# BC HANDS & VOICES

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We are a parent/ professional collaborative group that is unbiased towards communication modes and methods, believing that families will make the best choices for their child if they have access to good information and support.

Our goal is to support families in achieving successful outcomes for their children.



# Reflecting on Early Intervention

By Kim Shauer

Wikipedia defines Early Intervention as "a system of coordinated services that promotes the child's growth and development and supports families during the critical early years. Starting with a partnership between parents and professionals at this early stage helps the child, family and community as a whole".

I had vaguely heard this term prior to having our second child, but it had little meaning to me until we found ourselves needing it as a road map for the new path we found ourselves on once Julia was born. As we now prepare to transition our 4-year-old daughter, Julia, into Kindergarten this upcoming September, I feel excited for what is to come and wistful in knowing I soon must say goodbye to these early years and the many amazing people who have helped shape this stage of our daughter's development.

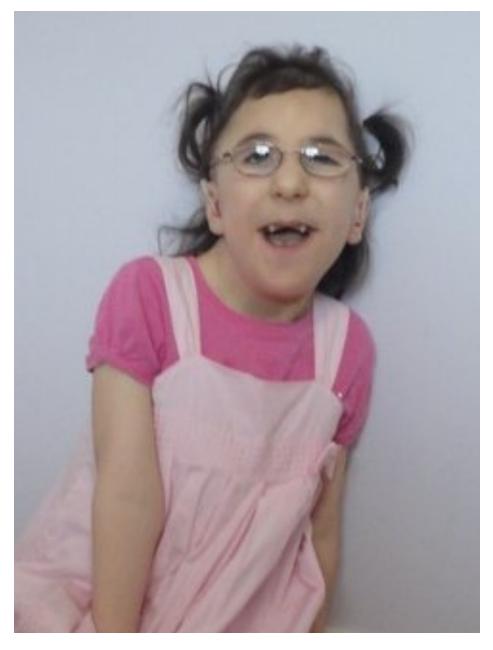
A little over 4 years ago, we took Julia home from the NICU at BC Children's Hospital with a variety of referrals and suggestions on how to care for our new baby with a diagnosis of a rare chromosomal condition. Although Julia's moderately severe to profound loss hearing levels bilaterally would not be identified until 17 months of age, from the beginning she required the expertise of many medical specialists and community therapists including occupational therapy, physiotherapy, feeding team,

I want to strongly encourage families to take full advantage of all of the early intervention services available to you.

vision therapy and IDP. With the hard of hearing diagnosis on top of everything else, we added audiology, hearing aids, speech therapy and Deaf/Blind consultation to our growing team of services.

Looking back on those first weeks, it was our "early intervention" teams and the experienced people on those teams that humanized all of our feelings, helped soften the blow of the many diagnoses and navigated the various twists and turns for us through all of the information that had been provided. Before long, we felt ready to participate in supportive group settings that gave us the chance to meet other families in similar situations and with likeminded goals. These early intervention programs provided a safe place to talk, receive parent to parent support and learn from the experiences of families and the diverse needs of children who have come before us. In addition to being an invaluable resource, the social and emotional aspect of "early intervention" to our family has been as vital as the therapies and equipment that support Julia.

We will also take away the knowledge of how to confidently and effectively advocate for our children, along with the understanding that it is okay to take a break and do something for ourselves...and not feel guilty about it! I want to strongly encourage families to take full advantage of all of the early intervention services available to you. The number of appointments may seem daunting and the paperwork at times can feel end-



less. The various assessments we complete remind us to stop where we are once in awhile, take a good look around, reevaluate the choices we have made and change direction if we feel it may be better for our child and our family.

Reflecting on our journey so far, I am glad we have made it a priority to capitalize on the opportunities available to us and develop

relationships with our early intervention partners. At 4 years old, Julia is a healthy girl with a complex condition, multiple needs, the developmental age of a 1-year-old and a smile that can light up an entire room. Through the help of our early intervention teams, I am feeling prepared for the next leg of our journey, and the road ahead seems bright with possibilities.

# **Spring Picnic**

# Sunday, May 6th, 11-2 @ Queen's Park, New Westminster

Google maps link: <a href="http://g.co/maps/dnje8">http://g.co/maps/dnje8</a>

Come join us for our 4th Annual Spring Picnic – it's a great opportunity to meet other families with children who are deaf or hard of hearing. We've rented a large picnic shelter with picnic tables (near the playground), so we're "good to go," rain or shine. We'll have parachute games, races, balloon twisting, crafts...and Queen's Park has a fantastic playground. You also might want to stick around afterwards and check out the Petting Zoo (entry by donation).

So bring the whole family, and a potluck dish to share. Beverages will be provided, and we will have ASL interpreters. If you live outside the Lower Mainland and need financial assistance to help with travel costs, please contact us – we do have some money left in our travel grant from BC Children's Hospital. RSVP by Wed. May 2nd to info@bchandsandvoices.com or phone 604-552-2254. Please include your names, the age(s) of your child/children and the potluck item you plan to bring. We look forward to seeing vou there!!

# They Came, They Played, They Laughed...

# Family Fun Day at Crash Crawly's

March 4, 2012 marked the second annual Family Fun Day at Crash Crawly's Indoor Play Centre hosted by the three BC parent-led organizations supporting children who are deaf and hard of hearing: CHHA Parents' Branch, FNDC and BC Hands & Voices. At 10am, there was a line-up of people standing along the side of the building waiting for the doors to open! Needless to say, the event was once again very popular with families and a success overall. There was something for every age group – laser tag for the older kids, a climbing gym, train ride, ball pit and soft play area for the younger ones. Despite the noise, parents seemed to really enjoy connecting with each other and catching up while the children played. The odd sock went missing, but luckily no hearing equipment! Looking out at the approximately 250 attendees at one point, I couldn't help but think, what a community, and what a great way to meet new people and make new friends. So if you didn't make it out this year, look out for the announcements in early 2013. You won't want to miss it!

# Keep 'em Safe, Wear 'em Proud!

# Tips for Keeping Hearing Equipment on Babies, Toddlers, & Preschoolers

By Teresa Kazemir

I remember driving home from the audiologist with brand new hearing aids in a box on my lap - little did I know what lay ahead in terms of keeping hearing equipment on a baby! Some things we learned:

Hearing aids tend to whistle whenever a baby's head leans against something – which happens a lot when young babies are cuddled and when they sit in car seats, strollers, swings, etc.

If babies spit up a lot while they are laying on their back, it tends to run into their hearing equipment. It can be tricky to find a hat that keeps the baby's head warm, keeps the hearing aids dry, but does not make the hearing aids whistle.

As babies get older, they like to put everything in their mouth - including their hearing equipment! When babies get to be toddlers, they think ripping off hearing aids and throwing them is a super fun game!

So if you are also finding it tricky to keep hearing equipment on your baby, toddler or preschooler -YOU ARE NOT ALONE!!

We've compiled some tips and websites suggested by other parents – we hope you find them helpful. (Please note: BC Hands & Voices does not endorse any particular product, nor do we benefit financially from the sale of any of the products mentioned below. These are merely suggestions based on what other parents have told us they have found helpful. Also, we recommend that you keep in mind any potential choking hazards if you are considering some of these products for a young child.)

## Tip # 1 – Wig tape

Wig tape can be really helpful for keeping hearing aids or cochlear implants in place on tiny ears, especially if they are flopping around. You can usually buy it at any store that sells wigs, or you can order it online at www.hairtape.net. "3M Surgical Tape" is recommended for hearing aids and is of just the right size and strength and is latex-free.

## Tip #2 - Covers, Cords & Clips

There are many products out there designed to keep hearing aids on. You may have to experiment and try a few before you find what works best for your child. Your service provider or audiologist might be able to request free samples for you to try. You can try the following sites, or search for "hearing aid retention" on Google.

Ear Gear (www.gearforears.com) - colourful waterresistant covers which can be attached to clothing with a clip. These are made in BC.

Huggies (www.huggieaids.com) – can stop the aids from flipping off of the child's ears, so they are less distracting and the child is less likely to yank them off.

#### **Critter Clips**

(www.westone.com/catalog/critter-clips) - a lightweight lanyard attaches to the hearing aid and clips to the child's clothing with a colourful clip (also Dino Clips and Sea Clips).

#### **Otoclips**

(www.westone.com/catalog/otoclip-and-otoclip-ii)

 plain clips and cords designed to attach hearing aids to clothing.

#### SafeNSound security straps

(www.getsafensound.com) – these fit snugly to the head and are hard for babies to reach; they can also work with glasses and they have one that connects to a hair barrette.

There are also some home-made options for keeping hearing aids attached to clothing. You can use dental floss or fishing line to connect the hearing aids and pin it to the back of the shirt. Pacifier clips can sometimes work or those cords that are meant to keep on eyeglasses - you can fit the flexible loop at the end around the hearing aid and pin the centre of the cord to the collar of the shirt.

### **Tip # 3 – Hats**

Some families find that using a hat is a very good way to keep babies and toddlers from pulling off their hearing equipment. Homemade bonnets that tie under the chin can also work well or here are a few commercially available options:

**Silkawear Bonnets** (www.silkawear.com) – unique and custom-made bonnets for young children who wear hearing equipment.

Monkey Gear (www.monkeygear.ca) - hats and bonnets designed to help keep on hearing equipment - one of these has a brim for summertime.

Hanna Andersson (www.hannaandersson.com) they sell lightweight hats that fit snugly on the head and are thin enough not to block sounds coming in. They are often tied under the chin.

While hats can be a solution, they can also be problematic. Depending on the type of hearing equipment your child uses, some families find it challenging to find a winter hat that will keep their child's head warm but will not cause feedback. Several parents suggest using a loose-fitting crocheted or loosely knitted hat or touque. For the rain, a loose-fitting hood on a jacket can work well.

You may need to experiment to see what works best for your particular child. One commercially available winter hat:

#### **Kiddie Caps**

(http://hal-hen.com/cgi-bin/info.cgi?id=3515-PG&l s=sw~3515%20PG) – warm winter hats, with an "acoustically transparent barrier."

### Tip #4 – Headbands

One of our BC parents has developed her own product, a headband to help keep on cochlear implants (see article insert on "Gina's Brilliant Bionic Headbands").

Families of children who use Bone Conduction hearing aids or softband Bone Anchored hearing systems (BAHAs or Bahs) are often looking for headband options. In addition to products available through the hearing aid companies, the following are available:

www.forwerd.net - headbands and other options for Baha hearing aids

www.hearbands.homestead.com - headband options for traditional bone conduction hearing aids www.meandmybow.com – headband options for traditional bone conduction hearing aids

#### **Tip #5 - Decorations**

One way to motivate young children to wear their hearing equipment is to make it bright and colourful and fun to wear. Here are some products that our readers recommend:

**Skinits** (www.skinit.com) – vinyl stickers specially shaped to fit on cochlear implants and are easily removable without residue. Countless designs available.

"We ordered these Skinit's after seeing families on Facebook ordering them. They are stickers that fit the Freedom or Nucleus 5 cochlear implants. They are wonderful, sleek, and thin. The Nucleus 5 has



lovely skins to order for the CI. They are nice, but bulky and you cannot put the snugfit over it. We ordered it from Skinit.com." Bobbi Taylor

"My son loves them! It MOTIVATED him to wear both his CIs more than ever! In public places, people were raving about them, he was so proud of them! I love them. I will order them again when it's time to replace them. They have thousands of designs to choose from!" Karen Jackson



Hayleigh's "Cherished Charms" are another decorative product, designed by a 12-year-old girl who wants to help kids and adults to be proud of their

hearing aids (www.hayleighscherishedcharms.com).

Tube Riders are yet another way to decorate and individualize hearing aids (www.otocool.com).

### Tip #6 – Some Less Conventional Ideas

A less conventional idea I heard recently was to use inflatable swimming arm bands. They can be decorated with stickers or felts markers and apparently prevent a toddler from reaching his or her ears to pull the hearing aids off. This was also suggested as a strategy for making earmold impressions in the audiologist's office.

Someone also suggested bandaids for keeping cochlear implants on during activities such as tumbling, and using a Bounce sheet inside a touque to prevent static electricity building up (also for Cl's).

# Tip #7 – Distraction, Positive Reinforcement and Rewards

Distraction, positive reinforcement and rewards are very useful parenting tools. Distraction can be one of the best strategies for babies and toddlers. Many parents find it works to give the child something to keep their hands busy when they are first putting in the hearing aids. This might mean having some special toys that only come out when the hearing aids first go on or a special game that you play. Unfortunately, as parents we do not always have time to entertain our baby every waking minute, but often young children will forget about the hearing aids in their ears if they've been distracted by something else.

As toddlers get a little older, positive reinforcement can work well. Children may respond to praise for wearing the hearing equipment and may also start to understand that the hearing aid or CI is helpful - "Now you can hear the music!" Children also benefit from seeing other children who are like them, either in person or through books, DVD's, or TV shows. (I remember there was a little

boy on the TV show "Barney" who wore the same type of hearing aid as my son did when he was young, so we'd watch that show occasionally and I'd point out the boy's hearing aid.) Children's books are sometimes available from the hearing aid or CI manufacturers and here is an example of one such book that is available online:

http://www.phonak.com/content/dam/phonak/b2b/Pediatrics/Junior\_Care\_Kits/028\_0284\_02\_Oliver\_gets\_hearing\_aids.pdf

And for the child who is a little older and understands the concept of a reward, you can always try candy, raisins, stickers and little dollar store toys as incentives for keeping the hearing aids on. Of course that also means finding a way to wean your child off of the incentives later, as the dentists of the world would probably frown on the idea of bribing our children with candy every time we put the hearing aids on!!

# Tip #8 – Some General Resources on the Net

There are some great sites on the internet that you can look at for more ideas, such as:

www.babyhearing.org/HearingAmplification/AidCh oices/practical.asp (shows many of the above ideas and products and more)

www.handsandvoices.org/articles/early\_intervention/b3\_corner.html (Q's 3 and 4 answer the question about keeping hearing aids on)

www.listen-up.org/haid/aids-out.htm (tons of information!)

So if you are struggling to keep hearing equipment on your child, we hope some of these tips might be helpful. Also, we hope you realize that you are not alone in this struggle. Many parents find this challenging, but it does get easier eventually! Every child is different, but by the time our son was two, he would not let us take off his hearing aids until after he had fallen asleep at night.

One last thing to keep in mind – it is always a good idea to check in with your audiologist regularly, particularly if your child is refusing to wear the hearing equipment or is responding differently than he or she has responded in the past. It's important to make sure the earmold or hearing aid isn't rubbing and making a sore spot and that your child doesn't have an ear infection. The audiologist can check to make sure that the earmold is fitting correctly (babies grow out of earmolds very quickly), that the hearing aid is working properly (children will sometimes pull off a hearing aid or implant that has a dead battery or is not functioning well), and that the hearing equipment is set correctly.

Lastly, we encourage you to talk to other parents. Come out to a BC Hands & Voices event, call your Parent Guide, ask to meet other parents through your early intervention agency or drop us a line on Facebook or by email. We can be such a great resource for one another!

# **Gina's Brilliant Bionic Headbands**

# How I Keep My Daughter's N5 Secure to her Head

By Gina Cooper Watt

Some children take to their cochlear implants immediately. My little Sara resisted her N5 for awhile. Some children's ears hold the cochlear implant on well. My little Sara's ear did not hold the N5 too well and it would flop forward and fall off. Then there was the straw that broke the camel's back: we lost our first CI in the house somewhere and



have yet to find it, after a year.

Invention is the mother of necessity. During this adjustment time, I needed something that would hold the N5 to my daughter's head securely, and would also allow for easy location in the event that she tossed it somewhere.

I tried everything from the mic locks (plastic tubing that secures the CI around the ear only) to wig tape to barrettes and almost attempted crazy glue (lol) at one point before running out and buying a

bunch of simple headbands that I was determined to adapt and make adorable-looking! After researching a few specialized cochlear implant headband designs, I came up with my own design that I found to be very simple to use, holds the CI close to the head and allows for 'feeling' around the ear. So, for about a year now, I have been producing various designs and styles of my "Gina's Brilliant Bionic Headbands" - from classic to glamorous - and they have proven to be very effective for both the unilateral and bilateral N5 cochlear implant wearer.

When it comes to cochlear implants, every child is unique and has different needs, and with "Gina's Brilliant Bionic Headbands" I am happy to be able to provide a stylish and practical option for the cochlear implant wearer. Whether you use the headband during your child's initial acceptance of the CI or for sporting activities like gymnastics or dance, or whether it's purely for special occasions, your child will find the headbands both effective and fun. And as the parent, you'll love the peace of mind!

For more information on styles and pricing, please feel free to contact: Gina Cooper Watt @ g.e.cooper@live.ca.

Please \*like\* Brilliant Bionic Bands Facebook page to see designs and styles!

# The Big Move

By Anja Rosenke

The countdown is on - my son turns 5 in a couple of months and is due to enter Kindergarten in September. Officially, early intervention ends at this point and I am already preparing for the distinct shift that will occur as he transitions into his next phase of life, that of the school-aged child.

I can't help but feel a mix of both apprehension and excitement about this - knowing full well how fortunate we have been over the past 3 and a half years to have received both comprehensive services for our son's needs and an incredible level of individualized support as a family. Like many of you, we have also developed close friendships with other families within our early intervention agency people who understand us simply because they are going through the same thing. Come September, many of these children will move on to a school within their local school district or an independent school of their parents' choosing.

So what awaits us out there in the "post-five" world? The Big Unknown! A new school, new teachers, new professionals, new schedules and new protocols. Daunting, right? It might feel like starting from scratch again, learning to navigate this new educational system. But with a bit of research and preparation, the move into the mainstream doesn't have to seem foreign or intimidating for very long.

In anticipation of the Big Move, I've attended several Kindergarten entry meetings and parent panel presentations over the past few months. From these, I've gleaned a few ideas that might make the move "into the mainstream" a bit smoother for you and your child. These tips are by no means

written in stone, nor are they exhaustive. You will notice that I have not included information on IEP meetings or timelines or the types of services available, as these will vary depending on your school of choice and your child's needs. Whether your child is joining his or her hearing peers in Kindergarten or at a different age, the following will hopefully provide you with some starting points for creating a successful transition for your child.

### Tip #1 TRUST IN YOURSELF

You know your child best! Always keep this in the back of your mind as you meet new professionals and teachers. While each of them is probably very experienced at what they do, they will just be getting to know your child. So as parents, be confident in your experience and your knowledge base. Your contribution is significant and will be vital to the successful transition of your child into this new environment.

# Tip #2 DO YOUR HOMEWORK

You have options as to school choice. Make a list of priorities for your child's school environment what are your goals for your child? Some considerations might include location, class size, the school's attitude towards communication access for your child and the school approach to social responsibility and bullying. If socializing ranks high for you, you might choose your local neighbourhood school for ease of building friendships with the neighbourhood kids. Research different schools that interest you, online or by asking other parents. Most principals will welcome your phone call and your visit and this is a great opportunity for you to ask questions and also to gage the school's climate.

# Tip #3 PREPARE YOUR CHILD

Most schools hold a Kindergarten orientation event around May for the children entering in the fall. However, if your child is older, it might be beneficial to request a tour in May or June. Be sure to bring your child and bring your camera so you can take pictures of the gym, library, office and classroom for their grade. During the summer break, you and your child can look through the photos. Often the school-based team will provide a little booklet about the school, including names and pictures of the principal, secretaries and teachers, details of daily routine and special events. In late August, you could bring your child back to the school for a refresher and walk through the school again. Many teachers will already be in their classrooms prepping for the start of school. If you have the opportunity, you might look to connect with some of the other parents whose children will be entering school with your child in the fall. This could give your child a sense of familiarity and comfort once September rolls around.

## Tip #4 SEPTEMBER HAS ARRIVED!

Kindergarten is now a full-day program throughout BC and shifting from a part-day preschool program to a full-day, full-week one regimen might be a big adjustment for your child. Many schools set up a 1or 2-week gradual entry program, building up to a full-day of school and also incorporate daily quiet time in the afternoons. In addition to this, you can also help shape your child's gradual entry into the classroom if you think your child needs it. Reach out to other parents and invite children from your child's class over to play at your house. Even staying after school on sunny days to play on the playground with the other kids will give your child more opportunities to forge friendships and a sense of belonging to his or her new school. Though Kindergarten is a busy year, full of many firsts, keep in contact with families from your early intervention centre if you can, as these friendships

are easy, well-established and comfortable for your child.

# Tip #5TOOLS FOR GOOD COMMUNICA-**TION**

These days, many classrooms are equipped with a computer and more and more teachers are available via email on their iPhones or iPads. Others teachers still prefer the more traditional method of correspondence: writing comments in a communication book and discussing your child's progress during parent/ teacher conferences each term. The amount of actual face time you get with your child's classroom teacher will vary from teacher to teacher, year to year. The reality is that teachers often have little time to chat at 3pm and parents often work and can't be present at the school every day. The home/school communication book can be a valuable tool. It will have space for the classroom teacher, the hearing resource teacher and educational assistant (if one is assigned to your child) to provide feedback on your child's day. There will also be space for you to convey comments or ask questions. A great idea is to set up the communication book in a way that your child can be involved with daily entries as well. For example, the sheets in the daily communication book could be in picture format - where the child can circle the activities they did that day, circle their favorite, least favorite and also rate their day (smiley face/ neutral/ unhappy face). In addition, some teachers are very open about their lesson plans and the themes or topics they will be covering each term. This type of information can be immensely helpful for introducing topics at home, reinforcing concepts or simply keeping track of what your child is learning.

## Tip #6 BE PRESENT, BE INVOLVED

If you are able, get involved at your child's school. There will be many opportunities to do so. Attend PAC meetings, volunteer in the classroom, supervise on fieldtrips. It's the closest thing to being a fly on the wall! For working parents, this may understandably prove difficult and if that kind of involvement is just not possible for you, be sure to attend concerts and any special events when you are able. This way, the school administration sees your commitment to and interest in the school and you can get the inside scoop on the school culture, the other parents and your child's peers.

### **Tip #7 THE TEAM APPROACH**

As parents, you are key players on your child's support team and taking a positive, collaborative approach will lay the groundwork for building good relationships with the various teachers and professionals who will be part of your child's school life. Continuity from your preschool/ early intervention program can be helpful for a successful transition to the new school. Your early intervention team is a great resource, as these professionals and teachers have come to know your child very well and can provide reports and assessments and possibly be present at IEP and transition meetings. Often the new school will send a group to the preschool to observe your child in that environment but apparently this is not guaranteed. A possible alternative suggested by some parents is to make a video of your child's "can's" and "can'ts" in preparation for the transition meeting with the school (usually held in May or June). It is important to present a realistic image of your child's mode and level of communication and functioning. The principal can afterwards share the video with other staff to gain a better understanding of your child.

# Tip #8 WHAT IF?

Despite the best laid plans, sometimes things don't play out as you expected. Should a concern arise, you will need to communicate this with the school, starting with your child's classroom teacher. For many parents, putting on the "advocate's hat" may

be new and seem uncomfortable but keep in mind that you are your child's representative and only speak for his or her best interests. Hopefully with a good communication system in place and a good working relationship with your child's school-based team, any issues can be ironed out. There is always room for adjustment along the way and you can change what's not working. For advice, you can always turn to your fellow parents, early interventionists and parent-led organizations like BC Hands & Voices, CHHA Parents' Branch and Family Network for Deaf Children (FNDC).

So as my son's final year of preschool enters its final term, I somehow feel like the student leaving to attend a new school! Yes, in some ways it is a daunting time with another big learning curve involved, but it's also an exciting time filled with opportunity. But I draw strength thinking about all that I've learned over the past few years. There are loads of resources available to help parents like us as we prepare for this next stage of schooling for our children. So get connected and get excited! The future awaits!

# **Hands & Voices Parent Coffee Nights**

# Mark your calendar and we'll save you a spot on the couch!

Are you interested in getting to know other parents of kids with hearing loss?

Would you like to share ideas on how to support your child with hearing loss?

Or do you just want to come out and enjoy a night off with coffee, treats and good conversation?

If so, this is the group for you.

We held our first Parent Coffee Night on November 26th with great success. Gathered on couches, we enjoyed coffee/tea and homemade baking. The group had a great time getting to know one another. We chatted about navigating the transition from early intervention into the school system, and also about available options in case the choice we made for school placement is not working as we had hoped.

In 2012 we will be meeting regularly, one Monday a month from January to June at Victory Hill - House #3 from 7-9pm. (\*look for the blue & orange balloons)

The address is 4334 Victory St, Burnaby, BC. Thank you to Services for Family & Community Development for allowing us to use this space.

Mark these dates on your calendar!

January 16th - How to talk about hearing loss with friends, family and strangers

February - no meeting

March 5th - Your child's identity and hearing loss - how to encourage confidence

April 16th - Literacy

May 21st - How to advocate for your child and yet encourage their independence

June 18th - Back by popular demand - Transitioning to Kindergarten

Contact Jennifer Towers at jtowers900@gmail.com with any questions. We hope to see you there.