In 2016 we increased our reach through programs, workshops and presentations. We expanded our multi-disciplinary team, hiring two additional speech language therapists and our second occupational therapist. This has allowed us to increase the number of program spaces and eliminate wait lists. Additionally, we opened our reading program in North Vancouver and increased our space in Surrey to accommodate growing demand. We also partnered with the Halton Down Syndrome Association in Ontario, piloting the reading program outside of BC. Overall, 2016 saw a 27% increase in the number of program spaces filled, with the largest increase being in occupational therapy services. With the addition of new staff, we expect further growth in 2017.

DSRF staff were involved in numerous presentations covering topics from toilet training and breast feeding to problem behaviour and Alzheimer’s/dementia. We partnered with Greater Victoria Down Syndrome Society on a one day conference bringing expertise from seven DSRF staff to Vancouver Island. We also responded to numerous requests for support from families and professionals, including queries on education, intervention, transitioning from school, support for new families, dementia, cognitive decline, mental health and many more.

In December 2013 we released three online videos that provide information and training on our One to One Reading program. These videos have now been seen over 70,000 times throughout Canada and around the world. One family in Kenya e-mailed to let us know how well their son is doing and to thank our staff for their support and encouragement. We are now preparing two new videos on communication which will be completed in 2017.

Seeking to increase the expertise available to the Board and staff, an Expert Advisory Panel was formalized. Currently the panel is composed of local experts, mainly from the health care field. The addition of international experts from other disciplines will follow.

over the next year we will continue to evaluate our impact and address the needs of families outlined in the Parent Satisfaction Survey conducted in 2016. DSRF programs, information and support received high ratings, while finances and location were seen as barriers to accessing programs for some families. With expansion of satellite locations and greater awareness of bursaries and external grant opportunities, we hope these barriers will be minimized. We are also in the midst of strategic planning, defining our goals and strategies for 2018 and beyond.

We are proud of our accomplishments over the last year and, with the support of our Board of Directors, are working hard to keep the momentum going. Our dedicated, enthusiastic team is excited about the future as we work with families and professionals to empower individuals with Down syndrome to reach their potential.
PROGRAMS/SERVICES

SPEECH AND LANGUAGE THERAPY SERVICES
Increased demand for speech therapy services, and the challenge associated with finding therapists who have the right combination of skill and aptitude, meant we had waitlists for much of 2016. Toward the end of 2016 we hired two new speech therapists. In response to growing demand in Surrey, we secured a larger space that will accommodate two staff members. In 2016 we held 2,249 individual therapy sessions, up 8% from the previous year, filling 197 spaces and serving 93 individual students. Through the generous support of the Ames Family Foundation we began work on a new communication video series; filming will take place in 2017.

OCCUPATIONAL THERAPY SERVICES
In 2016 we held 718 therapy sessions (filling 63 spaces for 31 individual students), a 52% increase from 2015. In the fall of 2016 we hired a new occupational therapist, so sessions held and individual students served will increase further in 2017.

ONE TO ONE READING
In 2016 we served 56 individual reading students in 107 spaces for a total of 1,238 individual sessions, up 14% from 2015. In addition, we saw eight students from eight different schools in our one-year school collaboration project. Staff time was also spent on further development of our DSRF reading assessment tools, as well as our program framework and resources. Our aim is to have materials that we can share with the Down syndrome community at other locations across Canada and to fulfill requests for information we regularly receive from the school community. We expect to hire a new teacher in 2017 to increase the sessions held and individual students served.

ADULT POST-SECONDARY PROGRAMS
In 2016 we served 22 individual students in post-secondary programs aimed at supporting transition from high school into the adult world of independence. We worked with BC Partners in Workforce Innovation to improve work-readiness, and provided opportunities for our students to hone interview skills. One current student and one past student gained employment as a result of our collaboration with this organization.

Reading and Communication Plus: 9
Social Communication and Navigation: 8
Budgeting and Money Math: 7
Read On! Group: 4 (this program became the new Learning for Life program, serving adults of all ages, in the fall of 2016)

LEISURE PROGRAMS
While our goal is that individuals with Down syndrome will be fully participating in their community, including leisure activities available through natural settings such as community recreation centres, our parent survey pointed to the need for programs for adults of all ages. In response, we developed a new Zen yoga program. Additionally, a new partnership with Burnaby Art Space spawned a new program, Art Exploration, offered in their fully equipped Burnaby art studio. Cooking is another area where we hope to provide services and we have been actively looking for a DSRF cooking instructor.

Yoga: 15 individual students (new)
Music in Motion: 18
Summer Program: 30

NEW PARENT SERIES
Beginning in September, DSRF launched a New Parent Series to support parents of children from newborns to age five. Once a month we provide an opportunity for families to meet other families while learning about Down syndrome from experienced professionals. Sessions cover topics ranging from overall development, communication, nutrition, feeding issues, toileting strategies, positive behavior support, health care, dental care, and early reading development.

FAMILY AND PROFESSIONAL SUPPORT
In addition to providing programs for students, we provide workshops, conferences, and online, in-person or phone support to address a variety of concerns and requests for information. This year topics we have addressed include reading, communication, toileting, behaviour, health care, mental health, complexities associated with dementia, and navigating provincial services.
When the Schouten family chose their daughter Sarah, they chose hope.

“We adopted Sarah six years ago,” says her mom, Phyllis. “We were ready to grow our family, and we knew there were kids that needed a family as well, so it was kind of a natural step.”

Sarah has already faced a number of challenges in her young life, including heart problems and several eye surgeries. In addition, her development has been delayed in many areas, including her speech, behaviour, toileting and walking.

But just as Sarah found a supportive family to care for her, so too did the Schoutens. When Sarah was four and a half, she began attending the Down Syndrome Research Foundation, a step that Phyllis describes as “literally life-changing.”

“It was the beginning of a new blossoming for Sarah,” she affirms. What began with weekly speech therapy sessions has expanded to include occupational therapy and reading lessons. Each step of the way, Sarah has grown remarkably.

“I discover things I didn't know she could do, and clearly she learned it at DSRF,” says Phyllis. “She has a chalkboard where she practices forming her letters. She loves to jump and read, and those are all things she’s learned at DSRF.”

Sarah’s dad Johannes appreciates DSRF’s holistic approach to family support. “The person with Down syndrome gets help, but they also have parenting courses,” he says. “It’s bigger than just helping one individual. It’s a bigger vision.”

Through their involvement at DSRF, the family’s vision for Sarah’s future has gotten bigger, too. “The hopes that we have for Sarah are similar to the hopes that any parent has for their children,” says Johannes. “You want to see them grow up and develop, and be all that they are created to be. And I have hope now that, yes, Sarah will talk, and she will write, and there is probably more that she can do than I can even hope or imagine right now.”
RESEARCH

While a large focus of DSRF revolves around the ongoing development of effective programs and services, we cannot discount the role research plays in informing our efforts. We continue to seek out best practice and the latest findings from published research, learning from experts around the world and incorporating this information into our daily interactions with our students. We also initiate and participate in research efforts that will provide new knowledge and insight to benefit individuals with Down syndrome. Translation of this knowledge is important as well, and we strive to disseminate this information to the wider Down syndrome and intellectual disability community so that others may benefit.

In June 2016 our paper “An Early Literacy Program for Young Children with Down Syndrome: Changes Observed over One Year” was published in the Journal of Policy and Practice in Intellectual Disabilities (JPPIID). Partnering with the School of Audiology and Speech Sciences, University of British Columbia, and with funding provided by Variety – The Children’s Charity, we conducted a year-long study of 15 children aged 3-6 years, involving 45 weeks of direct one to one reading intervention. The study supports the experiential observations of our service providers that early reading interventions, combining sight word training, phonological awareness, word analysis, shared reading and topics of interest to the individual student, provide long term benefits and promote a love of learning and of reading. Scan the code on the left to view the paper online.

During this project, we noticed that those students who had some sign language skills seemed to make better progress than those students who had no sign skills. We then embarked on a subsequent project, “Sign It, Say It, Read It,” to tease out whether or not sign language was actually making a difference. Over a period of 16 weeks, 19 students participated in the comprehensive one to one reading program. The students were broken into two groups, one receiving augmented sign language instruction, while the other did not. The findings suggest that this intervention is effective for students with an intellectual disability. It also appears that sign language augmentation favourably affects language and literacy outcomes.

Information from the Down Syndrome Survey we conducted in 2015 in collaboration with BC Children’s Hospital and UBC has been finalized and we are awaiting publication. The survey included 364 respondents, mainly from British Columbia, Alberta and Ontario. One of the most interesting findings from the survey was the difference in the number reporting sleep disorders breathing and sleep disturbances (85%), as opposed to the number with a confirmed sleep disorder diagnosis (22%). This has led to additional projects which are ongoing with our partners, including development of a sleep/wake/behaviour app and an online e-learning tool for physicians and medical professionals. We are endeavouring to bring awareness of sleep issues in the Down syndrome population to our families, medical professionals and the wider community.

THE DNA OF A PARENT
[CLINT AND MONICA WIELER]

We have been coming to DSRF for one-and-a-half years, and everyone has been very supportive. From Nimet to Dawn, there is always an open heart willing to help us in all possible ways. We can’t thank the therapists enough; they have become friends and have taught not only our son, Isaac, in a nurturing way but also we have learned to advocate better for him. We are amazed at the continual improvement in his communication skills and he has learned to read a wide variety of words. We are glad there is a place like this where Isaac will have the opportunity to grow and enrich his life in the years to come. We are sure there is not a better place for him to be involved at than DSRF.

THE DNA OF A STUDENT
[CLARA]

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. In 2016, DSRF student Clara Driedger was chosen as a recipient of the award for academics in reading (grade 5).

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.”

THE DNA OF A TEACHER
[Jillian, Registered Speech Language Pathologist]

My students with Down syndrome have taught me the power of time. My most precious memories with my students have come from waiting and listening supportively, resisting the urge to rush through a to-do list. Patiently pausing just a moment longer – giving my students time to think, express their ideas, explore a toy, study a picture, and so on – can lead to breakthroughs in learning and communication. It has also led to plenty of shared laughs! Giving sufficient time to check in with parents also results in rewarding interactions that lead to a more fruitful collaboration.

From a long-term perspective as well, the progress we see is owed in rewarding interactions that lead to a more fruitful collaboration. From a long-term perspective as well, the progress we see is owed to the time and effort invested by the student and their dedicated family, school, and therapy team. The pace of change over time can vary between individuals and specific skills, but every small victory should be noticed and celebrated along the way.

[clara]

[clint and monica wieler]
I began volunteering with the Down Syndrome Research Foundation summer school program. I enjoyed seeing the individuals in the program excel and have fun. Since then, I have also volunteered for the New Parent Series, which gives children a safe place to play while their parents learn about Down syndrome. The staff, families, and individuals involved in the centre are so caring, and make it a welcoming and uplifting environment to be a part of. I feel very lucky to be able to give back to the community as a member of such a great team!
The 20th Anniversary Run Up for Down Syndrome was one for the record books. What may have been the hottest day in Run Up history drew the largest crowd the event has ever welcomed, and shattered all Run Up fundraising records.

DSRF’s goal of making 2016 the first ever $100,000 Run was not only achieved, but surpassed. Thanks to the efforts of almost 1,000 runners and volunteers, and the support of lead sponsor Euro-Rite Cabinets, the 20th Anniversary Run bested the previous year by $25,000 in an enthusiastic show of support for individuals with Down syndrome.

ALL NUMBERS NEW RECORDS!
In February, Borden Ladner Gervais faced off against Phillips, Hager and North in their annual hockey showdown for the Mercy Cup. PH&N edged them out on the ice, but BLG won big in our books, raising over seven thousand dollars to empower students with Down syndrome.

The financial heavyweights of Toronto, Vancouver, Calgary and Montreal played the fictional market while making a very real investment in individuals with Down syndrome, raising over $260,000 through four Up the Down Market Dinners. The Toronto crowd got a “Great” surprise indeed when hockey legend Wayne Gretzky made a surprise appearance.

DSRF returned as one of five National Charities for the BMO Vancouver Marathon’s RUN4HOPE. 26 athletes combined to raise over $12,500 for Team DSRF, while 30 volunteers kept the water flowing on a hot day out on the course.

The Fortello Bros – founders of the popular summer event Benefits of Bocce - reclaimed their glory days when they took home the championship at the 16th annual tournament in August. More importantly, the participants raised over $15,000 for DSRF students.

Through Willie’s Corner, the brainchild of Barry Walker, supporters pledged money to DSRF for every corner kick taken from the legendary corner by the Vancouver Whitecaps. There were 26 kicks over the course of the 2016 season, bringing in $5,000.

In the early fall, Bill Der and his son Spencer took on two mountaneous challenges: climbing Mount Kilimanjaro despite Bill being legally blind, and raising $25,000 for individuals with Down syndrome. Though Bill had to stop climbing just short of the summit, Spencer made it to the top. There was no stopping them when it came to fundraising, though, as they exceeded their ambitious goal.
2016 was a banner year for DSRF fund development, as supporters new and old signalled their commitment to empowering individuals with Down syndrome through a tremendous outpouring of generosity. This has enabled us to expand program offerings, open satellite locations and serve more families, in fulfillment of our 2015-17 strategic plan.

Record fundraising results were achieved in a number of our staple events, including the BMO Vancouver Marathon, Benefits of Boccé, the DSRF Christmas Breakfast and, most significantly, Run Up for Down Syndrome, which exceeded the previous best year by 30% and topped $100,000 (net) for the first time.

Likewise, 2016 marked a new high in personal donations - a significant achievement in a year in which many non-profit organizations experienced decreases. Through your giving, you have enabled DSRF to expand in both scale and scope, and provide much-needed services for the Down syndrome community both locally and globally. However you have supported DSRF, whether as a monthly partner, a one-time giver or as a participant or volunteer at one of our events, thank you for your investment. You are changing lives and providing a bright future for children and young adults with Down syndrome and their families.

With your continued support, we look forward to exploring new opportunities and making an even greater impact in the years ahead. To learn how you can empower individuals with Down syndrome as a Triple-21 partner, visit DSRF.org/Triple21.

THE DNA OF A PARTNER [BONNIE CYRE]

I think DSRF brings an essential service to the community that wouldn’t otherwise be here. When I originally found out that families with children with Down syndrome do not receive equal support from the government, I was quite surprised. The Triple-21 program allows families to enrol their child. The programs that DSRF offers are wonderful, but there is a funding gap. A little bit of money from someone like me - $21 a month or $210 a month – will help DSRF bridge that gap between the cost and what is affordable to the families.
EMPOWERING INDIVIDUALS WITH DOWN SYNDROME TO REACH THEIR FULL POTENTIAL