DOWN SYNDROME FAMILY NETWORK BI-MONTHLY NEWSLETTER

OUR VOICE

“We speak out so our children can be heard.”

Issue 1, September/October 2014

Upcoming Events

October	**International Down Syndrome Awareness Month**
October 19th	**Buddy Walk** Nelson Mandela Park, Port of Spain
November 15th	**Advanced Self Advocate Training** Location TBD
December 6th	**Family Workshop & holiday party** UTT Valsayn

DSFN: Who are we?

DSFN is the first-ever advocacy group in the Caribbean focused solely on those with Down syndrome. Founded in March 2011 by Glen Niles, Margaret Timothy-Burgess, Gailann Le Bourne Bain, Rhonda Sieunarine and Joanna Owen (all parents of children with Down syndrome), the non-profit group’s main mission is to support families through advocacy, education and research in order for these individuals to live as independently as possible and become included, valued members of society.

Within the first two years of existence, DSFN has grown from zero to more than 200 registered families and has become one of the most respected NGOs in Trinidad & Tobago. Even without government subvention (for which it is currently applying), DSFN set up an office, built a resource website and manages four big programmes: quarterly family workshops, self advocate training, annual conference and annual Buddy Walk.

DID YOU KNOW?

Down syndrome is a genetic condition. There are *three* types of Down syndrome:trisomy 21 (nondisjunction) accounts for 95% of cases, translocation accounts for about 4% and mosaicism accounts for about 1%.

On Your Mark … Get Ready … For Buddy Walk® 2014

Third Annual Buddy Walk Trinidad & Tobago Set for October 19th

October is international Down Syndrome Awareness Month and to celebrate DSFN will stage our third annual Trinidad & Tobago edition of the internationally popular Buddy Walk® -- the only one of its kind in the Caribbean.

Themed "Your Voice … My Voice … One Voice", this year's Buddy Walk will be on October 19 at Nelson Mandela Park in St. Clair, Port of Spain. The event includes a one-mile walk to the Queen's Park Oval where a festival of family activities, food, live entertainment, and a benefit concert will thrill the crowd.

More than 1100 people have participated in the last two years, walking in an impressive mass through St. Clair in vibrant colours and family spirit. We expect the largest turnout, yet, for 2014 so get your family posse together, mark your calendars, and get ready for some amazing fun.

Registration will begin on September 20th and forms are available from DSFN's website and from Kenny Sports Centres at Carlton Centre San Fernando, Trincity Mall, Westmall, and Long Circular Mall. Registration fees also can be paid and all walk kits (including t-shirts) from Kenny Sports Centres.

Registration fees are $40 per person for DSFN registered families, $60 per person for general public and FREE for those with disabilities.

DSFN: Who are we? (continued from page 1)

BOARD OF DIRECTORS

Glen Niles
Laura Cotton
Charlene Cudjoe
Joymin Koon Koon
Natalie Morales
Natalia Neehall
Joanna Owen
Jerwiene Vesprey

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.

Parent Perspective

Wonder

By Sara Ali-Mohamed

> "When I was pregnant, I was being prepared and guided by the Good Lord and I did not even know it."

I used to come home after work and prepare dinner to music. I always gravitated to the song "Wonder" by Natalie Merchant. I used to play it over and over. Although it was quite a popular song at the time it resonating with me… something was whispering that I was carrying a "Wonder". One day, as my husband came into the kitchen, I asked him (quite out of the blue…) what would happen if we had a child with Down syndrome. It literally came *out of nowhere* (God is smiling at my faux pas) as I was reading about other abnormalities, like cerebral palsy, spina bifida, fused limbs, etc.

My husband said that would be God's work and we would just accept it! So, I carried on never thinking back. I was about seven months pregnant when I visited Toco. I was sitting on the beach and admiring the view when a little boy (about 6 or 7 years) left his family and came up to me and just touched my belly. He was non-verbal, just smiled at me and later I found out that he was an boy with Autism whose family were my beachhouse neighbours. I think that he instinctively knew that my son was going to be somewhat like him and they shared a bond. The other sign I received was when I was about 11 or 12 years old. I dreamt that I was on a four-poster bed in the middle of a green lawn located on a hill. A young man was lying next to me on the bed. I cannot describe the peace that I felt being in his presence. I knew that the young man had Down syndrome in my dream and it did not faze me. The peace was amazing!

I was admitted to St. Clair Medical on Sunday night (February 17th, 2002). That was strange as I had dreamt that my baby was going to be born on the 18th or 19th (which I had recorded in my diary) although his due date was Feb 25. The pain was so great that when the Obstetrician said that the baby's heart beat was too erratic and they recommended that a C-Section was necessary, I gave my consent.

I awoke after being wheeled from an elevator to my room. My husband was in the corridor with a huge smile and said, "It's a boy!" He pointed to the only incubator in the nursery and there was my son's name on the incubator, Naa'il. He was fast asleep and looking very peaceful. The peace was again felt (like in my dream) when he was first placed on my chest and I got to feel the sheer size of my love for him. For three days, I noticed that my husband was having many private talks with the doctor and on the third day, he said, "Sara, remember I told you that if our baby was not normal that that will be okay." I said yes. I thought immediately that he may have heart problems. Then Abu said that they suspected that he had Down syndrome. Initially, I was relieved, as my worst fears were not realized. Then for about 2 minutes I cried as I immediately started to worry about what kind of life he would lead. I never doubted my love for him but I worried 'for' him.

Then my slithers of illumination started to come together. For

… ‘Wonder’ continued

many days in the hospital I was visited by a boy who just smiled at me and said nothing. My husband told me while I was being discharged that the boy also had Down syndrome. A mother with long beautiful hair came to my room one day and said that she has a daughter who had Down syndrome and that she is very loving and kind and that her daughter does everything, but in her own time.

Telling my family, and then friends, was surreal as their initial reaction was disbelief as he did not show many typical signs of Down syndrome. I still felt all the love for him but it was tinged with fear of the unknown. I saw how many individuals feigned acceptance of him, yet there were others who shared my questions and ultimately shared my love for him.

I also saw a side of me that I did not like … that was the side of me that wanted to be accepted by all despite my child being diagnosed with Down syndrome. Further to that, I wanted my child to be accepted by all. I had a tough time at work as I felt that there was no one to share my story with or to understand my daily trials, so I resigned. Now, in hindsight, I thought that he would never be fully accepted by all. But by the grace of God he is now more accepted than ever with the raised awareness that is occurring in our times. Thanks to acceptance for kids with disabilities, parents now have the courage to say no to institutionalizing, no to aborting kids with disabilities, and saying NO far more often to what kids with disabilities are told they cannot accomplish.

How many parents see the simplest of milestones achieved and revel in the glory! It may not be in the time that a typical child achieves them but they “open their gifts … some kids just open them a little later…”

It does not minimize the joy that every parent, sibling, caregiver or teacher feels. But, there are many doubts that plague every parent of a kid or kids with disabilities. Who is going to help with the high medical bills to keep him/her healthy? Who is going to provide for the many special activities that they may need? Who is going to step up to the plate to lobby for their health insurance coverage? Who is going to look after my child when I die? How is my child’s inheritance going to be used? Who will ensure that my child can live up to his utmost potential? How is my child going to age? Who will ensure that we get the best education for not only my child but to the future kids with disabilities? Who will look after “Me”?

As soon as my son started to talk (and much talking he does) at about age 6, he asked me at breakfast if he would ever drive. I smiled and told him that of course he will drive one day. I explained that he had to wait until he was old enough to get a license. And that was that. To this day he says, “When I get big, I will drive you to the grocery, the restaurant etc.” And I believe that.

My son talked, crept, walked, ran, swam in the Special Olympics from age 9 … all in his own time.

I chose Naa’il as his name because it meant “One who acquires or earns”. This name was chosen long before his birth. After his birth, my husband chose the middle name, Asaaf which means “What is pure and genuine”. Now I appreciate the significance of what those names mean to him as he acquires what is pure and genuine.

I urge all parents of children with disabilities to just have patience and trust in the Lord! He will guide you! I still have my fears but I have learnt that worrying accomplishes nothing productive but we must have faith to believe that God is in control!

If we lose our dear ones, God is with them and we must console ourselves that we will be re-united again one day in a much better place where there are no stereotypes of what is ‘normal’.

Kids with Down syndrome are often called God’s angels because we sometimes see God in their eyes. Let us acknowledge that they are angels, and maybe one day that will be our new reality.

‘

“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

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 disabled students in 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"

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 in a yearlong leadership institute for parents of children with significant disabilities in New Hampshire. The institute's goal was to support parents to re-capture their dreams for their children, learn about best educational practices, and develop advocacy and community organizing skills. Tory soon decided to do everything she could to assure Charlie was a fully participating member of a general education class in his home school, learning academics alongside his classmates without disabilities. During high school, Charlie had summer jobs alongside a typical classmate. He marched at graduation with his class. 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 thousands of other students like Charlie, parents and professionals still face roadblocks based on outdated arguments about inclusion for students with Down syndrome. Here are three 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!

Let's apply this principle to Charlie, whose mom insisted he be included with his typical peers in every classroom lesson and activity. With the presumption that Charlie could and would learn, his educational team developed instructional, communication, sensory and behavioral supports. Now imagine if a new brain scan was developed that could determine conclusively that, in fact, Charlie didn't learn very much academics? Was harm done? Charlie was taught both academic and functional skills and seems to have a pretty good life as a happy, healthy, employed adult. Therefore, we might judge that no harm was done.

If Charlie's mom had believed he couldn't learn academics, shouldn't be included, and should only be taught functional skills, he might have been placed in a self-contained class with other students with significant disabilities. The goal of his education might have been to live in a group home and work in a sheltered workshop with few opportunities to develop relationships with his typical classmates. Now, what if the new brain scan showed Charlie was smarter than anyone expected, could have learned academics and moved on to life and work in the community?

SPONSOR SPOTLIGHT

A big up to the following organizations for their support of the Buddy Walk:

Blink/bmobile Foundation
KFC
Ministry of People & Social Development
Blue Waters
Sport Company of Trinidad & Tobago
103FM
CNMG
Zoom Caribbean
SMJaleel
Ross Advertising
Xceptional Events Ltd

THANK YOU!

Inclusion Works! (Continued from page 5)

Most people say that not presuming Charlie as competent did cause him harm. They say:

- We lost an opportunity to teach Charlie things he could have learned.
- We didn't include him as much as we could have and he did not develop a wide network of typical social relationships.
- He missed out on the typical high school experience.
- We might have negatively influenced his self-esteem by treating him as if he were not smart.
- We narrowed the possibilities for his future career or postsecondary education.
- We wasted a lot of money pursuing the wrong educational program.

Attitudes about students' competence are at the heart of many arguments against inclusive education. To presume incompetence could result in harm to our students if we are wrong and is not the least dangerous assumption.

Argument #2: Functional skills are more important that 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

To be continued in next issue. Full article available at www.ndsccenter.org/resources/general-information/ds-news-articles/inclusion-works-part-1