Reaching Out

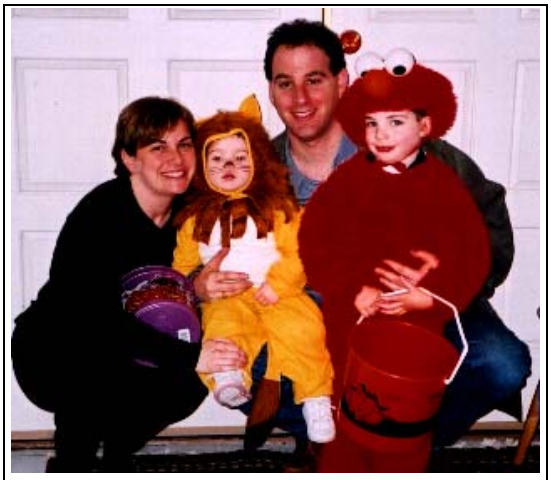
A Newsletter from the BC FAMILY HEARING RESOURCE CENTRE for Families with deaf and hard of hearing children throughout BRITISH COLUMBIA.

November/December 2002

Family Feature

A Roller Coaster Ride For Our Family

By Lisa Woogman



The Woogmans at Halloween:
(l to r) Lisa, Breanne, Dave & Noah

'A Roller Coaster' is how Lisa Woogman describes the time since she and her husband David learned that their son Noah has a mild sloping to moderate/severe sensorineural hearing loss. They find it hard to believe how far they have all come in the year and a half since the diagnosis. We recently asked the family if they would share their story with our newsletter readers. Here is what Lisa wrote about the highs and lows of life with Noah and his hearing loss.

Up - In the Beginning

Dave and I were married in 1996. Noah was born after 35 hours of labor and a C-section on May 21, 1998. He was the first grandchild on both sides of the family and was eagerly awaited. From the day he was born he was completely doted upon!

Noah's personality emerged very early on and was encouraged. He would stand in the middle of a restaurant and dance if there was music playing. We were in Mexico on a vacation when Noah was about 20 months old and he would get up on the stage every night after the show was over and dance with the performers. They all knew his name and on the last night they dressed him in costume and put him in the show. He loved it!

He still loves to perform and is also very artistic. He is very affectionate and sweet as well as being stubborn at times and a bit of a perfectionist. From the moment he started talking, which was about 15 months, he never stopped.

BC Family Hearing Resource Centre, #8-15355-102A Avenue, Surrey, BC V3R 7K1
Toll Free: 1-877-584-2827; Voice: (604) 584-2827; TTY: (604) 584-9108, FAX: (604) 584-2800
website: www.bcfamilyhearing.com; e-mail: elks@uniserve.com

Down - Discovering the Hearing Loss
When Noah was 2 years and 9 months his baby sister Breanne was born and there was a big adjustment from being the only child! When Noah was almost 2½ he started going to a 2 year old program twice a week. At one point the teacher mentioned that she thought Noah should get a speech assessment. We thought she was crazy, but we decided to pursue it. We knew there was a waiting list (for speech and language services) and thought that by the time we got in they would say everything was fine. We also decided to get a hearing test just to rule out hearing loss.

So when Noah was just over 3 and Breanne was 4 months old we went for the hearing test at the Richmond Health Unit, which came before the speech assessment. We had no idea what was involved. I waited outside and watched on a screen with no sound. When Noah came out, the audiologist said that he had a bilateral sensorineural mild to moderate/severe hearing loss. She then explained what this meant and that he should get hearing aids. I was in such shock because it was completely unexpected! It was difficult to not start crying right there.

When I came home and told Dave we both decided the testing must be wrong. We thought "He's only 3 so how reliable can it be? We would have known if there was a problem." We took him to get tested at a different facility and a second test back at the Richmond Health Unit. They all showed the same thing and at that point we couldn't deny it anymore and started making arrangements for hearing aids.

We then started thinking back to signs that we missed. We realized we were repeating ourselves a lot. Noah would say "Huh?" We thought this was developmental and he just didn't comprehend what we were saying. Since Noah was our first child we had nothing to compare to. We found out later that because he has a mild loss in low frequency sounds he managed to acquire most speech sounds and he was reading lips, so he was managing incredibly well.

Another incident that hit home was Noah had been using a 'musical toothpaste' for months. It's toothpaste that plays music when you open the cap. One day he had his hearing aids in while brushing his teeth and he said "What's that music?" We realized that he hadn't heard it the whole time!

Up - Facing the Challenges
We didn't really know where to turn. By coincidence we have a neighbor with a much more profound loss who was around 15 at the time. So we turned to him and his parents for information. We were very upset and definitely grieving. We worried about peer pressure and Noah fitting in as he gets older. Our neighbors were understanding but very nonchalant. They said "His hearing loss isn't that bad and he'll be fine." We couldn't understand this at the time but now we are closer to understanding where they were coming from.

After Noah got his hearing aids our biggest challenge was getting him to wear them. Helga and Wanda in Richmond Audiology, who we doubted at first, have been incredibly supportive and helpful, calling hearing aids 'super ears'. Noah only wanted to wear his 'super ears' when he went out to show people. We couldn't get him to wear them at home. At least he wasn't embarrassed about wearing them out. We were more worried about that and in fact had to fight the urge to tell him to take his aids out for pictures or special outings. It took a few months of encouragement to get him to wear his hearing aids all the time but he finally did. Sometimes he wants to take breaks but he always puts them back in.

Along with grieving we were obsessed with finding out the cause of Noah's hearing loss. One of our our biggest concerns is if it will get worse. Noah has gone through many tests including genetics and we still don't have any answers. We will probably never know why he has a hearng loss and will always be worried that it could get worse. We will monitor his hearing and hope. We try not to dwell too much on it because there is really nothing we can do. We also worry about Breanne but she has been tested twice so far with no signs of hearing loss.

About 2 months after Noah got his hearing aids we started with the BC Family Hearing Resource Centre, and began working with Kathy Cody. She has been a lifeline for us and Noah just loves her! Over the past year we have worked on speech and listening skills as well as working with Noah's preschool teachers. Noah's speech has improved dramatically and is now up to his age level. He speaks to his grandparents on the phone and they can understand almost everything he is saying and they keep commenting on how much clearer he is. He still loves to talk and sing a lot!

Having Kathy work with Noah's teachers has been very important. Most teachers have not worked with hard of hearing or deaf kids so its new ground for them. So far all his teachers seem eager to learn and we hope this continues.

One of our new challenges is to work with Kathy on Noah's ability to advocate for his own listening needs. Noah says "huh" a lot, or looks to me to repeat things. But he is about to enter kindergarten and I will be with him less. He will need to advocate for himself. We are trying to get him to say things like "Pardon me I didn't hear you. Could you tell me again". We want to work on handling when people ask questions about his 'super ears'.

Our other challenge is to decide which school to send him to and to get the support in place. We want him to go to private school where he will learn Hebrew and Judaic studies as well as the regular curriculum. There is a different process to go through to get help in a private school and we are going through that now. We worry if he can handle it but he is very bright and seems to learn easily. We want to give him every opportunity to succeed. We wish that the BCFHRC continued on past preschool!

Coasting Towards the Future

Our hopes and dreams for Noah and Breanne are to be able to do anything that they want to do, to be good people and good friends. We want for Noah to have the hearing loss be just a 'small thing' that makes him who he is not 'define' who he is.

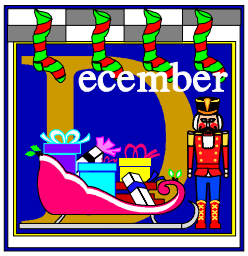
Our family and friends have been incredibly supportive, offering information they have come across or just being there to listen. Our family is extremely close and although a lot of our relatives live far away we make an effort to see each other often. It has been very important for us to have this support.

It has been a rollercoaster year and a half! Every so often something happens where it hits us again that Noah has special needs and things won't be simple for him. But then we think of the parents who lose their children and we realize how lucky we are. From our experience over this year I would tell other parents to ask a lot of questions, talk to a lot of people and keep going until you are comfortable with the answers. Above all else, love your children. Nothing helps them more than feeling loved.

On the Fly...Hints for Home

Count Down to Home For The Holidays

by Dyan Spear and Cathy Chow



The relatives are coming. The table is set. The food is cooking. Everyone is looking forward to catching up on the year. There are stories to be told and memories to recount. It can be a time full of sharing and receiving.

However, family gatherings may also be a big challenge for deaf and hard of hearing children and you, their parents. Difficulty with communication and noisy environments can place a child in a very stressful situation. What can you do to make this a positive and enjoyable time for your child and for you?

Lots! Here are 10 things you can do 'on the fly' to create a happy family holiday:

10. Be prepared for new experiences. Visit the library and get picture books to explain what will happen on that special day. Create your own book of drawings to describe the event. Who will your child see? Pull out the photo albums. Go through faces and names. Bring these books and albums with you in the car or to look at while dinner is being prepared.

9. Involve your child in the preparations for special events. Your child will benefit from all your wonderful family traditions and customs.

8. Repeat jokes and stories to keep your child involved. They may have missed it the first time.

7. Minimize background noise. Large family gatherings are challenging listening environments. Background music is great for the atmosphere but makes it impossible for your child to hear conversations. (It might take courage to ask your host to turn off the music. Be brave!)

6. Be patient with family members. Questions will be asked but think of this as an opportunity to educate both adults and children about hearing aids and communication strategies. Keep your explanations short and clear.

5. Be aware – don't compare. You will be seeing cousins, friends and their children. Sometimes this can be painful for parents when they compare the speech and language development of their own child to that of cousins the same age.

4. Focus on what your child can do rather than what they can't. Celebrate and share the exciting progress your child has made over the past year.

3. Relax and take time for yourself to enjoy and connect with friends and family. Find someone to buddy-up with your child to play with one-on-one while you catch up with the other adults.

2. Remember to support one another. Let family members know what is difficult for your child and how they can be supportive!

1. Love, laugh and celebrate! Have a great time with family and friends. You are building memories for a lifetime.

Sound Advice for Parents

by Terry Parson-Tylka, Teacher of the Deaf and Hard of Hearing

Typical classrooms are very noisy places! Improving classroom acoustics results in measurable gains in learning and speech perception for all children, and especially those with hearing loss.

Clear communication is an access issue for everyone. An optimal listening environment is essential for hearing and comprehension. Poor acoustics are a particular barrier to children with a hearing loss since even a mild hearing loss can have a significant impact on a child's ability to understand speech in a typical classroom.

What can parents do to ensure their children have access to education through optimal listening environments?

Learn all you can about acoustics. Here are some resources to get you started:

- Parents' Voices is a non-profit group dedicated to advocacy for classroom acoustics for functionally hard of hearing children. For more information on this group see their website at: www. parentsvoice.org
- Crandell, C. & Smaldino, J. Classroom Acoustics: Understanding Barriers to Learning. The Volta Review, 101 (5). Special issue on classroom acoustics.
- Classroom Acoustics, www.classroomacoustics.com
- Acoustical Society of America, www.asa.aip.org

Be aware of acoustics when selecting a program for your child and work with a team to advocate for changes where needed in your child's learning environment.

Even a little improvement to the acoustical environment can make a big difference to your child's learning. Consider these typical sources of noise and possible solutions:

- **noise from outside**: choose a program in a quiet location or provide noise isolation for the building
- **noise made by building systems**: apply noise control techniques such as centralized, ducted air conditioning; move teaching area away from the noise source
- **noise from adjacent spaces**: have doors and walls that isolate sound; keep doors closed
- **noise from inside the classroom**: choose teachers with good classroom management; use quiet equipment; make adaptations such as tennis balls on chair legs
- **reverberation (echo):** avoid rooms with high ceilings and hard surfaces; look for or request durable acoustic absorption for part of the ceilings and walls

In BC there is a working group called the 'School Noise Advisory Group'. SNAG was initiated by the Canadian Association of Educators of the Deaf and Hard of Hearing-BC when itinerant teachers became increasingly concerned about FM interference from poor lighting ballasts in schools. The group quickly became aware that ballasts are only one issue of many that impact accessibility to optimal listening environments for hard of hearing students in regular classrooms. SNAG members include: Teachers of the Deaf and Hard of Hearing, UBC Professors in the fields of Teacher Training, Acoustical Engineering and Electrical Engineering, an audiologist, a school principal and a representative of the BC Teachers Federation. Currently this group is compiling a check list on classroom acoustics for parents and teachers. For more information contact: Dr. Janet Jamieson @ 604-822-5262

Great Grads... Where Are They Now?

Reach for the Stars!

Chris Byrnes with Alayna Finley, and help from Dyan Spear, Teacher of the Deaf and Hard of Hearing and Leona Parr-Hamel, Interpreter

Alayna Finley

"Reach for the stars! It doesn't matter if you have a big dream," she added, "anything is possible." The words are those of 20-year-old Alayna Finley, but she has signed them rather than spoken them. I had asked: If you could give some advice to kids who are deaf or hard of hearing, what would you say?

Alayna was born deaf and she has been involved with the BC Family Hearing Resource Centre (formerly the Elks Family Hearing Resource Centre) since she was two years old, as a student – and now a volunteer.

I poke my head into one of the over-crowded rooms where parents, teachers, and children are playing, reading, and learning. We set up for the interview in the only available room at the very cramped BC Family Hearing Resource Centre, a now out-dated facility created some 19 years ago, largely through the hard work and benevolence of the BC Elks and Royal Purple Associations.

"I remember enjoying it here," Alayna says. "I really progressed. The Centre is a wonderful place because it's open and accepting. It feels like a second home. The staff helped me – and my family – with language, how to understand the world, speech therapy, improving language, socializing…"

"Who is your most inspirational person?" I ask. "My Mom," Alayna replies. "My parents have been a huge source of support to me – academically, socially, in sports. My Grandma who passed away in September has also been a great role model. She gave so much to other people. It was incredibly touching when people donated money in her name to the BC Family Hearing Resource Centre."

Alayna attends UBC, working on a degree in English Literature. The recipient of two scholarships, she is quite remarkable because literacy has typically been a challenge for deaf individuals, and she has excellent English and literacy skills. Historically, the average reading achievement for deaf students is around the level of grade four.

Alayna wants to be a teacher for the deaf. "I would love to come back and teach here," she signs. "It's really important for parents to have a place to go where the kids are accepted. I volunteer once a week with the preschool class and I'm also instructing sign language to help families connect with their child. It's challenging!"

When we say goodbye, I meet two young mothers of deaf children. They know all about Alayna. "I have two deaf children," commented Natalie Milne, "and it is important for them to have a good role model like Alayna. She's wonderful! It gives me great hope for the future!"

As I write this story, my eye is drawn to the Bright Futures capital campaign newsletter. The fundraising campaign is drawing to a close and the new facility is now being built at the corner of 152nd Street and 92nd Avenue in Surrey, yet help is still needed to meet the fundraising goal of $2.8 million. As I think about this, the logo for the Bright Futures campaign catches my eye, and the magic depicted brings a smile to my face. The logo pictures a hand reaching for a star.

Words of Wisdom (from Parent Group)

Equal Treatment Does Not Mean Equal Access

By Susan Lane, Director

"I treat all the children in my class the same. I would never treat a child with a hearing loss any different—I would never want them to feel different." This statement was recently made by a very caring preschool teacher. Her heart was in the right place. But does this philosophy really work for deaf or hard of hearing children who are integrated into a regular preschool or elementary programme? Well, yes and no. It is important for us to have appropriate expectations for a child's behaviour and achievement levels so that we help them acquire a 'can do' attitude. But the communication needs of a child with a hearing loss are different from those of a child with normal hearing.

In order to learn and participate at a level equal to their hearing peers, deaf and hard of hearing children need to have equal *access* to information. This may mean making changes or *accommodations* to the classroom environment, to the teaching style and habits of the teacher, or it may mean adding the services of a sign language interpreter. Deaf and hard of hearing adults face similar challenges in their lives. In order for a deaf or hard of hearing adult to fully participate in a meeting at work they may require a variety of accommodations including a quiet room, assistive listening device equipment, a captionist, or a sign language interpreter.

We want our deaf and hard of hearing children to grow up with enough knowledge, skills, and self-confidence to request the accommodations they need in order to fully participate in school, at work, and in their family and social life.

Let me introduce you to two young boys who are learning how to be excellent advocates for themselves. Curtis, age 6 years, and Brady, age 10 years. Curtis and Brady and their mother Lynn recently shared their experiences with our Monday Parent Support Group.

Curtis and Brady, who both have moderate-to-severe hearing losses, put their hearing aids on right after they take a shower in the morning and keep them in all day. They say their hearing aids are essential to them. But hearing aids don't 'fix' their hearing loss. In order to fully participate in conversations they need accommodations both at home and at school. This includes reducing the background noise level at home, changing communication strategies, using FM equipment, and in very noisy situations such as restaurants, their parents will sometimes use some sign language.

Children with normal hearing acquire a great deal of language and knowledge about the world by 'eavesdropping' on conversations of other family members. Lynn feels it is very important for her sons to have this same opportunity to 'overhear' conversations at home. She recognizes they have the same curiosity and need for information as children with normal hearing.

Curtis and Brady are fortunate because their parents are very aware of their listening needs. No one in the house attempts to have conversations with noise in the background. For example the family never has the TV or radio playing at the same time anyone is having a conversation. If the TV is playing and someone wants to say something the television is immediately muted.

Curtis and Brady use spoken language to express themselves and use speech-reading as well as listening with their hearing aids to receive information. To make sure communication is clear for everyone, their family has a house rule that when two people have a conversation they always give each other eye contact.

Lynn has this advice for other parents. "*As a parent your day is filled with repeating and commenting just to make sure your hard of hearing child can hear all of your message. It is so important to have patience. I have learned to never say "never mind" or "I already told you that twice." Because of their hearing loss they are not always able to understand clearly what other people are saying. I want them to learn to be advocates for themselves. They need to know it is okay to ask people to repeat themselves."*

(l to r) Curtis, Lynn and Brady Reeve

There are some challenging listening situations for Curtis and Brady at school and in sports activities. They find lunch time very noisy. Both boys are involved in many sports including soccer, golf, swimming, snow-boarding, and rollerblading. The roller rink, gym, swimming pool, and outdoor soccer field are all very difficult listening situations.

At one point Brady did not want to play games at the swimming pool. He was not able to hear the instructions to the games and so did not know what was expected of him. To help with this situation, Brady's mother initially went out on the pool deck and would 'sign' the instructions. Later she helped Brady develop a 'buddy system'. After that Brady was able to ask his friend to explain the instructions and rules of the games. Brady also learned to go last so that he would have the opportunity to observe the model of other children first.

Recently Lynn found herself feeling sad as she sat in a gym, watching her youngest son struggling during a soccer game. She could see he could not hear well enough to understand what was going on. Then she stopped herself from feeling sorry for herself and her boys. She told herself to 'move on' and she began planning a problem solving session with her son. She helps her boys learn to solve their own challenging listening situations by asking them to create a list of possible solutions. They then discuss the different options and the boys choose the ones they feel will most likely work for them.

Lynn knows her sons will face difficult situations throughout their lives. She believes her role is to help them become aware of their own listening needs and to be knowledgeable about possible accommodations or equipment that will help them. She also wants them to grow up with the belief that it is their human right to participate fully in life and to have the self-confidence to request accommodations so that they can do so.

On- Site..... New Building Update

Excellent Acoustics and Lighting Take Top Priority

By Susan Lane, Director

The facility we have spent years planning and fundraising for is finally taking shape. The shingles were put on the roof this week and soon the windows and doors will be going in. But more than mortar and bricks will make this new building for the BC Family Hearing Resource Centre a model facility for deaf and hard of hearing children.

We know that discriminating speech in the presence of any background noise is extremely difficult for anyone with a hearing loss. We also know that hearing aids do not solve the problem of interfering noise. Typically when a new building is designed the acoustics are ignored. Brand new schools being built in B.C. today are being designed without any attention to the acoustics. Often these new schools have no carpet, and a great deal of background noise from ventilation systems and sound 'leaking' from one room to the next. Some new schools have vaulted ceilings that create an 'echo' or reverberation of sound. Even children with normal hearing have difficulty understanding everything that is said in these kinds of listening environments. For children with a hearing loss such an environment means they do not have full access to important auditory information.

From the beginning of our building campaign we decided that excellent acoustics and lighting would be our top priority for a new building. This means that we have spent thousands of dollars on aspects of the building that people with normal hearing may not even notice at first. A solid fence is being built around the perimeter and the facility is situated in a way that decreases the impact of tire noise from nearby streets. We are building an exceptionally quiet ventilation system so that heating and cooling fans will produce no interfering noise. Rooms are being built so that they are insulated from any sound from surrounding rooms and hallways. Our classrooms, therapy rooms, meeting rooms, and entry way will all have high quality acoustic tile on the ceiling as well as along the top four feet of the walls to absorb background noise that can interfere with the understanding of speech. Those without hearing loss will also appreciate the benefits of our attention to acoustical treatments.

Lighting has been selected so that it does not produce glare, making it easier for people using speech-reading or signing to see clearly. We are also avoiding fluorescent lighting in all of our meeting rooms, classrooms, and therapy rooms so there will be no possibility of interference to FM equipment. Our hallways are wider than normal to allow for signing conversations as people move down the hall. Our main meeting room will have a built in multi-media projector for captioning and the room is being set up to allow for the use of a wide range of assistive listening equipment.

Creating an environment that is accessible to children and adults with a hearing loss is our goal. Keep watching for new developments as we get closer to moving to our exciting new home.

Making A Difference

Many thanks to the following donors since our last issue for helping to make a difference in the lives of our children and families.

- Boundary Health Unit - Guildford
- Butler-Sundvick and Associates
- Bryan & Jacqueline Clarke
- Don & Nicola Demens
- The Djwa/Hartley Family
- Maureen Donald
- G.Precious & Sons/Humeniuk Family
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- Sea to Sky Community Services
- Vancouver Foundation
- Lynda Watson
- **Elks**: Courtenay; North Kamloops; North Surrey (on behalf of Larry & Bev Carriere): Revelstoke; South Vancouver; Vancouver
- **Royal Purple**: Fort Nelson; Lillooet; New Westminster; Salmon Arm; Vancouver

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Kudos to the Royal Bank Financial Group

The BC Family Hearing Resource Centre extends its sincere thanks to the Royal Bank Financial Group for a recent $10,000 donation to the Parent to Parent Support Network Program and Reaching Out newsletter. The Network connects families to other families experiencing similar problems and concerns, helping them realize that they are not alone. Both of these services provide support, training and information to families with deaf and hard of hearing children.

Susan Lane, Director (right) accepts cheque from Balvinder Dhillon & Shalynne Ricci of the RBC Foundation

Special Thanks to Our Local Businesses

Sincere thanks to all the businesses in the area that made Halloween for our children so special.

Their bags were full of candies by the time they got back to the Centre and the children had such a great time seeing all ofyour costumes. As our moving date approaches, we are mindful of the fact that many of you have been supporting this event for several years. It is truly touching to see the willingness and energy that companies and individuals put into making this day memorable. Often, we have requested your assistance on a day other than Halloween and without worrying about what others may be thinking of your 'outfit', you participated. Now that's dedication!!

Bit & Pieces

Calendar of Events

Dec 23 to Jan 5	Christmas Break
December 25	Merry Christmas
January 1	Happy New Year
January 6	First Day Back after Holidays
February 14	Happy Valentine's Day
February 28	Itinerant Teachers of the Deaf and Hard of Hearing Conference
March 17 - 21	Spring Break
April 18	Good Friday Holiday
April 21	Easter Monday Holiday

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The Staff and Board of Directors of the BC Family Hearing Resource Centre wish all our readers a memorable holiday season. We look forward to connecting with you again in 2003!

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BC Family Hearing Resource Centre
No. 8-15355-102A Avenue
Surrey, B.C., V3R 7K1
Toll Free: 1-877-584-2827
Phone (604)584-2827(voice),
(605)584-9108 (tty), (604)584-2800 (Fax)

Executive Director: Susan Lane
Editors: Terry Parson-Tylka &
Cindy Adams

We are a Family Centered Early Intervention Provincial Resource Program committed to individual communication choices. We provide support and resources throughout B.C. to deaf and hard of hearing children, their families and Community Service Providers.

The purpose of the Reaching Out Newsletter is to provide information and support to our readers.

Articles and ideas are welcome! The opinions expressed therefore are those of the authors and do not necessarily reflect the opinions of the Board of Directors, or the staff. We reserve the right to edit contributions for brevity and clarity.

There is no fee for the Reaching Out newsletter, however, donations are gratefully accepted.

wish

B.C. Family Hearing Resource Centre
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Once your donation has been processed, we will send you a tax receipt. If you are making your donation by cheque or money order, please make it payable to the BC Family Hearing Resource Centre.

Thank you for your kind donation to help children who are deaf or hard of hearing. Please help us update our records. If you name or address is not as it appears on the newsletter, please correct it in the form below. Please print clearly in block letters.

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BC FAMILY HEARING RESOURCE CENTRE
#8 – 15355 102A Avenue, Surrey, BC V3R 7K1
Tel: 604-584-2827 TTY: 604-584-9108 Fax: 604-584-2800
Website: www.bcfamilyhearing.com - Email: elks@uniserve.com