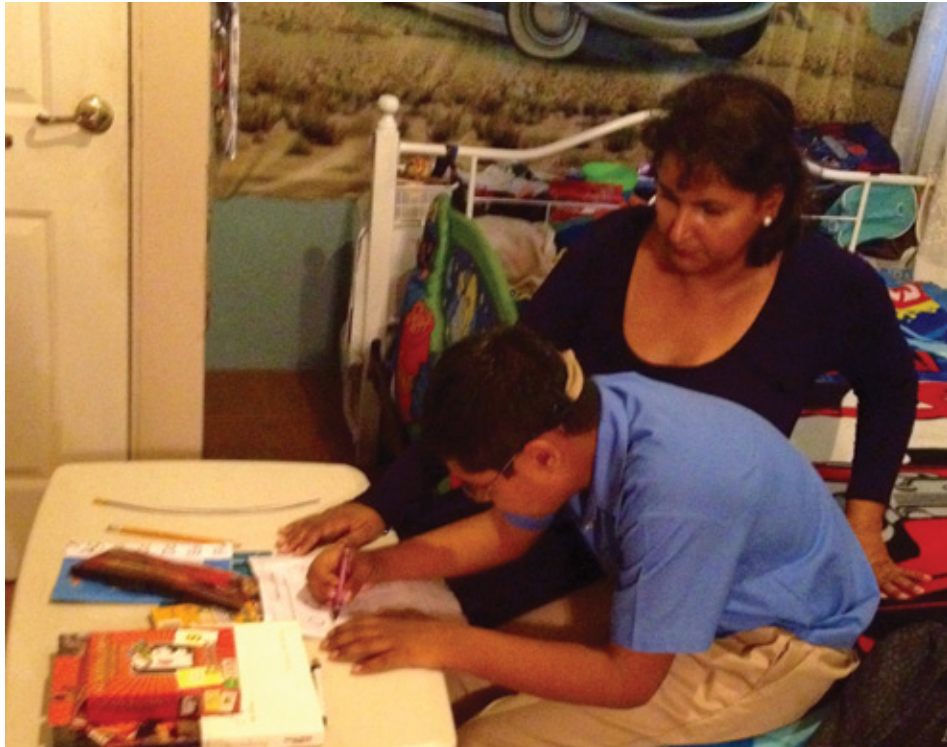


Cheryl Teixeira-Joseph

Cheryl's dedication to advocacy comes from her determination to keep the memory of her daughter, Chloe Isabella Joseph alive. Chloe was born with Down syndrome and died two days after her first birthday. Today, Cheryl effectively fills the position of Corporate secretary at the DSFN. Some of her responsibilities include recording minutes, posting information to the Network's social media pages and website, as well as counseling new parents... Oh, and that's her part-time job. Cheryl works as Programme Assistant to one of the Diplomatic Missions with over twenty years of professional experience in Administrative functions.

A PARENT'S PERSPECTIVE

Sara Ali Mohammed



“Know this child will be able, Know this child will be gifted... People see me; I’m a challenge to your balance...” Natalie Merchant’s 1996 single, entitled “Wonder”, still echoes in my soul as it did some twelve years ago when Naa’il was in my womb.

During my pregnancy, I became even more curious than I had ever been. I became fascinated with the intricacies of various conditions and disabilities. However, the one that stood out the most in my mind was Down syndrome. I can recall the evening I asked my husband as he walked into the kitchen, “Abu, what if we were to have a child with Down syndrome?”

On the night of February 17, 2002, was the beginning of another phase of the ride. My little ‘bundle of joy’ wanted to make his entry into the world and what a statement he made in expressing his need to me. I could still recall the

pains of labour and of love.

I was later awakened by the deepest smile I had ever seen. My husband greeted me, “It’s a boy!” Holding Baby Naa’il close to my chest for the very first time was an indescribable feeling. However, I couldn’t help but notice the many private conversations my husband held with the Doctor. On day three, my husband approached me with the same question I had challenged him with mere months before. He could not have been any clearer. Abu tried to explain that the Doctors had suspected that Naa’il had been born with Down syndrome. I could not console myself.

Sharing the news with family, relatives and friends was difficult. Some were in disbelief, while others pitied us. Though my love for my new born child grew, my fears of the unknown also intensified. As time passed, a side of me was revealed; one that I never knew existed.

I found myself struggling to be accepted by everyone. As I reflect, it wasn’t those around me. It was me!

Suddenly the days got better and the many milestones seemed attainable. Before I knew it, I had a young man with countless questions on my hand. My son talked...a lot! He crawled, he walked, ran, swam in the Special Olympics at the age of nine all in his own time. Naa’il talks of his dreams of driving me to the supermarket, taking me to a fancy restaurant and taking care of the family. I shall not let limitations get in his way.

Today, I am proud to be part of the Down Syndrome Family Network in Trinidad and Tobago. I belong to a body that believes in the abilities of my child and others with disabilities. Through the Network I have seen the accomplishments of persons like Dr. Karen Gaffney, David Egan and our own self-advocates Christy De Souza and young Pannist, Daniel Gulston.

My fears aren’t all gone but each day they fade away as I continue to believe.



JOIN THE CONVERSATION

#education21

Over the weeks leading up to World Down Syndrome Day on March 21st, 2015, Down Syndrome Education International, an international charity dedicated to raising levels of educational achievement among children with Down syndrome, would be highlighting 21 examples of how educational research helps and why it matters.

Follow #education21 online, and become part of a conversation on how educational research is vital for future advances for persons with Down syndrome and other disabilities. This is the first of 21 examples of how educational research improves the lives of children with Down syndrome today:

1. Signing improves early vocabulary learning and communication
2. Verbal short term memory presents specific difficulties
3. Reading can be a strength and support learning and language
4. Learning to talk is a particular challenge
5. Not global delay, but a profile of strengths and weaknesses
6. Inclusive education can provide better language and academic outcomes
7. Social strengths offer advantages, but not always
8. Developing clear speech is a particular challenge
9. Learning about numbers is difficult
10. Autism in Down syndrome is not typical Autism
11. Children with Down syndrome can be as motivated as other children. Motivation is important for learning

To be continued in next issue. Information available at:
<http://www.dseinternational.org/en-gb/education21>

OUR MISSION

To support relatives and care-givers of individuals with Down syndrome through advocacy, education and research in order for these individuals to live as independently as possible and become valued members of their community and society.

OUR VISION

To be the national advocate for the value, acceptance and inclusion of people with Down syndrome in order for them to have equal rights and opportunities.

INCLUSION WORKS!

Inspiration & Information to Counter Arguments against Inclusive Education for Students with Down Syndrome

By Cheryl M. Jorgensen, Ph.D., Institute on Disability, University of New Hampshire/UCED

In the late 1980s, Tory Madison's son Charlie was in third grade when she enrolled him in a yearlong leadership institute for parents of children with significant disabilities in New Hampshire. Tory asked Charlie's educational team to capitalize on natural opportunities to teach functional skills.

During high school, Charlie had summer jobs alongside a typical classmate. Between the ages of 18 and 21, the school district provided staff and support for Charlie to learn independent living skills in his own home and city, and to explore a variety of jobs through internships and volunteer activities.

Today, Charlie lives in his own apartment with his brother and another roommate, just celebrated 10 years of working at Sam's Club and has a full life in the community.

Despite the lessons that have been learned over the past 20 years from successfully including students like Charlie, parents and professionals still face roadblocks based on outdated arguments about inclusion for students with Down syndrome. Here are three common arguments against inclusion and rationale for why they are weak or unfounded.

Argument #1: Some students are just "too disabled."

Some argue that students with DS and other developmental disabilities are "too

disabled" to learn in a general education classroom. IQ and other tests given to people with significant disabilities are significantly flawed in their ability to identify people's gifts and talents and the supports they need in order to be successful; so how do we decide if a student is capable enough to benefit from inclusion and instruction in general education academics?

In 1984, University of Wisconsin researcher Anne Donnellan, described a principle called "the least dangerous assumption." She said: "The criterion of least dangerous assumption holds, that in the absence of conclusive data, educational decisions ought to be based on assumptions which, if incorrect, will have the least dangerous effect on the likelihood that students will be able to function independently as adults." Furthermore, "we should assume that poor performance is due to instructional inadequacy rather than to student deficits." Pretty powerful words!

Argument #2: Functional skills are more important than academics to students' futures.

Parents of children with DS are sometimes told it is more important to learn functional skills than academics. To weigh the merits of this argument, consider the functional skills students with developmental disabilities are

usually taught.

- * Telling time and using money
- * Brushing teeth and other personal hygiene
- * Recognizing safety signs
- * Cooking
- * Making beds
- * Crossing streets
- * Job skills like stocking shelves or assembling widgets

Each of us does most of them every day, so they do seem like important things to learn. But we do them to participate in the important things that make up our real lives—having satisfying relationships, earning a living, enjoying our leisure time and giving back to our communities.

Functional skills do not, in and of themselves, make our lives interesting and productive, yet they form the core of many self-contained educational programs. Functional skills are important, but acquiring knowledge and passion for lifelong learning makes our lives interesting! A student with DS may not learn the whole Periodic Table of the Elements but enjoying experimentation and discovery may mean a future job in a chemistry lab.

A love of Shakespeare might inspire an actor or writer. There are literally hundreds of opportunities to learn functional skills that make life interesting

and rewarding now and in the future: texting a friend, creating a Facebook page, knowing how to throw a great party, being part of a sports team and taking pride in victory while being gracious in defeat.

Argument #3: There is no harm in not including students.

In the 2004 reauthorization of the Individuals with Disabilities Education Act, Congress found: "Almost 30 years of research and experience has demonstrated that the education of children with disabilities can be made more effective by having high expectations for such children and ensuring their access to the general education curriculum in the regular classroom, to the maximum extent possible, in order to...be prepared to lead productive and independent adult lives..."

Several large long term studies have also found—even when controlling for factors such as students' socio-economic status, age, gender, and severity of disability—that there is a positive relationship between the amount of time students with disabilities spend in general education classrooms and a variety of positive outcomes, including (a) higher scores on standardized measures of reading and mathematics; (b) fewer absences from school; (c) fewer disciplinary referrals; and (d) improved post-school outcomes such as enrollment in post-secondary education, independent living, and gainful employment (Blackorby, Chorost, Garza, & Guzman, 2003; McGregor & Vogelsberg, 1998; Wagner & Blackorby, 2004).

Leading researchers have postulated that the general education classroom is the optimal place where access to the general education curriculum occurs (Wehmeyer & Agran, 2006). Furthermore, no research studies conducted since the late 1970s have shown an academic advantage for students with intellectual and developmental disabilities educated in separate settings

(Falvey, 2004).

Bolstering these positive outcomes of inclusive education are studies that show segregated education has negative consequences including: poorer quality instruction in academic skills (Wheelock, 1992); poorer quality IEPs (Hunt & Farron-Davis, 1992); lack of generalization of learning to regular environments (Stokes & Baer, 1977); disruption of sustained opportunities for social relationships (Strully & Strully, 2003); a decrease in confidence by general education class teachers for teaching diverse learners (Giangreco et al., 1993); and disruption of Maslow's theory that all human beings need to belong before they can achieve (Kunc, 1992).

Conclusion

Arguments against inclusive education are often rooted in firmly held attitudes and information that is prejudicial and inaccurate. Parents and professionals who find themselves in the position of having to justify inclusive education might engage in the following activities to educate themselves and develop supportive allies:

- * Know and be able to express your own deeply held values
- * Emphasize that children with DS are more alike than different
- * Understand the law and be able to cite research
- * Visit inclusive schools and help connect professionals from your school with them
- * Engage outside experts for professional development and consultation
- * Start an inclusive education task force in your school that includes other like-minded parents and professionals, as well as people who are not supportive of inclusion
- * Involve adults with disabilities in all your efforts so that they can share the wisdom of their experiences

Remember, the least dangerous assumption is to presume competence, and we must make decisions now that give students the best chance in the future for a typical life in the community.

To be continued in next issue.

Full article available at:

www.ndsccenter.org/resources/general-information/ds-newsarticles/inclusion-works-part-1

Q&A

Q: What’s the difference between “inclusion” and “mainstreaming”?

A: Inclusion is defined as “teaching students with disabilities in regular classrooms, rather than in special classes or pull-out session.”

Mainstreaming is placing students with disabilities only a few regular classes throughout the day, such as art or physical education, not the academic subject classes.

SAY WHAT?

“Being the parents of kids with special needs, you become advocates. For kids like Beau to be in roles like these is a great way for the world to see a 9-year-old boy on the big screen with Down syndrome that can (be physically active) and rattle off these lines. Kids just like him are capable of doing this.” Amy Wright, mother of Beau Wright, star of Sundance Film Festival movie “Little Accidents”.

WE’VE MOVED!

The Down Syndrome Family Network has a new address: 35 Methuen Street, Woodbrook, Port of Spain (868) 627-8509 dsfamilynetwork@gmail.com (Primary contact)

CHAIRMAN’S MESSAGE:



It gives me great joy to officially extend greetings, thank yous and good wishes to all our readers. Though we are well into 2015, it is my intention to take you back to some of those promises you made; personal or otherwise at the close of 2014. You know as well as I do that for many, once we get further into the new year, resolutions begin to fade. I implore you, please do not let your dreams and aspirations die!

As I look back at 2014, I must recall some of the significant milestones that we have achieved together; none of this would be possible without your presence and dedicated support. We hosted our 3rd annual World Down syndrome Day Conference and Workshop which featured international Self-advocate and Special Olympian athlete, David Egan.

The conference was held under the patronage of His Excellency President Anthony Thomas Aquinas Carmona. In Tobago, we partnered with Tobago House of Assembly and the Peters Foundation. The Network spearheaded the “Lots of Socks” campaign, to raise awareness of Down syndrome; popular radio stations, kindergartens, secondary schools and corporate offices participated.

In July, four families attended and represented DSFN at the National Down Syndrome Congress Convention

in Indianapolis, Indiana. It is my desire to see many more families attend and become inspired. In August, Blink Bmobile took the ice bucket challenge to another level; it was not just for ALS awareness but for DSFN. In October, we hosted our 3rd international “Buddy Walk”, while throughout the year we experienced four successful Family Workshops. Today, we continue to build a registry that exceeds 200 families. If you have a child, a relative, a friend with Down syndrome, or you would like to volunteer or assist our advocacy efforts; contact us. Help us to help others, we do need your help.

I urge you, self-advocates, families, caregivers, volunteers to never give up... never lose hope... never believe that you cannot make a difference. Now is a time of sowing; a time to pool our resources together with one common voice. I admit, many of us may never see or benefit from the fruit of our labor in our time, however, we must believe that if we forge ahead together, we would leave a legacy of a better life for others with Down syndrome or other disabilities.

I would like to thank God for our hard working Board of Directors, our sponsors, partners and volunteers for sharing our vision. I thank them for their continued commitment and stewardship during the past year and into this one.

Fitzherbert Glen Niles
Chairman and Founder
Down Syndrome Family Network

SPONSOR SPOTLIGHT

Heartfelt thanks to the following organizations for their support of the Down Syndrome Family Network, our World Down Syndrome Day Conference 2015 and Buddy Walk® 2014:

Ministry of Sport, Ministry of Health, Ministry of the People and Social Development, Ministry of Education, Ministry of Gender, Youth and Child Development, National Gas Company, Tobago House of Assembly, Petrotrin, REPSOL, BPtt, Lake Asphalt Limited, NLCB, Caribbean Airlines, First Citizen’s Bank, Guardian Media, Hyatt Regency, CNMG, CL Communications, Blink/bmobile Foundation, Dasaco Enterprises, Trinidad and Tobago Printing Works, Balroops, Media 21, Rent a Amp, KFC, Zoom Caribbean, SMJaleel, Ross Advertising, Island people, Xanadu, Blue Waters, Aeropost, Syrian Lebanese Women’s Association, Edoos Ltd and Xceptional Events Ltd.

Thank You!

“Wonder” Lyrics

By Natalie Merchant

Know this child will be able
Know this child will be gifted
With love, with patience & with faith
She’ll make her way
People see me
I’m a challenge to your balance
I’m over your heads
How I confound you & astound you
To know I must be one of the wonders
Of God’s own creation
And as far as you see you can offer me
No explanation
O, I believe



**DOWN
SYNDROME
FAMILY
NETWORK**