Please Help Us Help Others!

The DSRF has helped thousands of families, children and young adults with Down syndrome for the past thirteen years. We are recognized, world-wide, as providing the very best in education, training and support to improve the abilities of people with Down syndrome. Direct your donation towards your favourite program or project, purchase specific materials, or make a general donation.

We rely on your support. The ever-increasing demand for our services means now, more than ever, donations from our supporters are vital to ensure our continued success. Every dollar makes a difference. Please help us continue our work by sending your tax-deductible donation today.

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Welcome to the winter issue of Hand in Hand. We thought it appropriate to conclude the year with an issue on celebrating success. It contains articles that not only highlight the achievements of students and programs at the Down Syndrome Research Foundation, but also success stories from other organizations both near and far.

Staff member Hina Mahmood provides an article about this year’s George Klukas Award winner, Mark Stevens. While program director Joy Hayden discusses the equal opportunity employment program at Aquasafe. Our speech and language pathologist, Susan Fawcett provides an overview of a new program at DSRF. And our Latch-On students share some of their proudest moments.

Down Syndrome Research Institute founder and director, Andy Loebus shares some of the success stories from his organization in Ontario. And Greame Brown tells the story of a successful dance troop from Australia.

Merry Christmas and a Happy New Year to all our members and supporters, and we look forward to being a part of your plans for the new year!
A Word from DSRF’s Executive Director

Dawn A. McKenna

Sometimes the world seems like an unhappy place. When we try to catch up on the latest news, either in the paper, on TV or on the radio, it’s very often bad and unpleasant. Whether local or international news coverage, there are accidents, property damage, strikes, protests, wars, economic woes, and so on. Similarly, we as a society too often focus on the challenges or disabilities of people with Down syndrome or other intellectual disabilities. Not often enough do we focus on the positive aspects or the potential of individuals with Down syndrome. This issue focuses on and celebrates their successes!

We have received submissions from as far away as Australia, Ireland and Ontario which showcase a variety of programs and the successes achieved through these initiatives. From a simulated one-day parliament for individuals with Down syndrome, to educational programs, to a rock and roll dance club, the achievements and successes are impressive. For those who dare to dream, or challenge the concept of ‘disability’, success is a possibility and a reality, not an unrealizable fantasy.

As an organization whose mandate is to maximize the ability of individuals with Down syndrome, we also challenge disability and celebrate every success, no matter how big or small. We congratulate the initiatives and the work of all the organizations who work, as we do, to try to enhance their potential.

Also in this issue are updates on past events including the 10th World Down Syndrome Congress, details on research, an update on the Latch On program, and information on upcoming programs and events.

November 1-7 was Down Syndrome Awareness Week in Canada and to celebrate DSRF held a concert and Halloween costume fashion show at our Centre. The headliners of the event were the children in their great Halloween outfits, and of course the incomparable Gabrielle Embley or its staff.

The views expressed in the newsletter’s articles are those of authors and do not necessarily reflect those of the Down Syndrome Research Foundation or its staff.

Readers are welcome to excerpt or reprint portions of this newsletter if they notify and credit the DSRF.

A DSRF Publication

The 1st International Synod of People with Down Syndrome

Pat Clarke,
President, Down Syndrome International

The 1st International Synod of People with Down Syndrome took place in Dublin on the 19th August 2009 at the historic and picturesque Royal Hospital Kilmainham, The Synod preceded the 10th World Down Syndrome Congress. It was the culmination of four years of planning and trials, to get the most out of the event and to ensure that people with Down Syndrome had a proper opportunity to meet their peers from across the globe and discuss issues that affect their daily lives.

A forum where people with Down Syndrome could have an opportunity to have their views and opinions heard

Prior to the event Down Syndrome Ireland began a series of training programmes for its people with Down syndrome who were participating as ambassadors for the congress. Others from Ireland joined the Synod separately. A short position paper was distributed to all registered participants in advance of the Synod to enable them to prepare and to seek assistance if it were needed.

The event began with an opening ceremony where the Lady Mayors of Dublin, The presidents of Down Syndrome International and Down Syndrome Ireland as well as the Chair of the 10th World Down Syndrome Congress addressed the gathered participants. There were 120 people in attendance and 20 countries were represented. The topics chosen for the first Synod concerned Citizenship and Living in the Community which included Employment and Social Interaction.

After the opening ceremony the participants were addressed by Ms. Mairead McGuinness who is a Member of the European Parliament. Ms McGuinness spoke about active citizenship and being involved in community and political life. She further advised that like all walks of life the movement for change had to come from people with Down syndrome themselves.

The participants then broke up into smaller groups for discussions and this had the effect of breaking the ice and getting them to feel comfortable speaking and expressing their views very different forms of communication. The Synod was a powerful event and a final report of the proceedings, issues and outcomes is being finalized for publication.

Gabrielle Embley
DSRF Executive Director

Hand-in-Hand is published four times per year and is available by purchasing a membership from the DSRF ($35 CDN annually). To receive your membership and newsletter subscription, please send your name, address and telephone number along with the fee to the address listed on this page. Back issues of the newsletter can be obtained, for a cost of $5 each, by contacting our office.

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www.dsrf.org
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The Down Syndrome Research Foundation depends upon the generosity of numerous donors and sponsors to help provide the funding for our programs and services. The following people or organizations have provided us with their support for our vision.

Thank you for your generosity!

Burnaby Supported Child Development $25,000

BMO Employee Charitable Fund $5,000

CKNW Orphan’s Fund $4,500

Sook Ching Foundation $3,000

LBSC Literacy BC Society $250

Simon Fraser Society $390

UDMD Donors & Sponsors

The DSF’s Up the Down Market Dinners are supported by many corporations and individuals, too numerous to mention. But we would like to acknowledge our National, Silver and Major sponsors, who continue to support these events year after year. Without their support the event would not be possible. Many thanks!

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When Opportunity Knocks on the Door

Joy Hayden & Marion Kirk

Nestled in one of West Vancouver’s beautiful harbours is a company called Aquasafe Systems. When you stand outside the front entrance you have a panoramic view of the ocean, palatial homes and boats coming and going. On the front door is a sign saying “equal opportunity employer”. Inside you will find three employees Grace, Mark and Charlotte intensely focused and hard at work learning the intricate task of assembling water filters.

This unique staff team came together when Kim Taylor, a West Vancouver business woman approached the DSF with a potential employment opportunity. After recently purchasing Aquasafe Systems, a water filtration distribution business, Kim knew that the assembly division could be driven by individuals with Down syndrome and approached the DSF. Recognizing this as an incredible opportunity, we were thrilled.

It did not take much convincing on our part to participate but we did need to take into consideration the safety and training of our students and from there a partnership between Triumph Vocational Services and the DSF was formed.

Michael Hawkins, the Executive Director of Triumph understanding the value of this partnership, provided funding to hire a job coach. Michael says “Triumph is more than pleased to partner with DSF. Through our expertise in planning, assessments job development and job placement coupled with the expertise and long term knowledge the DSF has on Down syndrome this partnership provides exceptional client centered services to our mutual clientele”.

Early September, Marion Kirk was hired as the job coach to train DSF students Mark, Stevens, Charlotte Evens and Grace Chen. Kim’s vision is for the students to participate in all areas of the business from reception to data entry to assembling the systems. So to realize that vision the first order of business for Marion, aside from bus training, was to set up stations with visual and printed instructions, where the many detailed components of assembly could take place.

Each station requires concentration, fine motor skills, (something that does not come easy to people with Down syndrome) and patience. The students and Marion are learning and adjusting as they go. Yet like any of us, natural strengths and skills surface and in just a short time, each student found their niche.

Grace has an eye for efficiency and quality. She is able to look at the process and recognize how it can be “easier”. Using Grace’s skill Marion had her write the instruction manual which can be referred to at any time to refresh memories.

Aside from exceptional data entry and reception skills, Charlotte is the team builder, she knows when frustrations are mounting and will redirect the group with a laugh or a positive comment. She is very interested in learning more about the shipping and receiving part of the job and with her organizational skills she will be very proficient in that role.

Mark’s job is assembling the actual filter canisters. He has been able to set up his station in a way that he can do the entire process without any support and has complete ownership of his area. Mark’s production has progressively increased as has his confidence. It is his favourite place to be and he looks forward to going to work.

Some people may question the employability of people with Down syndrome, but for Kim, she has never looked back, it is the best decision she ever made. Kim sees what each of her new employees bring to their job and she looks forward to a very successful business and hiring more individuals with Down syndrome.

About Aquasafe Systems

Aquasafe Systems was conceived with the vision to allow every home the ability to have a drinking water station that delivers the purest water possible on demand. Through research and development this vision was quickly realized. Their water purification systems employ state of the art filtration processes that result in 95-100% pure water. Drinking water produced by Aquasafe Systems is free of any harmful chemical conditions and pathogens that are known to cause various forms of health related issues. Aquasafe also caters to the salt water Aquarium hobbyists by offering its line of Aquariums water filtrations systems. These systems have been in production since the conception of the company and are now the standard for Aquarium filtration.

Aquasafe’s goal is to remain a leading provider in home water purification. This goal is achieved by never compromising quality while simultaneously staying below the cost of the competition. This model allows for a great majority of people to experience the extraordinary health benefits and monetary savings of employing in home water purification.

Donation

On November 12th, DSF’s Executive Director Dawn McKenna spoke at the Rotary Club of Lions Gate. As a thank you the club donated the equivalent of 20 polio vaccines by making a contribution to the Rotary Foundation Polio Plus Program on behalf of DSF. For more information about the Rotary Foundation Polio Plus Program please visit www.rotary.org.

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What is Success?
Jake Stone
Early Foundations Preschool Practicum Student
In this article I talk about success and its possible relation to happiness. Before we talk about success for children with Down Syndrome, we need to consider how we understand success not only for ourselves but also for the people we care about. We all seek success and must travel a unique path and attain it under our own unique conditions. These paths to may differ for children with Down syndrome, but still depend on our understanding of success.

The hope of any parent, teacher or researcher connecting with the children we care about is that they grow into happy and successful people. Perhaps we could refine this by simply saying we want our children to grow up happy.

Success depends on those around us recognizing and supporting our personal goals, helping us find new goals and keeping our goals at the right level of challenge and meaningfulness.

After all, isn’t being happy, in itself, a way of being successful? Then again, can anyone be happy without being successful?

How then does one achieve the goal of happiness? There are few, if any, arguments that happiness resides solely within the mind. Even Buddhism, which suggests that true happiness can only occur after many lifetimes of disciplined mindful practice, stresses the importance of how people engage with their fellows. Few, if any, Western psychologists or philosophers suggest that happiness is truly determined from within. The burgeoning field of positive psychology (or the psychology of happiness) emphasizes the importance of successfully engaging with others—as did the philosopher Annette two thousand years earlier. Happiness, contemporary psychology suggests, depends on a feeling of involvement with the activities that surround us and also a perception of the self as successfully engaging with others.

And so, one might argue, to achieve happiness one needs to perceive successful engagement with one’s world. Perhaps success is a condition for happiness. If so, it is easy to understand why we aim to bring success to the people that we care about. We want to bring success because we want to bring happiness.

If we want success for ourselves and the people we care about, we need to know what success is. Let’s consider some possibilities.

Possibility one: Success does not exist. That is, success is a fleeting notion of our society. Success has no more basis than Ancient Greek notions of muses. A brief review of eighteenth century journals and newspapers offers some credence to this possibility. Two hundred and fifty years ago, people were not described as successful. Rather strategies and plans were successful. Success simply meant achieving a goal or continuing from one goal to the next. Referring to people as successful became more common in the nineteenth century—perhaps with the social mobility of the industrial revolution.

And yet, there are two ways in which success clearly does exist. It would take a highly imaginative philosopher to suggest that the achieving of a goal is non-existent. A child tries to button her coat. Success.

Notice that the pattern of activity in both conditions is very similar. In contrast, we found some striking differences in individuals with DS (see Figure B).

Possibility two: Success is determined by our social values. If success, in terms of being a successful person, came into existence with social mobility, then it may be a norm created by society; a norm against which each one of us is measured. We can ask whether a twenty five year old minor league hockey player is successful. It is hard to come up with an answer to such a question without NHL contracts springing to mind. For example, I may say to myself, “well, he didn’t make the NHL, but ....” It would seem then that social values are at least partially determining of how we understand success.

And yet, it is not society that thinks “he didn’t make the NHL,” it is my own understanding of social values. Social values may play a role in determining what success is, but so does individual reasoning.

Possibility three: Success is a biological mechanism that may mean no more than the achievement of a functional act. If a frog catches a fly, that is the success of a functional act. Moreover, people, just like other biological organisms, seek to maintain an equilibrium with their surroundings—an equilibrium that some would say is associated with our feelings of happiness. As with animals, people are innately “driven” to seek that equilibrium and hence it might be argued, people are innately driven to succeed.

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The Mirror Neuron System in Down syndrome

When considering the motor development of children with Down syndrome (DS) or other developmental disabilities, the primary focus has been on identifying strengths and weaknesses in relation to achieving developmental milestones. Viewed from this traditional developmental framework, DS has long been associated with delays in cognitive and sensory-motor development. However, our ability to interact with, and understand the world around us is not simply based on how well we perform movement, but the interaction of a number of factors in the environment. These include perceptual information about our own actions, the impact of these actions on the external environment, and social-cognitive information related to perceiving and interpreting the actions, intentions and emotions of others.

Our focus at the DSRF over the past few years has been directed at understanding how individuals with DS process information about the world they interact in. Specifically, we have been examining the interaction between action, and the physical and social environment. The link between perception and action has recently received a lot of attention with the discovery of “mirror neurons”. These neurons are activated both when a person performs an action, and when the person observes the same action performed by another person. This mirror neuron system is thought to play a crucial role not only in how we understand the actions of others but also how we interpret the emotions of others.

Given the difficulties in perceptual-motor processing evident in individuals with DS, we hypothesized that there may be a dysfunction in the mirror neuron system in DS. We investigated this hypothesis by asking adult participants with and without DS to lift a coffee cup, and then observe someone else lifting a coffee cup. We imaged participant’s brains using magnetoencephalography (MEG) under both conditions (Virji-Babul, Moiseev, Cheung, Weeks, Cheyne, & Ribary, 2008).

Figure A shows the activation in the brain in one adult without DS when she is lifting the cup and when she is watching someone else lift a cup.

Figure A: Adult without Down syndrome

Movement Performance

Movement Observation

Research at the DSRF is conducted by a unique group of scientists covering a broad range of disciplines to understand disability and translating research findings into services that optimize skill in affected individuals. Core leadership comes from our team of DSRF Principal Investigators who hold posts at major universities and health centres across British Columbia and beyond. The interdisciplinary nature of research at the DSRF is opening new domains of investigation in basic and applied science and suggesting new approaches to enhancing quality of life for people with Down syndrome and other disabilities.

possibility five: Success is measured against the expectations of those around us. We have already touched upon this with the “looking glass self.” There is some consistent evidence from the social sciences, such as psychology, sociology, and anthropology that success is substantially determined by the expectations of those close to us. While Bill Gates, NHL athletes and movie stars may set a distant backdrop to our lives, it is the expectations of those we share our lives with on a daily basis that help us set our personal goals and help us recognize our own success. This is one reason why the children of professionals are more likely to become professionals and the children of successfully married couples are more likely to stay married.

And yet, even though success may be substantially measured against the expectations of those around us, social values are still a strong influence. Typically, we don’t expect our children will become successful mule drivers or be a successful spouse to multiple wives or husbands. Goals, success and happiness also have biological requirements and depend on personal goals.

Success is multifaceted and depends on a balance of all the aspects we have discussed. There is no simple answer to the question “what is success?” There is plenty of room for each of us to make up our own mind about this. There is, however, a simple and important take home message that applies to us all. We will all be continually perturbed from feelings of happiness and well-being. We will all seek success in order to maintain or restore these feelings. We will all be buffeted by social demands and influences and struggle to find manageable and meaningful personal goals.

Jake Stone is a Ph.D Student in Education Psychology at Simon Fraser University who is currently completing a practicum at the DSRF Early Foundations Preschool.

Naznin Virji-Babul, P.T., PhD DSRF Director of Researcher
Everyday Success at DSRI

Andy Loebus & Marjorie Shields, Down Syndrome Research Institute

My name is Andy Loebus and I am the director and founder of the Down Syndrome Research Institute, located in London, Ontario.

My wife Jennifer and I started our journey into the world of Down syndrome when our fourth son Kristov was born in Pakistan. His birth was by no means normal. We were hosting a Halloween party with costumed ex-patriots in the remote community of Gligit, two hundred miles south of China in the middle of the Himalayas, where Andrew and I arrived just prior to 9/11. After having lived over a year in isolated conditions with little or no support, I was excited by the opportunity to get the help of our local Down Syndrome Society (CDSS) conference held in St John, Newfoundland. My eyes were opened to the possibilities for our kids when I was entertained by a young man with Down syndrome who could play five musical instruments at a concert level. I met many young men and women who were living independent lives and their success led me to hope for my own son, that he could also one day live his own life, independent from his parents.

I was motivated and truly touched by a presentation by Jo Mills, the original founder of CDSS and also the founder of the Down Syndrome Research Foundation. She started her organization out of a trailer, training young adults in numeracy and literacy skills so they could be functional in the workplace.

Back in London, I realized the deficiencies of inclusionary education without the appropriate support of professional development for staff to provide the basic knowledge of what it takes to effectively teach our students. Kristov was falling through the cracks, and I was unwilling to allow this to happen. In 2005 I set up the Down Syndrome Research Institute, a summer secondary school composed of 8 students. Over the years, we have developed unique models designed to offer optimum support for our students. We practice total collaboration between professional teachers and speech pathologists who all work with the students in the morning literacy, numeracy and communication sessions. This year in 2009 we had 43 students working in secondary, elementary and pre-school settings. Families from all over the province have attended our school. We also have Ontario affiliates in Peterborough and in York Region.

From five years of offering summer programs, homework clubs and our personal insights in raising our own son, we are quite fortunate to have many success stories to tell. They may not be as grand as playing musical instruments or as powerful as communicating in five languages, but all accomplishments dramatically impacted the student, their family and the teachers and professional staff who work daily with these wonderful kids and young adults.

Here are a few success stories that make all of our efforts worthwhile.

E was a young lady who read and wrote well enough that she could keep minutes at a student meeting. The praise she received for these abilities she accepted with composure. She didn’t seem to think such gifts were very important. Then came the day during gym when E scored her very first basket. She was delirious as she told us that it was her first, the first time the ball had gone through the hoop. The praise that poured down from other students and staff she accepted with pleasure. The moment was a highlight of our summer and a momentous event in E’s life.

GIFTS: Mothers Reflect on How Children with Down Syndrome Enrich Their Lives

Kathryn Lynard Soper

Woodbine House 2007

Having a baby with Down syndrome is not something most parents would willingly choose. Yet many who travel this path discover ich, unexpected rewards along the way. in this candid and poignant collection of personal stories, sixty-three mothers describe the gifts of respect, strength, delight, perspective, and love, which their child with Down syndrome has brought into their lives.

The contributors to this collection have diverse personalities and perspectives, and draw from a wide spectrum of ethnicity, world views, and religious beliefs. Some are parenting within a traditional family structure; some are not. Some never considered terminating their pregnancy; some struggled with the decision. Some were calm at the time of diagnosis; some were traumatized. Some write about their pregnancy and the months after giving birth; some reflect on years of experience with their child.

An exceptional memoir that provides emotional support for parents, and practical advice. It’s like planning a trip to Italy, only to get off the plane and discover youre actually in Holland. You need a new road map, and fast... When Jennifer Groneberg and her husband learned they’d be having twin boys, their main concern was whether they would need an addition on their house. Then, five days after Avery and Bennett were born, Avery was diagnosed with Down syndrome. Here, Jennifer shares the story of what followed. She dealt with doctors-some who helped, and some who were disrepectful or even dangerous. She saw some relationships in her life grow stronger, while severing ties with people who proved unsupportive. And she continues to struggle to find balance in the hardships and joys of raising a child with special needs. This book offers a resource, a companion for parents, and above all, a story of the love between a mother and her son, as she learns that Avery is exactly the child she never knew she wanted.

Common Threads: Celebrating Life with Down Syndrome

Cynthia S Kidder and Brian Skotko

Bard of Angels Press 2001

Common Threads: Celebrating Life with Down syndrome is an essay and photographic celebration of inspirational accomplishments of people with Down syndrome. Photographs are by nationally recognized Kendra Dew. This book is a perfect inspiration for new parents of a baby with Down syndrome. It is also ideal for parents of older children who see the great potential in their child. Common Threads received the 2002 National Media Award for print publication by the National Down Syndrome Congress. Recently, the book also received the Excellence in Media award from the State of Massachusetts.

Cynthia Kidder is the mother of three sons, the youngest of whom has Down syndrome. She is a writer and presenter to families and educators regarding maximizing the potential of young people with Down syndrome. Brian Skotko is currently in his third year as a student at Harvard Medical School. He has two sisters, one of whom has Down syndrome and has committed a great deal of his professional energy to increasing awareness of the capabilities of persons with Down syndrome.
to be an individual characteristic that is relatively stable from early childhood to early adolescence. The finding that early mastery motivation is significant for later achievement has important implications for the focus of early interventions.

The Down syndrome advantage: fact or fiction?


The “Down syndrome advantage” is the popular conception that children with Down syndrome are easier to rear than children with other developmental disabilities. We assessed whether mothers of children with developmental disabilities would demonstrate a consistent Down syndrome advantage as their children aged from 12 to 18 years. Results did not reveal significant differences between mothers of children with Down syndrome and mothers of children with other developmental disabilities on most maternal functioning variables. Although the prior group reported a consistent advantage in terms of personal reward and subjective well-being, these diagnostic group differences disappeared when maternal age and child adaptive behavior were controlled. We concluded that these variables may help to explain the Down syndrome advantage.

Samm's Journey to "Reach for the Stars"

Mayer, S. Exceptional Parent, v37 n2 p34-36

In this article, the author shares her experiences as a parent of a child with Down syndrome. Although her son Sam’s first years were filled with numerous hurdles and visits to pediatrics, which she feared would further delay his development, she soon discovered an organization (NACD) and a National Association of Child Development (NACD), founded by Robert J. Dorman, Jr. NACD’s programs are based on the belief that all children—challenged, typical or gifted—can learn faster and accomplish more if they are provided with the opportunity. The key to success is parental involvement. NACD has, over its twenty years of existence, related to its work with 25,000 clients, developed a unique and effective view and approach to enhancing the development and function of children and adults.

D spoke very little. He used some informal signs but mainly relied on others to anticipate his wants. He was in the group which was to buy groceries for breakfast and to prepare and serve the meal for staff and students. He was uninterested in the purchasing, but next day, helped lay out the food. When the dinners appeared, he carefully asked each person to choose “cereal or toast?” “orange juice or milk?” D smiled throughout his stint as head waiter and didn’t eat himself until everyone else had been seated.

When we introduced drama as a major component of the summer school, we had teachers and assistants help students plan short scripts and simple actions for their skills. The students loved the chance to perform. By the next day students, more talented students no longer needed adult assistance. One peer, confronted with the task of thinking up a scenario to illustrate a use for the question, “Can you help me?”, put on a skit that had D as an actor on stage foraging his lines, worried and nervous, until he breaks down and asks for help from V who immediately replies, “I’ll help you. We’ll do it together.” The audience saw a situation where asking for help made sense while they thoroughly enjoyed the performance.

D had both physical and emotional problems and was often a discipline question mark. During one noon break, he asked a teacher to dance with him. She accepted but very gingerly, holding herself stiffly, his hand at her side. D told her to put her hand on his shoulder, and the dance went better after she complied. It was a slow piece of music and D kept good time. At the end of the dance, he stepped back, bowed formally from the waist, and thanked the teacher for her dance. When she raised herself by his grandmother, and his sense of old-fashioned courtesy had implanted itself in the young man and it overrode his fear and disbelief. We could not believe that she took such a bold risk as leading a class in anything, especially dance.

Samm had enjoyed his time too.

For information about the Down Syndrome Research Institute visit www.dsrri.ca.
Club Slick: Rockin’ All Over the World

Graeme Brown
Club Slick Coordinator, Down Syndrome Society of South Australia Inc.

In 2001, the Down Syndrome Society of South Australia conducted a survey amongst members. An issue identified was that parents would like to see more involvement by people with Down syndrome when it came to promotion, fundraising and public awareness. Essentially, doing it for themselves and not having everyone else do it on their behalf.

Through a small series of events, we ended up with 31 people with DS, aged 10 – 31, who were interested in attending 50s & 60s Rock n Roll dance classes hosted by the Executive Director, Vicki Brown and myself, early 2002. We had decided to produce a show performed by members with DS, as our major fundraiser so that they would be ‘doing it for themselves’.

I still recall comments by a couple of parents who said “you’re gonna do what?” and “Good Luck”. After 3 months of Sunday afternoons learning the basics of live and a further 3 months of Sunday afternoons learning their roles in a seven act show, we presented ‘Slick...following in the trail of Grease’. The response by the capacity house where the troupe performed, was deafening! As staff, we hadn’t silenced the critics...the performers had.

Later that year we launched a Rock n Roll Club for all people with intellectual disability. This would be their night club to rock n roll. Demonstration Team and Show performers constantly impress onlookers with their team spirit, public social behaviour, professionalism and confidence. This was highlighted when staff, families and performers attended the 9th World Down Syndrome Congress in Vancouver, Canada. Canadian delegates were invited to join the Club Slick performance at the Gala Dinner. After just a few rehearsals, new friendships were formed and our guest cast members from the other side of the world learnt a new dance style and could be proud of their latest achievement.

This year 14 people with DS, supported by families and staff, ran two dance workshops at the 10th World Down Syndrome Congress in Ireland. The culmination of their hard work was a fifteen minute performance at the Congress Gala Dinner which was met with a standing ovation and shouts of “We want more, We want more!”

Club Slick has become something of an institution in South Australia for so many people. Some patrons who have initially come along lacking a little self confidence, have grown in so many areas. Others who may have been considered “unruly”, want to join in with their peers and have readily adopted the ‘Team Spirit’.

Seven years ago, there was a 14 year old girl who started dance classes. She would only talk to her family and closest friends and would not interact with anybody outside of this circle. Today, she is a beautiful, confident young woman who has rarely missed a Club night, performed at numerous demonstrations and been a cast member of every international show. She has achieved more than anyone thought might be possible, in such a short space of time... I guess you just have to find the right button to press sometimes.

There are many stories like her’s at Club Slick. Sometimes it’s just about giving opportunities and a little support to find out how much someone can achieve.

Two years ago, the Down Syndrome Society of South Australia also began a junior club for 5 – 12 year olds with Down syndrome and other disability. The future is so bright for these young people and we are sure we will see them on the world stage soon.

Our philosophy is that “it is not about being the best, but being the best that you can be, beyond others’ expectations.”
Latch-On; Literacy Beyond School
Anne Jobling, on behalf of the Latch-On team

Although some researchers have prescribed to a narrow and restricted view of development in individuals with Down syndrome, this has not been the case for those of us who have worked as researchers on the Down Syndrome Research Program (DSRP) at The University of Queensland since 1977. From our initial work with infants through to our later work with adolescents and young adults, the researchers have continued to challenge the typological thinking often found in textbooks and the community.

As a result of our confidence in the competence of young people with Down syndrome in 1997, the Latch-On (Literacy and Technology-Hands On) program was established. This program brought together the considerable research of the DSRP, the growing needs of parents for some educational programs post school, and the considerable knowledge and experience of Dr Karen Moni in literacy education and secondary English curriculum.

To begin with, a literacy program was established in the School of Education at The University of Queensland with the help of funding through the then Disability Services Queensland “Moving Ahead” program. This program adopted a socio-cultural approach to literacy and used as its theoretical framework the Four Resource model, a model that has been developed for use in both primary and secondary school literacy programs. Dr Moni and I developed the curriculum, taught in the program and employed additional teaching staff, and soon Jan Lloyd and Michelle Morgan became an integral part of our continuing team. We decided that the program would be for two years post school and would be operated for each student two days a week from 9am – 3:30pm. Initially all our young adults were those with Down syndrome, but after the first two years students with other intellectual disabilities joined the program. The Latch-On program has four core modules (each module is one semester long). They take the student on a journey, moving their thinking, ideas and experiences from their own family into the community at large.

After five years at the University the program moved into the community, and since 2003 the Endeavour Foundation, a community-based service for individuals with intellectual disabilities in Queensland Australia, has had an exclusive license to operate the program. From 2008, programs have been operating in Brisbane, Townsville, and Bundaberg and in 2010 it will be established in two more regional centres.

This partnership was recognised with a University of Queensland, Social and Behavioural Science Faculty Research commercialisation award.

In 2007, we had interest from the Community College sector on Vancouver Island and the Down Syndrome Research Foundation in Vancouver, Canada and together they have been able to obtain funding through the British Columbia Provincial Government to start the program. In August 2008 Jan, Karen and I went to Vancouver Island to train six teachers. In 2009, four are working on Vancouver Island in classes at North Island College and two are working in the program in Vancouver that is attached to the Down Syndrome Research Foundation there. This is all very exciting. In September, 2009 we all met again for a two day professional development workshop and progress has been great. We are very hopeful that the program will be able to continue.

We are unashamedly delighted that this program has its birth in Queensland, Australia and hope that many young adults will have an opportunity to experience Latch-On and be able to develop their literacy skills. Please visit www.latch-on.net for publication details and other information.

Rick Scott Concert
To celebrate National Down Syndrome Awareness Week (November 1st – 7th), our Goodwill Ambassador, Rick Scott performed a concert on Sunday, November 1st. Many families attended, with children of all ages joining in the fun and showing off their Halloween costumes!
The George Klukas Achievement Award Recipient; Mark Stevens

Hina Mahmood
DSRF Administration

This year’s George Klukas Achievement Award recipient is a shining example of strength and perseverance. He has overcome more in one year than some people do in a lifetime.

Mark Stevens is a 22-year-old student who is currently enrolled in the DSRF Latch-On adult literacy class and has also been involved with the Employment Training Program as well as Summer School.

However, last year proved to be a challenging and difficult one for Mark as he missed a significant portion of his classes due to a 21-month hospital stay that left him incredibly weak and exhausted.

Mark is a favourite among his classmates. Despite the challenges that lay ahead of him, he never once lost his smile and positive attitude. He not only worked hard to catch up with his school work, he continued to participate in his extra-curricular activities. Mark is an avid Canucks fan, and enjoys listening to music, watching movies and going to the gym.

Mark was recognized for his strong work ethic and commitment, which is evident in his improved ability to read, write and communicate. This is an important year for Mark because not only will he be graduating from the Latch-On program, he is also taking on a new challenge as an employee of Aquasafe, a water filtration company where he works at the assembly line.

Mark is also involved with the Employment Training Program as well as Summer School.

In the 6-week pilot program, run by a Speech-Language Pathologist and two trained volunteers, the students worked on improving conversation skills and using clear speech. Conversation skills included showing interest in others by asking questions of peers, how to keep a conversation going, and what to do if you don’t understand someone.

The teenagers practiced these skills with one another in the comfortable, familiar environment of the DSRF, and then we took the skills into the community. The students visited a variety of community locations, including Science World, a bookstore and a restaurant. The teenagers were encouraged to interact independently with one another, as well as members of the community, e.g., store clerks and servers. We found that the students were generally reluctant to do this at first, perhaps afraid of not being understood or just used to parents or other adults carrying out these tasks for them.

But all of them seemed to stand just a little taller when they were able to interact with a peer or community member on their own.

For details on or to register for the Chat Pack program, please contact Hina at hina@dsrf.org or Susan at susan@dsrf.org.

Photo (from left to right): DSRF staff members Hina Mahmood & Susan Fawcett, with Chat Pack members Andrew, Sadie, Karen, Matt, Austin and volunteer Karen.

Introduction to Chat Pack

Susan Fawcett
DSRF Speech & Language Pathologist

Some of the Sinatra fans amongst our members may catch on to the “Fat Pack” reference in the name of our newest social language program for adolescents. In fact, this feeling of a “pack” of pals cavorting around town, perhaps even making mischief, is the focus of this program.

We know that teenagers with intellectual and social disabilities are motivated to improve their social communication skills. They want to have boyfriends or girlfriends, lasting, meaningful friendships, or good relationships with coworkers at a regular job. At the DSRF, we have incorporated a social language focus into many of our programs, from the Latch-On program to Language Express in the summers. While this is a good start, what has been missing is helping the students generalize newly learned skills to other environments. Being able to have a conversation in a classroom is good, but not of much use if you forget how to have one once you are with friends in your community. This is what we have been seeking to do with the implementation of the Chat Pack program.

In the 6-week pilot program, run by a Speech-Language Pathologist and two trained volunteers, the students worked on improving conversation skills and using clear speech. Conversation skills included showing interest in others by asking questions of peers, how to keep a conversation going, and what to do if you don’t understand someone.

The goal of the staff working with the Chat Pack was to interact with the students as little as possible, therefore encouraging the peers to interact independently amongst themselves.

The teenagers practiced these skills with one another in the comfortable, familiar environment of the DSRF, and then we took the skills into the community. The students visited a variety of community locations, including Science World, a bookstore and a restaurant. The teenagers were encouraged to interact independently with one another, as well as members of the community, e.g., store clerks and servers. We found that the students were generally reluctant to do this at first, perhaps afraid of not being understood or just used to parents or other adults carrying out these tasks for them.

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Photo (from left to right): DSRF staff members Hina Mahmood & Susan Fawcett, with Chat Pack members Andrew, Sadie, Karen, Matt, Austin and volunteer Karen.

Chat Pack Success Story

Recently, while visiting Las Vegas, my daughter Sadie was able to meet one of her idols, singer Taylor Swift. Sadie was so excited to meet Taylor, who was very kind to her, engaging in conversations about school, clothes and all sorts of girl talk. Watching Sadie interact with Taylor was such a proud moment for me because not once was there any need for me to interrupt and clarify what Sadie was trying to get across. It was entirely their conversation with Sadie taking ownership of the dialogue and speaking clearly. It was a great feeling for both of us to witness how much progress she has made.

I think Chat Pack has given Sadie a great opportunity to go out into the community and actually apply what she has learned in the classroom and therapists office. I give it an A+ and would love for Sadie to continue with this program and strengthen her communication skills.

~Abbie Gates, Parent