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A Word from DSRF’s Executive Director

The expression “time flies” has never been truer for our organization. This summer, often a season to unwind and catch up, seemed for us to be more hectic than ever. Between a very busy Summer School and various other projects, we were extremely busy. Some of the projects included: preparing for the Conference in Victoria “Embracing Success: Educating Students with Down Syndrome” which is in collaboration with the Greater Victoria Down Syndrome Society; developing the New Parent Series which will provide monthly information and networking for families with children up to age five; beginning preparations for new videos on communication; working with the Halton Down Syndrome Association (Ontario) to implement our One to One Reading program in their community; trying to find suitable space for programs in Surrey and North Vancouver; and much more.

In the daily hustle and bustle we can often focus on the negative, the problems and the little emergencies that need solving. For an organization like DSRF, there is so much we want to do, so many needs we would like to provide solutions for – so many things we can’t do yet because of the lack of resources and funding. This week I was reminded, by two separate families on two separate days, why I am proud to work at DSRF… our students and our families. To know that we have made a difference, and that the caring, supportive culture of our organization is appreciated, energizes me to do more. So thank you to our families for your kind words, and for trusting us to help your children reach their potential.

This newsletter includes articles on good nutrition, how occupational therapists can help individuals with Down syndrome master skills for independence, and some of the great books found in the DSRF library. Also included is an article on King Arthur’s Night, a play written in collaboration with Niall McNeil, an artist who happens to have Down syndrome. The play will be premiering in Toronto in 2017 at the Luminato Festival.

As always, we are grateful to our donors and supporters without whom we would not be able to continue to provide the programs and services needed by the Down syndrome community. On behalf of the entire DSRF team, thank you, and all the best for a great fall.

Yours sincerely,
Making Good Nutrition Choices: It’s Up to You!

Adrienne Dall’Antonia, RD

Your family member may receive help from speech therapists, occupational therapists, teachers, and other professionals, but helping them to learn good nutritional habits is an often overlooked life skill that will have an important impact on their health and quality of life. How can a registered dietitian help? A registered dietician can help the whole family make good nutrition choices to fuel the body with the correct amount of energy and the right balance of nutrients with appropriate timing. It is the goal of dietitians to give you and your family all the information you need to make good nutrition choices and build lifelong habits. Here are some step by step suggestions to maximize nutrition:

**Step 1: Become Familiar with Canada’s Food Guide**

You can order a copy of the food guide or view it on line by accessing the food and nutrition area of the Health Canada website: [http://www.hc-sc.gc.ca](http://www.hc-sc.gc.ca)

Important points:

- The four food groups are: vegetables and fruit, grain products, milk and alternatives and meat and alternatives

- Get to know serving sizes: a serving of vegetables and fruit is usually ½ a cup, a serving of grain products is the equivalent to ½ cup rice or pasta, a serving of milk is 1 cup and a serving of meat is 2 ½ ounces (check the food guide for a more comprehensive list)

- Determine how many servings of each of the food groups you require each day (talk to a dietitian for the most accurate information or take a look at the food guide for average recommendations)

**If you have Down syndrome you can deduct 2 servings of grains per day from the average estimates.**

**Step 2: Add Some Structure by Creating a Generic Meal Plan**

Most people require 3 meals a day as well as 2-3 snacks. Create your own meal plan (or hire a dietitian to help you) by spreading your servings of each of the food groups throughout the day in a balanced, realistic way.

Important points:

- Make your meal plan practical by taking into consideration your schedule

- Eat every 3-4 hours, NOT more or less frequently (unless there is a medical reason)

- Every meal should contain at least 3 of the 4 food groups

- Every snack should have some carbohydrate (vegetables, fruit or grain products) AND some protein (milk or meat or their alternatives)
• Eat breakfast within an hour of waking up

Here is what your meal plan might look like:

5 grains (G), 7+ fruit/vegetables (F/V), 2 meat (M), 3 dairy (D)

<table>
<thead>
<tr>
<th>Time</th>
<th>Food Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breakfast</td>
<td>1.25 cups Shreddies, 0.5 cup berries and 1 cup milk</td>
</tr>
<tr>
<td>Snack</td>
<td>0.5 cup raw veggies and 1/3 cup hummus</td>
</tr>
<tr>
<td>Lunch</td>
<td>1 roasted chicken sandwich on whole wheat bread and a piece of fruit</td>
</tr>
<tr>
<td>Snack</td>
<td>1 banana and 1/4 cup yogurt</td>
</tr>
<tr>
<td>Dinner</td>
<td>0.5 cup pasta, 1 cup veggie tomato sauce, 1/4 cup lean ground meat</td>
</tr>
<tr>
<td>Snack</td>
<td>1 apple, 1.5 ounces cheese</td>
</tr>
</tbody>
</table>

Step 3: Personalize Your Options

Make a list of options in each of the food groups that you like or would consider trying. You can use a pie chart (like the one below) and add pictures of the foods you like.

You could also write a preference list that may look something like this:

Fruit and Veggies: steamed beans, cherry tomatoes, applesauce, asparagus, blueberries

Grains: pasta, sushi rice, polenta, quinoa, whole wheat bagel

Milk and Alternatives: soymilk, cheese strings, Greek yogurt, skim milk latte
Meat and Alternatives: BBQ salmon, almonds, smoked tofu, chicken breast, peanut butter

It is also a good idea to have a list of snacks that contain both protein and carbohydrate that you like. Examples might be:

• ½ cup trail mix (nuts and dried fruit with no added salt or sugar)
• An apple and some cheese
• Some raw veggies and some hummus
• Greek yogurt with some berries on top
• A skim milk latte and a pear

Step 4: Set Yourself Up for Success

• Stock your fridge with fruits and vegetables that you enjoy
• Prepare your food so you know what is in what you are eating
• If you eat at fast food restaurants, look up the nutrition information ahead of time so you know what the healthiest options are
• Prepare a snack jar (drawer or box) of single serving healthy snacks to make choices easier
• Be as active as you can so your metabolism is as revved as possible and you are as fit as you can be!

Step 5: Take into Consideration Any Underlying Medical Condition that Relates to Food Intake

Advice from physicians and/or dietitians may be required if you have been diagnosed with:

• Celiac disease
• Hypothyroidism
• Diabetes
• Constipation
• Issues to do with your teeth or jaw
• Texture Sensitivities

Putting it all Together!

You have learned about Canada’s Food Guide and understand the four food groups. You know how much energy you need each day and have prepared a meal plan as well as a list of preferences. You have convenient, yummy, nutritious food ready to go at home and you enjoy an active lifestyle. Congratulations... you have achieved nutrition freedom! The choice is now yours.

Adrienne has 3 children, the oldest of whom has Down syndrome. She works as a Registered Dietitian at Eating for Energy and can be reached at Adrienne@eatingforenergy.com.
King Arthur’s Night

By Chelsea Haberlin

Neworld Theatre is very excited to be collaborating with the Down Syndrome Research Foundation on the creation of King Arthur’s Night, the culmination of a decade long collaboration between Neworld’s Artistic Director Marcus Youssef, Niall McNeil, Veda Hille, and James Long.

As the Associate Artistic Director at Neworld, I’ve had the opportunity to watch this project evolve from a big idea to a national touring production. And I’ve watched how this has all been done with Niall McNeil and his desires at the center.

Niall is an artist whose life experience includes Down syndrome. He is someone who grew up in the theatre community and who has acted in many shows. It was his idea to adapt King Arthur to the stage and he came with a very clear idea that he wanted to write the play with Marcus Youssef. The two of them have a history of working together. In 2011 they co-wrote an adaptation of Peter Pan called Peter Panties which played at the Cultch as a part of the PuSh Festival, garnering rave reviews and sold out houses.

One of the most important outcomes was Down Syndrome Research Foundation Executive Director Dawn McKenna’s reaction to the production. After seeing it, she immediately contacted us and asked us to come to a meeting. She described the project as, “the most profound example of creative inclusion I have ever experienced.” She also suggested that should we ever undertake something similar again that we consider working with them to expand the impact of the project to include the wider Down community.

We took her up on that offer and are developing King Arthur’s Night in full partnership with DSRF. Marcus and Niall have taken their collaboration forward into the community with a series of workshops for DSRF clients. Joined by Veda, James and myself, they have conducted sessions exploring stories, movement, and music. From these workshops, we’ve met three new collaborators: Tiffany King, Matthew Tom-Wing, and Andrew Gordon. These artists, who also have Down syndrome, will join a cast of professional actors and musicians in the premiere of King Arthur’s Night.
Last week I sat down with Niall to ask him a bit more about the project. Here’s a bit of our conversation.

**Chelsea Haberlin:** How long have you been working on *King Arthur’s Night*?

**Niall McNeil:** I think about 3 or 4 years.

**CH:** And why did you want to make a play about King Arthur?

**NM:** I think he’s really cool. He has power. And he dies in the end when his son Mordred kills him. I’m playing the lead role.

**CH:** What is your favourite part of the play?

**NM:** Helping and translating with Tiffany.

**CH:** Can you tell me more about that? That’s interesting to me.

**NM:** Tiffany does beautiful art. Her paintings, drawings… she’s artistic, and she has experience in theatre. Tiffany, every time she says something I translate her language into mine, because we both have Down syndrome. I know Tiffany since floor hockey and she’s a really good, talented woman. She’s an incredible dancer. I teach her some moves. She’s beautiful.

**CH:** What part does she play?

**NM:** She plays the second lead role Guinevere.

**CH:** And what’s the relationship between Guinevere and your character?

**NM:** My character and her character are engaged. I made her because she’s beautiful, she’s powerful and the Queen has a power and Arthur has power. That’s why they’re connected, those characters.

**CH:** What do you enjoy the most about that?

**NM:** The King himself? I think I like to know more… I don’t know. Like I said, the King’s always nice. The King can’t yell at Lancelot. But Lancelot is a guy who’s having an affair with my wife so I think I’m connected.

**CH:** Is there anything else that you want people to know about this play?

**NM:** Be at the door, get a ticket and sit down.

There has been a great deal of excitement nationally about this project and we have big performance plans in the coming years. *King Arthur’s Night* will premiere at a big festival in Toronto in 2017 and subsequently be presented in Ottawa. After a post-premiere period of development, it will then be presented in Calgary and then in Vancouver, by Neworld’s long-time local presenting partner the PuSh Festival.

We’re just at the start of a ton of work we’ll be doing on *King Arthur’s Night* over the next year. Curious? Follow along by joining Neworld Theatre’s mailing list at newworldtheatre.com.
October is National Occupational Therapy (OT) Month, and as a newly minted occupational therapist, I am excited to share how OT can be a valuable component in the development of functional life skills for individuals with Down Syndrome.

OT is a client-centred health profession that focuses on promoting health and well-being for individuals of all ages and abilities, and empowering them to live life to the fullest. OTs work with clients to develop or recover skills required for participation in activities of daily living that include self-care (toileting, bathing, eating, grooming, dressing), productivity (work, school, volunteering) and leisure (extracurricular activities, hobbies). These activities are referred to as ‘occupations’— anything an individual wants to do or needs to do in their daily life. The OT approach is based on research that an individual’s ability to engage in occupation increases health and well-being.

OTs are regulated health care professionals and work in a variety of settings including hospitals, long-term care homes, community programs, schools and private practice. Their training enables them to understand not only the medical and physical limitations of a disability or injury, but also the psychological and social factors that affect an individual’s ability to function independently.

OTs work with a diverse population ranging from pre-term infants to the elderly, and assist clients in overcoming challenges resulting from a wide range of diagnoses including traumatic brain and spinal cord injuries, arthritis, mental illness, neurological disorders, developmental disabilities and chronic health problems.

At DSRF, OTs work with children, teenagers and adults towards mastering skills for independence through self-care such as toileting, feeding and dressing, fine and gross motor skills, school performance, as well as play and leisure activities.

During infancy, OTs can assist children with feeding challenges due to limitations in sensory processing, postural stability, and fine and gross motor skills. Furthermore, OTs are involved in feeding assessments, and provide strategies and interventions for positioning and feeding techniques.

In early childhood, OTs can focus on mastering fine and gross motor skills to facilitate independence, by providing interventions and treatment for low muscle tone, loose ligaments, visual and auditory deficits, sensory processing difficulties as well as cognitive and psycho-social skills. OTs accomplish these goals through play; as children open and close containers, pick up and release toys of different sizes and shapes, stack Lego blocks and build, and manipulate knobs and buttons, these activities build and strengthen skills that can be transferred to everyday activities. Tasks can be modeled and adapted to maximize independence.

School-aged children with Down syndrome benefit from an OT’s ability to address self-care skills such as zipping a jacket, and fine and gross motor skills such as cutting or completing multistep classroom routines to facilitate participation in school activities. OTs can assist in the classroom by enhancing the child’s communication skills through printing, handwriting, and keyboarding. Other issues that can be addressed are adaptations to the classroom—such as the position of desks and chairs—for optimal performance, based on the child’s physical abilities.

Adults with Down syndrome benefit from occupational therapy in searching for and retaining productive work, learning independent living skills, and participating in active recreation programs in order to maintain overall health and well-being.

OTs working at DSRF believe in a holistic and functional approach to therapy and find value in collaborating with other therapists and teachers as well as a child/adult’s family and school support team. The child/adult is an active member of the client-centred therapeutic process and, together with the OT, goals and interventions are developed that are specific to the clients and geared towards success and maximizing independence.

If you have any questions regarding OT services provided at DSRF please contact our therapists:

Hina Mahmood M.OT (Provisional) 604-444-3773 hina@dsrf.org
Lillie Ryan M.Sc. OT 604-444-3773 lillie@dsrf.org
Did you know that the Down Syndrome Research Foundation has a resource library? The library has a variety of books on the topic of Down syndrome including health, development, speech, language, learning to read, inclusive classrooms, transition—to name just a few. We are looking for a volunteer who is skilled in library classification systems to help us make our library easier to navigate. If you would like to help with this project, please contact DSRF. We are always adding to our collection, so if you have new titles that you would like to see, please let us know.

Here are a few highlights from our collection:


A child doesn’t want to leave the toy store, so he stops and flops. Another bolts across a busy parking lot, turns and smiles at his mom. An eighteen-year-old student bursts into tears when asked to change activities at school. Sound familiar? These and other common behavior issues in children with Down syndrome can quickly become engrained and may even persist into adulthood. No parent wants that to happen, and thankfully, help is available! Dr. David Stein, a psychologist and Co-Director of the Down Syndrome Program at Boston Children’s Hospital, shares his approach to behavior management in this new book for parents.


The Down Syndrome Transition Handbook helps parents prepare their child for independent adult life. It’s full of practical tips and step-by-step instructions to help families envision their child’s future, develop a transition plan, and implement it. There’s also a wealth of information about adults in their twenties or thirties living at home who are still struggling with finding a job, locating housing, or establishing a meaningful life in their community, and who could achieve more independence with the right guidance and supports.


provides invaluable insight into what health problems are more common in their patients, and how medical issues can present differently in people with Down syndrome. In a clear, empathetic style, they discuss how to promote a healthy lifestyle to prevent problems, and how to recognize health problems early on to ensure appropriate care and the best outcome. THE GUIDE TO GOOD HEALTH is a resource families and caregivers can refer to over and over again, whether it’s to find strategies to get a teen or adult to cooperate with treatment, or to consider if a symptom is being misdiagnosed or misunderstood.


Newly revised and updated, this compassionate and authoritative guide is based on Libby Kumin’s thirty years of experience of working with children and adolescents with Down syndrome and their families. Dr. Kumin draws on her vast experience to show parents how they can support and encourage their child’s speech and language development from birth to age 6 (or when a child can form 2- to 3-word sentences). Parents and teachers learn how to work through characteristic challenges, including hearing loss, intelligibility issues, apraxia (difficulty planning oral-motor movements), or a slower pace of development. Families soon see that many children with Down syndrome are natural and willing communicators.

**Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality (2007) Terri Couwenhoven**

Parents of children with Down syndrome and other intellectual disabilities are accustomed to paying close attention to their child’s physical, cognitive, and emotional development. This proactive approach should also include their child’s sexual development, which for many parents may not seem as obvious or urgent, especially to those with young children. Drawing on her unique background as both a sexual educator and mother of a child with Down syndrome, the author blends factual information and practical ideas for teaching children with Down syndrome about their bodies, puberty, and sexuality. This book gives parents the confidence to speak comfortably about these sometimes difficult subjects.
Yes She Can!

Each year, the BC Council for Exceptional Children celebrates the achievements of children and youth with exceptionalities through the BC CEC Yes I Can! Awards program.

We’re very proud to announce that DSRF student Clara Driedger was chosen as a recipient of the award for academics in reading (grade 5). Way to go, Clara!

Clara’s mom attributes her success to the many hours she has spent at DSRF receiving specialized reading instruction. The school does a great job reviewing the practice materials with Clara, so DSRF and Clara’s school are working in partnership. Clara’s mom says “We are grateful for the program and the wonderful teachers at DSRF for encouraging Clara’s love of reading.”

We are so pleased to be able to help empower Clara to achieve her full potential!

Fortello Bros, Individuals with Down Syndrome Win Big at Benefits of Bocce

20 teams braved one of the hottest days of the year August 20 as they gathered in North Vancouver for a DSRF summer tradition: the 16th Annual Benefits of Bocce tournament, presented by Raymond James/HMB Financial.

It was a spectacular day of fun, food, friends and fundraising in support of the Down Syndrome Research Foundation. It didn't take long for newcomers to learn why others have described it as their favourite charitable event of the year, as good-natured rivalries quickly sprung up amongst the 80 players vying for the championship trophy.

The Fortello Bros., one of the tournament’s founding teams, lived up to their formidable reputation, fending off one challenger after another to make it through the round robin schedule undefeated. The number one seeds then swept their way through the playoffs to claim the championship trophy.

The Aon Athletes put up a great fight, making it all the way to the final before falling to the champions and settling for silver. In the bronze medal game, Best Coast Bocce (representing Westcoast Actuaries) got the better of Happy Money Balls, who did our lead sponsors proud.

Even more important than the results in the pits was the fact that the event raised over $15,000, which will help empower individuals with Down syndrome through DSRF’s research and educational programming.
Vancouver Financial Community Makes 6-Figure Investment in Individuals with Down Syndrome

Over the past 23 years, the Down Syndrome Research Foundation has hosted 73 Up the Down Market Dinners in four cities, collectively raising over $5 million dollars for individuals with Down syndrome.

Last week, Vancouver’s financial community joined together to raise over $110,000 for this important cause, making the 2016 Vancouver dinner the second-most successful in the event’s history.

The guests accepted - and exceeded - the ambitious goal of $25,000 in personal donations, which will cover the funding gap for 100 students in the Down Syndrome Research Foundation’s effective one-to-one reading program.

The event wasn’t all serious, of course.

Danielle Juilfs Wins Klukas Achievement Award

One of the major highlights of Up the Down Market was the presentation of the George Klukas Achievement Award to Danielle Juilfs.

The Klukas Award was created to acknowledge personal growth in a person with Down syndrome, and is awarded annually to a DSRF student who has achieved significant success in life.

As the 2016 winner, Danielle exemplifies what individuals with Down syndrome can achieve. Danielle is filled with determination and strives to do her best in all she does. As a rhythmic gymnast, Danielle has excelled on both local and provincial levels, winning many meets and Special Olympics medals, including three medals at nationals. Thanks in part to the skills she gained through her involvement at DSRF, Danielle’s self-confidence has grown tremendously, leading to her living on her own, securing employment and being a mentor in the young adult Down syndrome community.

Danielle has been and remains an asset to DSRF, working countless volunteer hours at our dinners, breakfasts and many other events. She now works at the front desk at our Centre one day a week as an assistant, answering phones and doing administrative tasks as needed. Danielle is friendly and always has a warm smile for our clients. She is truly a joy to have around, and we congratulate her on her achievements.
Upcoming Events

19th Annual DSRF Christmas Breakfast
Friday, December 9, 2016
7:30 - 9:30am
(breakfast served 7:30-8:30)
Hyatt Regency
655 Burrard Street, Vancouver

Entertainment by Rick Scott
Christmas Tree Decorating Competition
Christmas Gifts and Crafts for Sale
Silent Auction of Decorated Trees
Visit from Santa

Adult Ticket: $40
Children 5-12 years Ticket: $20
Children under 5 years: FREE
Table (10 seats): $350

To purchase tickets, visit DSRF.org/Christmas.
Family accommodation is available Thursday night for $159; for bookings call 1-800-233-1234 and quote HOTEL: Hyatt Regency Vancouver, CODE: HOHO16.

Montreal: Nov. 17, 2016

DSRF.ORG/UDMD
Thank You for Lending a Hand

Borden Ladner Gervais
In August, our friends at Borden Ladner Gervais LLP held their annual charitable volleyball tournament. Their team representing DSRF battled to a hard fought second place finish, winning $800 for individuals with Down syndrome in the process. Many thanks to BLG!

G&F Financial
G&F Financial granted $9,000 to purchase much-needed new laptops for the DSRF adult education classrooms - a critical investment in our students. Thank you, G&F!

John Hardie Mitchell Family Foundation
The John Hardie Mitchell Family Foundation donated $1,000 to DSRF programs. We are grateful for their support!

Lohn Foundation
For the third consecutive year, the Lohn Foundation donated $3,000 to DSRF programs. We appreciate their ongoing commitment to individuals with Down syndrome!

Sook Ching Foundation
The Sook Ching Foundation gifted $5,000 in support of students with Down syndrome. We thank them for their generosity.

Triple-21 Partners
A big thank you to our newest Triple-21 partners: Nikhil Ekanayake and Kaitlyn Lawson. To learn how you can empower individuals with Down syndrome to reach their full potential through a donation of $21 or $210 per month, please visit DSRF.org/Triple21.
Like most children with Down syndrome, David struggled with reading. However, when David was in grade 4, he began to exhibit a strong desire to learn to read. He would often pull out chapter books and sit on the couch, pretending to read them like his sisters did. So when his mom, Rose Marie, heard that the Down Syndrome Research Foundation was starting a new one-to-one reading program, she jumped on it.

The progress that David has made since starting the program is remarkable. He's learned to read many words, and his dad Steve notes, “His vocabulary has expanded enormously. The chatter that goes on around the house now is just great.”

Rose Marie credits DSRF with helping David progress in his confidence and skills. “I appreciate everything about DSRF’s programs,” she says. “They’ve been a lifesaver for our family. We’ve noticed David grow so much since he started there; he’s very confident in himself now. We’re so grateful that we have somewhere like DSRF that we can turn to. We plan to continue taking David there for many years to come.”

Your donation to DSRF helps write success stories just like David’s. We are grateful for your generosity, and we value your trust that we will use your money wisely.

An online donation is the easiest way to contribute to the DSRF. All online donations receive an immediate tax receipt by e-mail. To give online, please visit www dsrf org.

Thank you for standing together, hand in hand, with David and with all those who are walking the lifetime journey of Down syndrome.