In preparing for this annual summary, we are reminded of the numerous activities that have taken place, and the high level of commitment shown by our staff and our many volunteers, including our Board of Directors. 2013 has been another year of exceeding many of the goals we set, as well as achieving a modest surplus for the sixth successive year. Highlights of the year are summarized throughout this 2013 Annual Report in the various sections of programs and services, research, fundraising and finance.

Internationally there has been increased awareness of the challenges faced by individuals with Down syndrome, as well as the wide variety of abilities and potential. This awareness has come through annual World Down Syndrome Day events, international “Spread the Word to End the Word” campaigns, television shows like *Glee*, and commercials including individuals with Down syndrome. Social media has played a key role with popular postings on Facebook and Twitter, videos on YouTube and photos on Pinterest and Instagram. Celebrities have also lent a hand, including Avril Lavigne and John McGinley who helped support the “Spread the Word” campaign with personal messages.

Despite increased awareness, there are still challenges which need to be addressed. These challenges are found in services, schools, employment and community, not just in Canada but internationally as well. The landscape continues to change for this population, and families and organizations continue to adapt in order to support their children.

At DSRF we strive to empower individuals with Down syndrome to achieve their individual potential. Our programs are continually evolving, thanks to our tireless and innovative staff, who are constantly learning from experts and students alike. We do not rely on canned curricula. Instead, we incorporate best practices and allow the latest research to inform our interactions with students. Furthermore, our approach is highly individualized. Whether a student is working on their speech and language, reading and communication, money math and budgeting or basic life skills critical to independence, lessons are built around each student’s personal interests. This makes learning fun and keeps students motivated.

Your help is critical to our success and directly benefits the students and families we support. With your assistance we will continue to address the changing landscape and changing needs with effective educational programs and services, and relevant and reliable information and supports. Next year will be DSRF’s 20th anniversary, and we hope you will join us as we celebrate 20 years of success in providing information, education, services and supports for the Down syndrome community.
DSRF summer school students were treated to two new programs: Bollywood dance and zen yoga. Both were such a hit that we’ve brought them back for several additional sessions since then.

Chefs Antonio and Morgan from Kitchen Riddles hosted DSRF’s Reading and Communication Plus class for a fun morning of pasta making. The students made fettuccine from scratch, along with a delicious sundried tomato sauce and arugula with grapefruit salad.

In July, DSRF students created colourful works of art that focused on their interests. Each student completed an individualized challenge project, which were featured in an Art Exploration show and kept on display for several weeks at Vancouver’s Sweet Tooth Cafe.
DSRF was proud to be nominated for the 2013 Burnaby Board of Trade Non-Profit Organization of the Year.

In September, DSRF celebrated 20 years of investment by the Vancouver business community in individuals with Down syndrome at the 20th annual Up the Down Market Dinner.

Rick Scott delighted children and adults alike with a concert that was fun for all ages, as part of Down Syndrome Awareness Week.

The year concluded as it always does, with the 16th Annual DSRF Christmas Breakfast. Over 230 guests gathered together to ring in the season and cap off another wonderful year for the DSRF family.
Research continues to be an important area of focus for the organization. Best practice and research findings help to inform our staff and this information is used in our ongoing program development. We continue to take advantage of opportunities for collaborations and partnerships that will further research benefitting the Down syndrome population.

The **Variety Early Foundations One-to-One Reading program**, which ran from June 2012 to May 2013, was a research initiative looking at the effectiveness of the weekly program over a twelve month period. The program uses a strength-based approach, focusing on two components: visual modality and high meaning words. In total 15 children ages three to seven participated in the program, which was held in three communities: Burnaby, Abbotsford and South Surrey. Reading assessments conducted before and after the program have been reviewed and we are in the final stages of analyzing the language samples, in partnership with researchers from UBC School of Audiology and Speech Sciences. Once completed the results will be published and shared with the families and the community at large.

Another project we are embarking on will look at oral placement therapy and whether or not it is an effective approach for some children with Down syndrome. The **Talk Tools therapy program** has been developed by American speech and language pathologist, Sara Rosenfeld-Johnson, as a method of teaching accurate speech sound production for children who have exceptional difficulty producing clear speech. This therapy is being used extensively in the U.S and has also been introduced in Canada. Many parents are seeking out therapists who will offer this therapy in the hopes of improving their child’s opportunities for success. The costs for speech and language therapy are significant, and DSRF has been asked to provide our professional opinion on the effectiveness of this approach as well as to offer Talk Tools therapy services to the children we serve. We are currently working on an ethics application and seeking funding that will enable us to proceed with this research initiative.

We continue to support external research initiatives by providing information to our families on opportunities to participate in research projects. Researchers must submit a formal application and have already obtained ethics approvals from their host universities and/or institutions. Only projects which we feel may have potential benefits to the population are approved and then shared with our families. Currently there are four initiatives which we are supporting. They are:

- **“An international study of bilingualism in children with special needs”** This project focuses on bilingualism and children with developmental disabilities and is spearheaded by Dr. Elizabeth Kay-Raining Bird (Professor, School of Human Communication Disorders, Dalhousie University, Halifax, NS). Susan Fawcett, lead speech-language pathologist at DSRF, along with local researcher Stefka Marinova-Todd (Assistant Professor, School of Audiology and Speech Sciences, UBC) are part of this international project being carried out across six different sites in four different countries (Canada, USA, United Kingdom and the Netherlands).

- **“Costs of Caring”** is a research initiative looking at the financial costs of caring for children with developmental, intellectual and learning differences. Realizing that there are many costs of caring for children with intellectual disabilities that are not covered by the health care system, Patricia Birch (Assistant Professor, Department of Medical Genetics, UBC) and her team have developed a survey that will help to better understand the costs to families and society. Calculation of such baseline costs can be used for future studies of
the effect of introducing new medical tests or therapies, and can be used by families and support groups as evidence of financial need.

- **“Genetic Causes of Autoimmune Disorders in Patients with Down syndrome”** Individuals with Down syndrome have markedly increased risk of developing certain autoimmune diseases because of the triplication of genes on the 21st chromosome. Dr. Richard Spritz (Director, Human Medical Genetics and Genomics Program, University of Colorado) and his team have identified a susceptibility gene which may be associated with this increased risk, and are examining DNA via saliva swab to investigate this further.

- **“Action-Observation in People with Down syndrome”** There is brain-imaging evidence to suggest that the process involved in action observation in individuals with Down syndrome is different than for individuals without Down syndrome. Dr. Nicola Hodges (Professor, School of Kinesiology, UBC) and her team have devised a key-press/video study to investigate the question of how individuals with Down syndrome respond to simple finger actions shown in videos. The study will help to better understand information processes in this population and to develop evidence-based practice methods for aiding motor skill learning from watching demonstrations.

There has been continued growth in research into pharmaceutical and biological interventions relating to the Down syndrome population. A central goal of this type of DS research is to understand which of the genes on human chromosome 21, when present in three copies, lead to each of the different DS-associated phenotypes underlying DS pathology.

Three human clinical trials are currently underway to evaluate if these therapies improve cognition and learning. The trials are being conducted by Roche Laboratories, Balance Therapeutics and Elan Pharmaceuticals. The Roche and Balance trials are investigating compounds that are shown to restore more balanced neuro-transmission, and improved learning, in mouse models. The Elan trial is testing a compound that may reduce beta-amyloid aggregation. This aggregation is a contributor to plaque formation observed in persons with Alzheimer’s disease. DSRF is hoping to participate in the Roche trial in the near future as one of the Canadian sites, partnering with Dr. Sylvia Stockler, Program Director, Biochemical Diseases, and her team at BC Children’s Hospital.
As our expertise increases, so too does our ability to meet the growing needs of the Down syndrome community. Our mission has always been to fill the gaps that exist in the community, not to duplicate services. We do this through our ever expanding educational programs and services.

This year we responded to over 200 inquiries from families and other community members on topics ranging from education and intervention strategies, supports for older adults experiencing cognitive decline, health care topics, behavioural support, and support to navigate provincial support systems. Our staff made 21 community presentations and hosted an information booth at 7 community events throughout the year. In addition, we hosted practicum students from Douglas College, University of British Columbia and Simon Fraser University, and participated in community roundtables addressing the topics of education and employment.

**Speech and Language Therapy Services**

In 2013, the demand for individual speech and language services continued to grow as we increased our services from 1468 individual sessions held in 2012 to 2052 sessions in 2013. Our speech therapy department also held monthly language groups for adult learners in our Reading and Communication programs, assisted with the development of a new Social Communication and Navigation course, and worked within this program once a week to increase social communication skills among students. The team continued to collaborate with teachers in our one-to-one reading programs to support the link between reading and expressive language development. Baby Sign Language continued in 2013, and provided additional opportunities for families to learn about language development through input from our speech language pathologists. The speech and language department continued to develop their professional expertise by participating in workshop and training events in Canada and the U.S, including Hanen Early Language program’s “It Takes Two to Talk”, and Talk Tools training for oral placement therapy. This training will enable new programs for 2014 and responds to needs identified in the community.

**Occupational Therapy Services**

In 2013 we hired a part-time occupational therapist and began preparing for the launch of this program in early 2014.

**Reading and Adult Post-Secondary Programming**

Through our research, we have been focusing on reading development across the lifespan with our team of five BC-certified teachers. We offered the Early Foundations, Success Builders, Launch Pad and Read On! programs for learners of all ages through one-to-one reading instruction in the three communities of Burnaby, Abbotsford and Surrey. These individual hourly sessions totaled 1229 hours in 2012 and 1296 in 2013. This includes 15 children served through the Variety Early Foundations Reading Program grant from June 2012-May 2013. We continued with the successful small group Reading and Communication and Reading and Communication Plus programs for young adults in Burnaby and Surrey and Pathways to Independence for an alumni group in South Surrey. A Reading Comprehension course was offered in Burnaby as well as a Budgeting and Money Math course. These programs are designed to build on prior reading skills with an emphasis on comprehension, writing, presentation
skills, and practical money management skills. Programs like these were developed because we recognized that the adolescents and young adults in our reading programs lacked these basic and necessary skills which would lead to greater success in their employment and community experiences.

**SOCIAL DEVELOPMENT**

A new course, Social Communication and Navigation was launched in the fall of 2013 with a focus on developing the communication skills to support conversations with co-workers and community members, the development of mature social behaviour, skills to navigate the community on transit, and problem solving related to navigation and social encounters. This year’s Summer School provided a successful blend of educational curriculum with a rich Art Program, Bollywood Jazz dancing, Zen Yoga, and Language Express---a two week intense focus on social communication skills. The Sweet Tooth Café featured our student’s art work at a community art show and Burnaby’s Kitchen Riddles hosted our students for an afternoon of pasta making; both opportunities to showcase the talent of our students while providing another valuable connection to the community. The Music in Motion was a popular program again this summer, giving our students the opportunity to work with professional musicians to sing old favourites and explore a variety of musical instruments.
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.

DSRF’s reading program has helped unleash David’s true potential.
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 both his confidence and his 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 just 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.”
The Down Syndrome Research Foundation’s 2013 financial statements were audited by the independent chartered accounting firm of Tompkins, Wozny, Miller & Co. This is done to ensure the efficiency and transparency of our financial records.

We are thrilled to report that, for the sixth year in a row, DSRF has posted a positive bottom line. The year ending December 31, 2013, was a tough one financially in some respects, but we prevailed in the end, thanks to the hard work of our fundraising team and judicious expense management.

Again this year the Up the Down Market Dinners were our largest event and brought in the most income after donations. After expenses and payments to our event partners, DSRF netted over $232,000 from the four dinners. Aside from the Dinners, DSRF’s largest fundraising event was the Run Up for Down Syndrome, which saw a 13% increase this year. We have even higher hopes for this event in 2014. While we were pleased that the Gaming grant remained the same as 2012, overall grants decreased. Programs and services income had a small increase due to the addition of another speech therapist and continued one-to-one reading through the summer months.

Salaries are up for the year due to the addition of full-time fundraising and speech therapy staff and, as mentioned above, the continued one-to-one reading program. Bank charges and processing fees saw another 20% increase over 2012 as more and more clients and donors are using credit cards for payment. For the most part, however, expenses remained constant thanks in part to services donated by generous corporate supporters including Champion Window Cleaning, Earth Enterprises, Woodhouse & Associates, and Callaghan Photography. We are sincerely grateful for their assistance.

The 2013 surplus allowed DSRF to continue to reduce its debt. At year end the line of credit balance was nil, and we managed to pay down $32,216 of the mortgage, both positive outcomes from the year. Our intentions are to continue this trend of debt reduction throughout 2014 and beyond.

To view DSRF’s financial statements, visit DSRF.org/financials2013.
2013 marked the sixth consecutive year that the Down Syndrome Research Foundation finished with a financial surplus. This achievement is a testament to the generosity and faithfulness of our donors and sponsors, and to the tireless efforts of our staff and volunteers.

As always, our calendar was highlighted by a number of successful events. For the second consecutive year, a record was set at the Run Up For Down Syndrome, where more than 800 participants combined to raise over $83,000 (net) for the work of DSRF. At Up the Down Market Vancouver, where we celebrated 20 years of investment by the financial community in individuals with Down syndrome, we topped $100,000 (net) for the second year in a row. It was a strong year as well for Up the Down Market Toronto, where the event netted $79,000.

DSRF was honoured to be the beneficiary of several community charitable initiatives. In February, Borden Ladner Gervais LLP competed on behalf of DSRF in the Mercy Cup hockey game versus Phillips, Hager & North Investment Management Ltd., raising $8,800 for the cause. In May, DSRF was an official charity of the BMO Vancouver Marathon’s RUN4HOPE, where eight runners raised over $8,000 for DSRF’s educational programs. And in September, DSRF received approximately $11,000 as the beneficiary of the 2013 Burnaby Board of Trade Golf Tournament.

Donations to the Down Syndrome Research Foundation continued to grow, totaling approximately $296,000 (an increase of 3.2% from 2012). Year-end giving through the DownSide Up campaign rose to $34,000, a 54% increase from the prior year.

We extend our sincere appreciation to every individual and organization who gave financially in 2013. Thank you for empowering individuals with Down syndrome to reach their full potential.

**LEMONAID**

On May 23, 2013, the Down Syndrome Research Foundation hosted LemonAid: an evening of art and entertainment at the River Rock Show Theatre in Richmond, BC. The event featured special guest Lauren Potter, an actress with Down syndrome who stars on the television show *Glee*. After thrilling more than 20 DSRF families who came out to meet the star at our Centre, Lauren delighted the LemonAid audience with her energy and enthusiasm as she spoke about her experiences in life and acting. Lauren helped egged on bidders during the live auction portion of the event, which included many original artworks by well-known artists and celebrities, as well as a number of unique items from the world of music.
Volunteers

Volunteers are the lifeblood of any non-profit organization, and DSRF is certainly no exception. Whether it’s delivering newspapers and selling fortune cookies to Up the Down Market guests, frantically serving up water to thirsty runners at DSRF’s Vancouver Marathon water station, course marshalling at Run Up for Down Syndrome, refereeing at Benefits of Bocce, helping with administrative tasks in the office, preparing supplies for summer school, assisting staff in one of our many programs, or stuffing envelopes for a mass mailing, there’s never a shortage of work to be done – and never a shortage of supportive volunteers who are ready and willing to sacrifice their time for the benefit of the individuals and families whom DSRF serves. Thank you very much to each and every person who has given freely without expecting anything in return. You are appreciated.
Borden Ladner Gervais was playing for individuals with Down syndrome when they faced off against Phillips, Hager & North in the Mercy Cup hockey game in February. BLG lost a tense battle that came down to a shootout and a controversial missed goal call. Team BLG raised $8,800 for DSRF.

Howie English walked 21 miles throughout BC’s Lower Mainland on World Down Syndrome Day, March 21. Howie undertook his trek in solidarity with all families who are on the lifetime journey of Down syndrome, and raised over $1,200 in the process.

On Sept. 4, Burnaby’s business leaders hit the links for the Burnaby Board of Trade’s annual golf tournament. The event raised $11,000 for individuals with Down syndrome.
Eight dedicated runners competed in May’s BMO Vancouver Marathon on behalf of DSRF, combining to raise over $8,000. Meanwhile DSRF kept marathoners refreshed at a mid-course water station.

16 teams of four took to the pits on August 17 for the 13th Annual Benefits of Bocce in North Vancouver. The summer’s most exciting fundraising event brought in almost $10,000 in support of DSRF’s activities.

On June 2, over 800 people ran, walked, strolled and scooted their way through the SFU campus for the 17th Annual Run Up for Down Syndrome. A record-setting $83,000 was raised.

In October, high school student Nancy Yang and her friends worked together to raise over $300 for DSRF through chocolate sales, and a Halloween carnival that they organized and hosted at Lochdale Community School.
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