

ONTARIO ASSOCIATION FOR FAMILIES OF CHILDREN
WITH COMMUNICATION DISORDERS
O.A.F.C.C.D. NEWSLETTER

May 1998

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OAFCCD

Annual General Meeting

May 30th, 1998

2:00 - 4:00pm

Grand River Hospital
Kitchener, Ontario

All members are invited to attend the fifth Annual General Meeting (AGM). The meeting provides an opportunity for members to meet with each other and share experiences. It is also an opportunity for an update on OAFCCD activities at the provincial and local level.

The meeting is held in conjunction with a Board Meeting, to which all Chapters are invited to send one or more representatives. The Board Meeting will start at 11am, and the AGM will follow at 2pm. Features of this AGM will include Chapter updates, a report on the implementation of preschool speech and language funding, and a discussion of the new education funding model.

The AGM will be held in the Board Room of the Freeport Hospital campus. There is no charge to attend, but please register in advance, by calling Sharen Heath at (519)842-9506.

Special Features of May Newsletter:

- ✓ **OAFCCD 1998 Directory of Speech and Language Summer Camps**
- ✓ **Provincial Enhancements for Preschool Speech and Language Systems**
- ✓ **A Mother Asks "Will My Son Talk"?**
Parent story by Genette Brest
- ✓ **OAFCCD on the Internet**, Story by Susan Richards, Lanark Chapter, *WebMaster*

MAY is Speech and Hearing Month!

OAFCCD members have a lot to celebrate this year. In the past three months thirteen million dollars in new preschool speech and language services have been announced. This should translate into almost two hundred new Speech-Language Pathologists, and services for 80,000 additional children.

In addition, the new Education Funding Model provides funding specifically for Speech-Language Pathologists in both the Foundation Grant and in the Special Education Grant. Provision of funding for Speech-Language Pathologists in the Foundation Grant means that the Ministry of Education and Training recognizes that speech and language services are direct classroom costs. The funding model also includes a new grant, the Intensive Support Amount (ISA), which recognizes that some students have individual support needs which are very expensive. The ISA can be used to cover special equipment or resources for a student who uses Augmentative Communication.

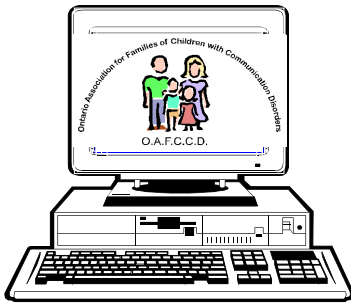
These are all promising signs, but parents will not be satisfied until all our children are receiving the services they need.

Increased Awareness is Needed

There are still lots of children with communication disorders who have not been identified, who are on long waiting lists or who are not receiving adequate services.

It is important for members of OAFCCD to help increase public awareness of communication disorders. One method of increasing awareness is to share a success story with the local Newspaper. If you are willing to share a personal story contact your Chapter Leader or Speech-Language Pathologist. People love a real life story and it may help alert a parent to the signs of a communication disorder.

O.A.F.C.C.D. on the Internet!



OAFCCD web site has been up and running since March 06, 1997. What started out with a few pages now contains over 100 pages with over 1100 visitors to date. We have had visitors from Canada, USA, Australia, United Kingdom, Mexico, Hong Kong, Philippines, Netherlands, Ireland, Malaysia, Portugal, Israel, Guatemala, Kuwait, Old style Arpanet, Belgium, USSR (former), Germany, Finland, Brunei Darussalam, Japan, Croatia, South Africa, Norway, Romania, Taiwan, Switzerland, India, Spain, Greece, Singapore, Italy, Korea (South) and Slovak Republic. I find it amazing that our little site has reached out to so many people from so many different countries.

The site contains information on our Provincial group, local chapters, membership information, inspirational poems, newsletters (past & present), links to many Speech & Language sites on the world wide web, kids' sections and lots of other information.

In December many new features were added to the web site that I am very excited about. I added a guest book where visitors to the site can sign and leave comments. It is very encouraging to hear from our visitors. Here are a few of their posts:

Diane from Indiana wrote, *"I have been reading the poems page. I think it's great! I'm a mother of three special needs children and also a care provider for special needs children. I'm looking forward to reading more poems. Thanks, keep up the good work!"*

Brandi from Elkin, North Carolina wrote, *"I am so impressed and excited by your work! These web pages are amazing! I am presently studying at Appalachian State University to become a Speech Pathologist. I hope to achieve many things and all of these pages are very encouraging. Thank you and best of luck!"*

Another new feature is the Discussion Board where parents, professionals and interested parties can post questions, answer a question, make comments or just vent. Since December we have had 7 people post on the board. They include parents asking questions, about things like FM transmitters and sign language, and a Doctor offering to answer any questions on Chiropractic care. I hope that as our site grows that it will become a very active message area.

We are also members of two Webrings - The Special Needs Children Ring and The Special Angels Ring. A webring is a way to group together sites with similar content by linking them together in a circle or ring. The idea is that once you are at one site in the webring, you can click on a "Next" or "Previous" link to go to adjacent sites in the ring and if you do it long enough you end up back where you started from! We get several visitors a week that are following a ring.

Just recently our site has received some awards:

- *"The Angel's Touch"* Award for making a difference in the life of children,
- *"Live Well"* Award for sites that promote health and good living,
- Greensan's *"Share in the Sunshine"* Award for bringing sunshine into the lives of others.

The site also contains an E-mail address **oafccd@cyberus.ca** where visitors can E-mail me directly to ask questions. I have had about 20 people E-mail asking about our group. I answer all questions that I can or I direct them to the people or web sites where they might get an answer.

I hope that all OAFCCD members are able to visit the site at some point in time. If you do not have Internet access at home you can usually go to your local library and book time on their computers. Also check with your Town Hall to see if there are any government funded Community Internet Access programs in your community. In larger urban centres there are Internet Cafés where you can do your surfing. When you do visit our site please sign our guest book or post on the discussion board!

Happy surfing!

Story submitted by Susan Richards, WebMaster

A Mother Asks “Will our son ever talk?”

Story submitted by Genette Brest, Mount Hope

Our son, Vincent was about four years old when we took him to see our family doctor. We were concerned about Vincent not talking. Family and friends were always asking if Vincent was talking. We replied, "No, not yet." It always puzzled us why it was so important to other people if Vincent was talking or not. He never said too much at the age most kids were supposed to talk. Our oldest son had a limited vocabulary at that age as well. However, our daughter was talking at an early age and she hasn't stopped! We thought Vincent was developing in a similar manner to his older brother, and therefore we were not overly concerned in the beginning, however, as the school year approached and Vincent was still not talking, the need for intervention became apparent.

Our family doctor made a referral to a pediatrician, who felt that perhaps Vincent was not hearing properly, and sent us to have Vincent's hearing tested at the local hospital. Waiting for the test seemed like an eternity. Our minds were racing. What did the future hold for our son? In the midst of our confusion and unanswered questions we were sent to see a developmental pediatrician. We didn't know that there were two different kinds of pediatricians. The appointment was made and several questionnaires followed along with renewed hope.

Finally our appointment day arrived, and we were eagerly anticipating some answers. You can't imagine our disappointment when this doctor could not provide us with any answers. However, he did say that we would have to build a bridge so that Vincent could communicate with his family. We left his office more confused than we came in. We didn't talk on the way home. We didn't know what to say any more.

We thought that our youngest child was never going to talk. I thought to myself “how in the hell is my third child going to get along in the world without being able to talk?”. For days my husband and I were in a daze. We didn't know how to tell other family members and friends that Vincent may not ever talk. A few weeks later we saw the pediatrician again, and he told us that the best way to communicate with Vincent, was going to be with our hands. He told us that our family would all have to learn sign language. What a

great idea! I couldn't wait to learn. Through the process of signing Vincent would be able to talk to us with his hands. He was already doing some of his own signing; for instance, if he wanted a drink or something to eat, he would put his hands to his mouth. He also used pointing to enhance his communication. In a way, Vincent knew before we did that signing was the bridge. The pediatrician was surprised at how well we took the news and of our enthusiasm to learn sign language. He told us that other parents took months before they decided to learn signing. We had already been through the stages of helplessness, disbelief and denial, now it was time to put all our efforts into helping Vincent. Vincent and I enrolled in a signing class. I couldn't believe how much fun I had taking the course. Not only did I learn a lot about signing, but perhaps even more important, I learned that Vincent needed to be treated like a normal child.

We started off with simple signs like mom and dad. When he was doing the signs on his own, we would teach him another one. When a new sign was difficult, Vincent would give us his hands. Vincent was picking up the signs really fast. After only four months Vincent was signing up to 65 words! Vincent wanted to “talk” and that’s why I think he was learning so fast. We also noticed that Vincent wasn’t as frustrated as he was before - because we knew what he wanted!

Vincent's progress has continued to amaze us. Initially, some people thought if Vincent learned to sign that he wouldn't learn to talk. They're wrong! Prior to his learning of sign, Vincent never said any words, but made a lot of sounds, such as an airplane flying or cars crashing into each other. Vincent soon started to say many of the words he was signing, like "bro" for broken and "pa" for pop and "da" for daddy!

Vincent is now five years old and has a vocabulary of approximately 50 words. With each new word comes a celebration. No one knows for sure what the future holds for Vincent. The doctors are amazed at the progress he has made in such a short time. They think the reason Vincent is doing so well is our attitude. Our ultimate goal is for our son to talk fluently. It doesn't matter how we get there or how long it takes. We know the path to success is a long and bumpy one, but we will always be there for our son.

COMING EVENTS

Parent Workshops (London) - Stuttering can be Prevented - If Detected Early (Tuesday May 12 or Wednesday June 17, 1998) **Contact: J. Anthony Wray, (519)675-0449.**

Information Fair, (Newmarket) May 2 -3, 1998 - The Third Annual Information Fair for Parents of Children with Special Needs, York Regional Administrative Centre, Newmarket. **Contact: Josie Demartino (905)898-3000**

Lanark Chapter Meeting, May 13, (5:00pm) - Sharen Heath, President OAFCCD and Alison Morse will be the Guest Speakers. This is a great opportunity to come out and talk about OAFCCD and how the organization can help parents. **Contact: Connie Beckett (613)284-1227**

"Childhood Communication - Let's Get practical" (Peterborough), May 22 Full day workshop featuring Professor Carla Johnson from the University of Toronto. Will provide parents and professionals with strategies to promote communication from birth to school age. **Contact: Wendy Bishop (705)743-1000.**

Autism/P.D.D. Workshop, May 27, 9am to 4pm, (Woodstock). Practical Teaching Strategies for Individuals with Autism/P.D.D., Salvation Army, 769 Juliana Drive, Woodstock. **Contact: Woodstock & District Developmental Services, (519)539-7447.** "More Than Just Talking Workshops" for parents and educators are held monthly at the London Speech and Language Centre. **Contact: Kerry Erle, (519)642-2172.**

"A Two-day Fluency Refresher for Children Who Stutter" July 23-24, 1998 at The Speech Therapy Clinic in Ottawa. Cost: \$250. **Contact: Josée Charbonneau, (613)746-4414.**

BIG THANKS

The Lanark, Leeds, & Grenville Tri-County Preschool Communication Assistance Project have donated \$450 to OAFCCD for the purchase of the Internet access to the Centre for Philanthropy Foundation Directory. This will be a great help in obtaining funding for OAFCCD!

Especially for ADD or ADHD Children:

Camp Kirk - a residential camp for children 6 to 12 years of age with Learning Disabilities, ADD or ADHD. **For information and brochure, call (416)782-3310.**

Social Skill Camp (Burlington) - a multi-faceted group approach to teaching social skills for ADD children. Six half day sessions, July 14-23 (or August by request). Cost \$300 per child. **Contact: Pauline Schein, (905)335-8321.**

Parents Wanted!!!

Special Education Advisory Committee:

OAFCCD have received requests from the following school boards for **Special Education Advisory Committee (SEAC)** members. Big changes are occurring in the education system and parents are needed to represent the concerns of our children. SEAC membership involves ten meetings per year, and OAFCCD representatives are provided with information mailings and provincial support from Alison Morse. Please call Alison at (519)688-0369, if you think you are interested.

- London District Catholic School Board
- Waterloo District Catholic School Board
- Durham District School Board
- District School Board 14

Other school districts may still have SEAC vacancies. Please call Alison to find out.

Preschool Services:

OAFCCD has also been asked to find parent representatives to participate in the implementation of the Toronto **Preschool Speech and Language Plan.**

•**Toronto - South Quadrant:** If you live in either "old" city of Toronto or East York, please call Elaine Weitzman at the Hanen Centre (416) 921-1073 for further information.

(See Insert for more information on Preschool Speech and Language Plans)