

25 years of making futures bright



BC Family Hearing Resource Society

Reaching Out

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



Summer 2008

Family Feature

Kathy & Mikyla – Fulfilling Each Others' Lives



Proving that families are wonderfully varied, providing its members with unexpected joys and challenges, Kathy O'Rourke graciously shares her unique story of raising her precious granddaughter Mikyla with our newsletter readers.

Mikyla Jersey Elaine O'Rourke was born out of love on July 16, 2004 at a healthy 9 lbs 4 oz. It was touch and go and no one really knew, even the doctors, if Mikyla would survive from a serious birth defect called "congenital diaphragmatic hernia." **(see Editor's Note below)*

**Editor's Note: Congenital Diaphragmatic Hernia is malformation of the diaphragm; this allows the abdominal contents to protrude into the chest thereby impeding proper lung formation. Newborns with CDH often have severe respiratory distress which can be life-threatening unless treated appropriately.*

There were three babies in the hospital at the time who had the same defect. One child, the most severe who had been on an artificial lung machine, then Mikyla who was on a ventilator and in an induced coma for 3 weeks until she was stable enough for doctors to operate and the other child with a mild defect who went home in less than three weeks.

After 3 months of being in the hospital Mikyla came home. Unfortunately, Mikyla did not arrive home to live with her parents and it is them who truly are the only ones who can explain why. It was me, Kathy, Mikyla's maternal grandmother that before long became the primary caregiver and legal guardian of the most beautiful precious little girl in the world. Mikyla's personality speaks volumes once you get to know her, even with strangers she often smiles and says 'hi' in passing.

Mikyla is a blessing in disguise. Unannounced to me right away, every challenge that has come my way has been met with perseverance and a strong determination to find the answer. My new challenge was to not only do what would make Mikyla's life fulfilling but also my own. Although the golf clubs may be collecting dust and the

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fancy dinners out now replaced with simple meals at home, there isn't a day that goes by that would make my decision to fight to raise Mikyla any different.



It was a bright shiny day in the summer of 2005 that I received a phone call while at work from my sister to tell me Mikyla's test showed a sloping mild to profound hearing loss and further tests were needed. A hearing loss that was most likely caused by a side effect from a ventilator that saved her life at birth. As I remember it, my sister was much more upset than me about the news and at first I didn't understand it.

My thoughts were, because Mikyla had been through so much in her short life already this was no big deal. Thanks to my sister who is a special needs foster parent and was caring for three children at the time; it was her experience with one of the children who is severe to profoundly deaf that made her realize Mikyla's need to be tested. It all seemed surreal because for two years prior to Mikyla's birth this severe to profound deaf child had been in my care every second weekend for respite preparing me for what was yet to come. I already had knowledge of sign language and was used to communicating with my hands and facial expressions, this was going to be easy!

Looking back now it maybe was not as easy as I thought because today there remains a lot to learn, decisions to make, resources to find and people to trust. The same important question remains; I ask myself almost every day "what do I have to do to make Mikyla's life fulfilling along with my own?" People often ask me once I give them a summary of my life how I do it. Telling my story used to make me cry a lot and now I cry less because my reality has given me an inner strength I never knew I had. Today, Mikyla is a striving, happy child surrounded by plenty of love, hugs and kisses. Mikyla's great grandma and grandpa care for her Monday to

Friday while I am at work, mostly out of the goodness of their hearts. To help Mikyla, my mother is taking sign language lessons while Mikyla is in preschool and I receive a lesson on Thursdays on my lunch hour at work. Mikyla did her first year of preschool at the BCFHRC and for this year and upcoming year at the Centre for Child Development in Surrey.

Mikyla and I meet at the BCFHRC with Dyan Spear once a week. Dyan has never let us down as she continues to use every possible resource and teaching tool to give Mikyla the best care and attention needed and beyond. And for me Dyan gives me the guidelines to be a good role model - Thanks Dyan! Our regular weekly visit with Dyan is Mondays and like clockwork Mikyla says as we are leaving my parents house to see Dyan "*that way, Dyan.*" And she gets mad if it's not the day!

This summer Mikyla is expecting to receive the new Phonak Naida® hearing aids that hold promise of improving her hearing. This will mean some extra visits to the Guildford Audiology Dept. Some summer fun includes a garden tea party, a visit to Powell River, a 7-week science theme preschool, BCFHRC's "Mingle and Play" in August (as well as our appointments at the Centre), a few soccer lessons in late August and finally some more 'R & R' just Grandma and Mikyla. And finally, a must do, several bus/sky train trips as this is Mikyla's absolute favourite thing to do right now.

Some of my personal ways of coping with the challenges of a hard of hearing child or living with someone who has a disability, is number one; plenty of sleep/rest. In today's busy world I must have down time. Second, and equally important, is to learn all I can about time management because it brings me peace of mind instead of trying to juggle everything and burning out; and yes, sometimes the dishes can wait until tomorrow! Last but not least I have had to limit my giving to a point where there must be time without strict commitments to others. For me, I would not be doing the best I can do for myself and/or Mikyla if I didn't cherish special times or moments without interference.



On the Fly

Cued Speech - A Visible Option

In May, two of our speech-language therapists, Tamara Pelletier & Zara Newnham, joined a Cued Speech workshop in Kelowna.

This is one of many communication options available to families of deaf and hard of hearing children and so we went to find out more.

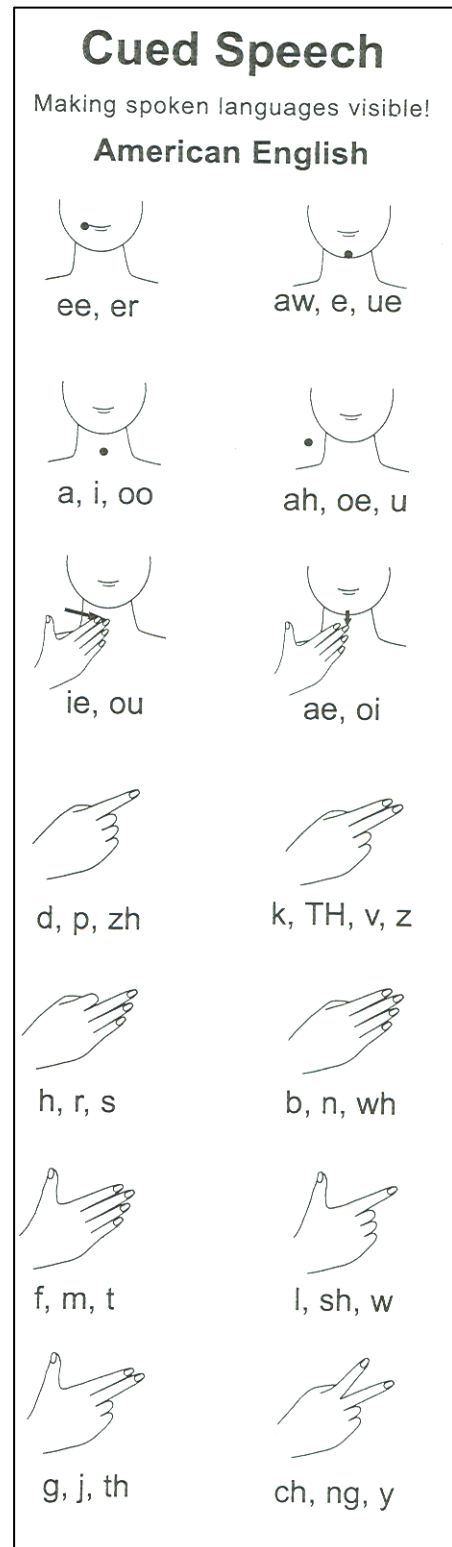
Cued Speech aims to make spoken languages visible. Consonants are represented through 8 different hand-shapes, while vowels are indicated by four different locations near the face. Speech is then cued according to the way it sounds rather than the way it is spelled...even Zara's English accent would be apparent to a person familiar with cueing!

A strength of cueing is that it can be done alongside your regular language-you don't need to learn any new words. Because it is based on sound it can also give a child access to more than one language. A challenge though, is to be able think about how you pronounce things, (e.g. 'phone' would be cued with an 'f', not a 'p') and how this changes when you are talking in sentences (vowels usually change as words run together). You've then got to produce the correct hand-shapes at the rate of speech...that means every 20 milliseconds!

You can cue with children from birth onwards and like any system it needs commitment from the whole family so that the child has access to language in every situation.

A brief overview is available at <http://www.cuedspeech.org/PDF/Overview.pdf>

If you are interested in finding out more please contact us!



Special Feature

Mingle & Play Summer Program

Families throughout the province currently receiving services from the BC Family Hearing Resource Centre are encouraged to attend all or part of the 'Mingle and Play' program being offered this summer. Join us at our Centre for socializing, activities and learning from our staff and other participants. See below for more information.



Looking for something fun to do with your children this summer?

Do you want to meet other families with children with hearing loss?

Do you want your children to meet other children with hearing aids and cochlear implants?

**BC Family Hearing Resource Centre is opening its doors to all of our families
from
August 11th to Aug 15th
10:00 am till 2:00 pm**

Come check out our library and resources and see our state-of-the-art Centre. Meet our friendly staff who will be available to help you answer questions. Meet and mingle with other parents who share the same joys and challenges. Come have fun in our garden and participate in a language rich environment.

Activities

- Arts and crafts
- Games
- Face painting
- Water and sand play
- Special visitors
- Sign language

No Charge

Parent participation is required.

Lunches are included.

Please advise us of any allergies.

Come for one day or for all 5 days but please try to let us know when you will be here so we can better plan and prepare for you. Call toll-free 1-877-584-2827 or email us at info@bcfamilyhearing.com

Schedule

Monday: August 11 2008

- Guest: **Cupcake the Clown** {10:30-11:30} Has been providing services to the Centre for many years with balloons, surprises, magic and games

Tuesday: August 12 2008

- Guest: Critter's – **Mike's Critters** {10:30-11:30} A traveling show including reptiles, birds, amphibians, arachnids and mammals.

Wednesday: August 13 2008

- **Winter Wednesday** - a fun day of experiencing winter in the middle of summer and eating snow cones
- **Snow cone** machine on site

Thursday: August 14 2008

- Guest: **Max-i-mime** {10:30-11:00} A mime artist who uses the classic mime techniques of flexibility and strength, combined with physical comedy and expression.

Friday: August 15 2008

- Guest: **Cinemazoo** – Exotic Animals {10:30-11:30} Cinemazoo offers a unique approach to animal conservation, by presenting rescued animals and critters as nature's ambassadors at educational events, seminars, and presentations.

Words of Wisdom

Moving Forward – Looking Back

Monique and Ron Preer have two children, Michael and Kaiya, who were born with sensorineural hearing loss. The family has been involved with many of the programs at BCFHRC over the past FIVE years. Two years ago Michael graduated from our program and went on to Bear Creek Elementary School. This year Kaiya will also be moving on to Kindergarten at Bear Creek. We will surely miss working with this family and are happy to share with you some of the things that Monique has had to say about meeting all of you through the Centre...

Being involved in programs like parent groups, the parent participation preschool and taking advantage of opportunities to meet other deaf and hard of hearing families has helped our family in so many ways.

Other parents who are in the same or similar situation sharing experiences; what more could we ask for? These parents have an understanding that many friends and some family members will never have. The days when we feel, “Is this ever going to get easier;” “Will we ever be able to get over this hurdle?” the best support has been talking to parents who “get it” because they have a child with hearing loss themselves. They can share their ideas about how they dealt with certain challenges and they can tell us what they learned. Sometimes just hearing that someone else was going through a similar situation was all we needed to feel better about our situation.

We too have been able to share in very informative parent groups what we have dealt with for technology, the school system, even tax information and family dynamics. We have learned about different types of hearing loss and communication methods. We have been able to access other supports and services that we would have never known existed if we had not

participated in these programs. The icing on the cake is always the chance to learn from the true experts; the other parents and children!

Michael and Kaiya really enjoy meeting other kids and adults who are deaf or hard of hearing. It is great for them to meet older children who are hard of hearing that can communicate and are involved in all types of activities. It has been a great confidence booster and has helped them to understand hearing loss, self-advocacy and equipment care.

We really enjoy being able to give back what we have been lucky enough to be part of. The smallest bits of information may help another family. Whenever I meet parents who have younger deaf or hard of hearing children it feels good to help ease their fears by sharing our experiences or just introducing them to our children.

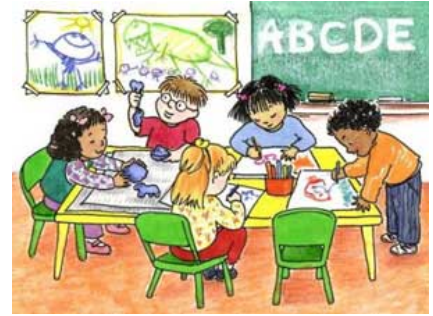
One of the things that we will miss the most about the BCFHRC will be the parent group and other programs that gave us these opportunities to be involved. We were lucky enough to have five years at a centre that organized so many great activities. These programs have guided us and have really given us great tools and resources that we will continue to use as our children get older.

Parent Chat

We are very excited to introduce to you our ‘Parent Discussion Board’ available on our website at www.bcfamilyhearing.com/my_child_has_a_hearing_loss/parents_discussion_board.asp. Many parents of deaf and hard of hearing children have expressed the need for some sort of parent chat forum in BC. A place where they can share their stories, ask questions, get support and learn from one another. Remember that our Board is only starting up so there will not yet be many postings or responses. Continue to make your own posts and check on a regular basis and please share any comments you might have. I look forward to seeing you on the Board! -Cathy Chow, Family Support Parent

You and Your Deaf or Hard of Hearing Child

The BCFHRC's PEER group is a program designed for families whose deaf and hard of hearing preschoolers are transitioning to Kindergarten. PEER provides parents access to the information they need to be the best advocates for their child throughout their school years. At the same time, the children attend a fun group program facilitating independence with hearing equipment, self-advocacy, self-confidence, positive self-esteem and a sense of belonging to prepare them for their Kindergarten placement.



This year, in conjunction with the BCFHRC PEER group, the CHHA-BC Parent's Branch presented the 'Supports for your Mainstream Student' Workshop. Featured speakers included Karen Taylor, Provincial Outreach Administrator and Loretta Richardson, Itinerant Teacher of the Deaf and Hard of Hearing, who provided information on services available in the public and private school systems. This workshop also offered the opportunity for parents to share their questions and concerns in friendly discussion. Karen Ethier and her daughter, Katie, participated in our 2-day program and shares their experience below.

I attended the PEER Group program this year on May 2nd and 3rd because my daughter, Katie, will be transitioning into Kindergarten this September. I wasn't entirely sure what to expect, thinking I already knew a lot about the public school system because I have an older hard of hearing child in grade three. Well, I couldn't have been further from the truth – I have so much to learn! And PEER Group was a great place to learn it!

Starting on the first day, we heard from a panel of teens about their experiences in school and life in general. It was very informative to hear about things that did or didn't work for them in the classroom, to hear about their hearing resource teachers (both good and bad!), and what challenges they face on a day to day basis. They were all such good role models and confident young people, it was truly encouraging!



On the second day, we heard from Karen Taylor who is with the Provincial Outreach Program for Deaf and Hard of Hearing Students. She provided valuable information about the IEP (Individual Education Plan). What is it? Why do we need it? Why should we be involved in it? Again, it was encouraging to hear from someone who is so passionate about helping our children receive the supports they need.

Of course, PEER Group wasn't just for the adults. There was also a program set up for the kids for both days as well. Katie couldn't wait to go back for the second day! She had so much fun with Kristyn, Jaimee, and Nikki and learned so much. She was so eager to test her own hearing equipment and embraced the independence and responsibilities they gave her.

It is hard to believe she will be going to Kindergarten soon but I think we are a step ahead. PEER Group provided so much information that I didn't even know I needed! And thanks to Cathy Chow I've got a BIG binder to refer to whenever necessary!

You and Your Deaf or Hard of Hearing Child

Quick Tips:

Night Light



We all know that a lot of kids are afraid of the dark... but, is this different for a child with a hearing loss? Your child may not have any difficulties at all but consider that when it is dark we do not tend to rely on our vision but on our other senses. When navigating in the dark we listen and feel for clues. When your child does not have the auditory skills to be able to do this it may be a frightening experience. Several families have found this is the case with their children. One mom has discovered that using a night light in their room and bringing a night light or a flash light with them on holidays was very helpful!

Key Finder



Do you ever turn your back for mere seconds only to turn around and your child is nowhere to be found? You call and call but, you're not sure your child can hear you, let alone respond. One mom in the North tells us that their family's solution has been to attach a key finder to the child's clothing. If they ever lose sight of him they have only to press the key finder and the locator on the child's clothing makes a noise which helps them locate their lost child quickly. Their son is a CI user and he now recognizes the sound his clothing is making so he now stops and waits for someone to come to him.

Raincoats for Hearing Aids



Hearing aids can be a huge expense. Yes, we know you already know this first hand! Parents have shared with us their panic when they misplace or drop hearing aids. Also, there seems to be a lot of concern regarding protecting these expensive devices from the elements. We know of a product called "Super Seals" to protect (not waterproof!) hearing aids from the rain or summer sprinklers. Check them out at:

http://www.justbekuz.com/Super_Seals_Hearing_Aid_Covers_Moisture_Protection.htm



25 Years of Making A Difference

In Appreciation of our Supporters

Since our last issue, the following individuals and organizations have continued to make a difference in the lives of our children and their families by generously donating to our Centre either monetarily or through goods and services.



Elks & Royal Purple Fund for Children

\$120,000 annually!



Elks

- Campbell River
- Parksville-Qualicum
- Port Coquitlam
- Prince Rupert
- Smithers
- Vancouver
- White Rock

Royal Purple

- Campbell River
- Kelowna
- Keremeos
- Merritt
- Nanaimo
- North Kamloops
- North Surrey
- Port Coquitlam
- Prince Rupert
- Quesnel
- Salmon Arm
- Terrace
- Williams Lake

Individuals & Organizations

- Elsie Alton
- CanadaHelps (on behalf of Habanero Consulting Group)
- Maureen Donald
- United Way – Vancouver Airport Authority
- Joyce Wood – Campbell's Soup Program

Walk-a-thon 2008



The 7th annual Elks & Royal Purple Walk-a-thon to support BC Family Hearing Resource Society's young deaf and hard of hearing children and children with speech and language needs was held Sunday, May 25.

This fun, non-competitive event was hosted at Campbell Valley Park and **raised over \$10,000!** Volunteers, walkers and donors participated to make this year's event a success. A special thank you to Jim McGregor, past Langley Fire Chief, who kicked off the event (and has done so for many years). Afterwards, families enjoyed a barbecue and lots of fun family activities.

We are grateful for the ongoing support of the Elks & Order of the Royal Purple who founded our program and continue to support our charitable efforts. If you're interested in helping out with next year's Walk-a-thon, please contact Ellen Peterson, Acting Executive Director at the Centre. Next year's Walk-a-thon is scheduled for May 24, 2009 – see you there!!



Accreditation Update

BC Family Hearing Resource Society Receives Three-Year Accreditation!

by Ellen Peterson, Acting Executive Director



Surveyors Margo Van Kleeck and Polly Davis conducted our second site survey on March 27th and 28th, 2008. Since 1966 CARF has assisted organizations like ours, throughout Canada and the United States, in achieving

and maintaining top-notch programming for our clients and a first-rate working environment for our staff. Being accredited demonstrates that we comply with the highest possible internationally accepted standards of organizational integrity and service provision.

We worked very hard to prepare and it showed. We reviewed policy, developed surveys, refined outcomes measurements, created file review protocols, and completed dozens of other small and large tasks aimed at demonstrating our compliance with the standards. This is some of what CARF had to say about BCFHRS:

“BCFHRS has an exceptionally dedicated and forward-looking board of directors that has been involved in fundraising, promoting the organization, and advocating on behalf of the organization. The board is committed to recruiting diverse membership to strengthen board abilities. Having board members with hearing loss brings added focus to the mission and values of the organization.”

“Positive, strong, and vibrant leadership is provided by the acting executive director and management team that is highly motivated and dedicated to the organization’s mission.”

“Funders appreciate the professionalism and quality of services provided to persons served. “I have complete confidence in the staff of this organization,” stated a Ministry of Children and Family Development staff member.”

“The organization has dedicated and enthusiastic professional staff members who are responsive to the needs of persons served. There is a noticeable

commitment to improving the quality of the lives of persons served.”

“A culture of teamwork, mutual respect, cooperation, and open communication is evidenced throughout the organization.”

“There appears to be great collegiality among peers in the local area as well as throughout the province within the outreach services. This was noted through discussions with staff as well as professional peers contacted. It was consistently observed that the staff of BC Family Hearing Resource Society takes a leadership role throughout the province, and staff members are very free with sharing their knowledge.”

“Parent satisfaction is very high. Each and every family contacted had glowing praise for individual staff members as well as the employees of the entire organization”.

BC Family Hearing received two exemplary conformance to the standards.

“The organization demonstrates exemplary conformance to the standard of responding to the diversity of its stakeholders with respect to language. The organization has published an excellent book, *My Turn to Learn, An Up-To-Date Guide for Parents of Babies and Children with Hearing Loss*, in five different languages.”

“The physical facility of BC Family Hearing Resource Society continues to be an outstanding environment for meeting the needs of the children served. It is highly reputed across Canada.

Sincere thanks to our many families, volunteers, funders and staff who participated in our site survey. They shared their experiences and stories with our surveyors which ensured our tremendous success. We could not be more proud of our collective accomplishments.

Bits & Pieces

Children's Festival Gets 'Hands Talkin'

by Kristen Pranzl

Family Community Resource Worker (SFCD)



This year saw the 31st annual Vancouver International Children's Festival happen! This great festival for kids of all ages took place from May 12th to 19th at Vanier Park in Vancouver. Services for Family and Community Development (SFCD), which is part of the Provincial Services for the Deaf and Hard of Hearing, was involved over the May long weekend with their own tent at the festival.

SFCD partnered with Deaf Youth Today (DYT) and the Canadian Deaf Blind Rubella Association (CDBRA) - BC Chapter to create the "Hands Talkin" tent that had activities that allowed children and parents to discover the culture and language of the Deaf and Deaf blind through crafts, personal interactions, and the ability to ask questions - all using ASL (American Sign Language).

SFCD also collaborated with the Festival organizers to provide two interpreted performances. Overall, it was a wonderful experience of ASL bookmarks, mini American Sign Language lessons, an American Sign Language ring toss and the infamous I Love You tattoos! We will be doing this again next year so we hope to see more families out for this wonderful event---- Join us for the 32nd annual Children's Festival, May 11-18, 2009! If you're interested in learning more or volunteering at next year's festival please check out the website at www.childrensfestival.ca.



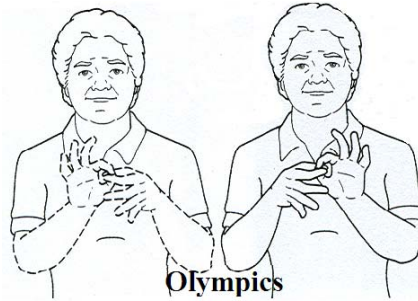
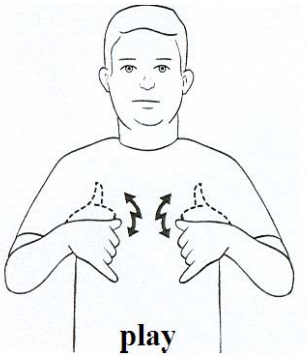
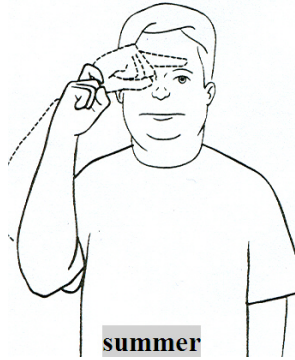
In addition to our participation in this festival, SFCD offers a range of programs and supports for BC families with deaf and hard of hearing school-aged children who use sign language for all or part of their communication. Please feel free to check out our services on our website at http://www.mcf.gov.bc.ca/psdhh/services_for.htm#learn.

Plush Hearing Aids

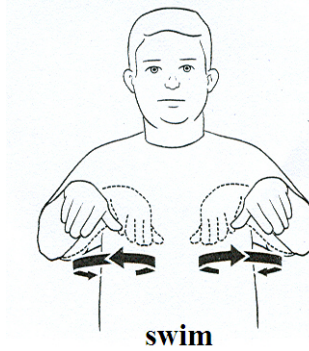


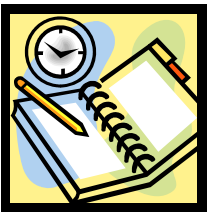
A parent shared that her hard of hearing child's sibling wanted so badly to have hearing aids like his brother. She was able to find plush hearing aids at a Build-a-Bear store and her child loves them! If you'd like to check these out there is a Build-a-Bear store in the Metrotown Mall in Burnaby.

Summer Sign Language Vocabulary



Olympic Games





Calendar

- July Fieldtrips with a Focus – BCFHRC Summer Program
- July 2 – 6 Canadian Hard of Hearing Association & International Federation of Hard of Hearing People – Congress 2008: A Global Community of Communication
- August 11–15 Mingle & Play – BCFHRC Summer Program

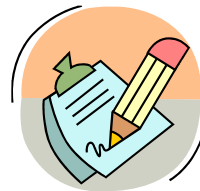
Our Outreach Consultants visits to Communities Throughout BC

- June Nicola Swain – Campbell River; Comox
Dyan Spear – Kelowna
Judy Chrastina – Quesnel & 100 Mile House
Noreen Simmons & Cathy Chow – Creston
- July Judy Chrastina – Bella Coola
Zara Newnham -- Kamloops

Satisfaction Surveys – Due July 10, 2008

BC Family Hearing Resource Society has sent out our annual satisfaction surveys to local and outreach parents, and professionals province wide.

We rely on this information to continually improve our programs and services. We are committed to delivering exemplary service and strongly encourage you to take the time to give us some feedback on how we're doing. We have revised our surveys this year to be a shorter, more focused format. We are also very pleased to provide these surveys **on-line** for your convenience at www.bcfamilyhearing.com.



*We thank you for your time, and want to remind you that **we welcome your feedback at any time**, particularly if you have a worry or concern.*

Newsletter - Mail, On-Line or Email?

Would you prefer to receive our newsletter emailed to you? Are you aware that our newsletters are posted on our website? In our efforts to "Go Green" we would like to offer those interested the electronic distribution option.

To receive your newsletter this way, simply email info@bcfamilyhearing.com with the email address you would like the newsletter sent to AND the current name and address it is being sent to by mail in order to have your name removed from the list.



**The Staff and Board of Directors of the
BC Family Hearing Resource Centre
wish all our readers a fun and relaxing summer!**

Reaching Out

Newsletter published quarterly by

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Acting Executive Director:
Ellen Peterson
Editors: Cindy Adams & Carolyn Trengrove

We are a family-centered early intervention Provincial Resource Program committed to individual communication choices. We provide support and resources throughout BC 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.

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