AUGUST 2013

BUDDY WALK IS COMING!

Saturday, September 21st

Register at 10:00 a.m., Walk at 11:00 a.m.

Delaney Park Strip, 10th & I St.

Face Painting! Raffle Prizes!

Balloon Artist! Bounce House!

Bring your buddies and come ready for a short walk - rain or shine!

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akdownsyndrome.org

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677-6677

DON'T FORGET TO MARK THIS ON YOUR CALENDAR!

Bouncin' Bears Party

Saturday, August 17th

6:00 - 8:00 p.m.

Calendar of Events

August	September	October
17th - Bouncin' Bears Party 6:00 - 8:00 pm 22nd - Buddy Walk meeting BP Energy Center 6:00	21st - BUDDY WALK 10th & I St. 10:00 a.m. 26th - DS board meeting BP Energy Center 6:00	24th - DS board meeting BP Energy Center - 6:00 26th - 27th - Local Special Olympics Bowling at Center Bowl
November	**December**	
2nd - ANNUAL MEETING/ SPEECH & LANGUAGE WORKSHOPS BP Energy Center Workshops - 10:00 & 2:00 Meeting & catered lunch - 12:00 22 - 24th - State Special Olympics Bowling	1st - HOLIDAY FAMILY POTLUCK Kincaid Park 1:00 - 5:00 25th - Merry Christmas!	If you would like to volunteer to help with the Holiday Potluck, contact Linda Wooster at 360-0652 or e-mail her at lindawooster@gci.net

Are you on FACEBOOK? Be sure to search ALASKA DOWN SYNDROME and join our group.

The AK Chapter's personal library is located in the S.T.E.P Center library, which is at the Anchorage School District headquarters on the corner of Boniface and Northern Lights. You can look up titles on their website by going to: STEP Center Anchorage School District, click on library search, then type in "Down Syndrome" in the space after "select a category". Click on search now, and you will find the many titles that our chapter has donated to this library of resources. The S.T.E.P Center can send books through your child's school's mail, so you don't even need to make the trip yourself. For out-of-towners; call Karen Schudel at 346 - 3191 and she will personally mail it to you. The check out time frame is typical of any library. Not only are there resources for new parents, there is reading for young adults and children's books as well. Have fun reading!

Our website has a new address - check it out!
akdownsyndrome.org

NOW HEAR THIS!

Speech/Language Workshops AND Annual Chapter Meeting

Saturday, November 2nd

!0:00 a.m.

B.P. Energy Center (900 E. Benson Blvd.)

Two speech/language therapists will present workshops on speech and language development in Down syndrome. Both June Takagi and Molly Thompson are long-time Alaskans and have extensive experience working with young children with Down syndrome. They work very differently, and their information should be most helpful in understanding how we can help our children to develop good language and clear speech.

Schedule for the day:

10:00am - 12:00pm - June Takagi "It's Not a Phase - moving through the developmental stages of communications skills." June will address the definitions of attention, saliency, child-directed play and following directions. This will be an informal session with discussion about key learning/teaching strategies quite specific to children with Down Syndrome, which can be applied from birth to young teens.

12:00 - 2:00pm ANNUAL CHAPTER MEETING for ALL families, with catered lunch. Please plan to come if you possibly can, to talk about our current status as a Chapter, help create new goals for the future, and participate in the election of officers for the board.

2:00 - 4:00pm - Molly Thompson "Making the Most of Language and Speech Skills in Children with Down Syndrome." Molly states her goals as, the learner will:

* understand the characteristics of speech & language in DS
* identify their speaking rate and how it applies to best listening
* understand cognitive strategies in teaching children with DS
* be aware of different therapy strategies and their purpose
* learn how literacy affects speech and language in children with DS"

Plan to come to both of the wonderful workshops, and/or enjoy the great company at our noon meeting.

PLEASE RSVP to Donna Davidson at 694-2545 if possible in order to get a reasonable head-count for lunch. Space is limited and we will seek a bigger venue if needed.

Genetic advance in Down's syndrome
By Helen Briggs BBC News
July 17th, 2013

US scientists say they have moved a step closer to being able to treat disorders caused by an extra chromosome.

They have "switched off" the chromosome that causes the symptoms of Down's syndrome in human cells in the lab. The research, published in Nature, could one day lead to new medical treatments for the condition. Future work may be of real benefit to people with Down's syndrome, said the UK Down's Syndrome Association.

Humans are born with 23 pairs of chromosomes, including two sex chromosomes, making a total of 46 in each cell. People with Down's syndrome have three - rather than two - copies of chromosome 21. This causes symptoms such as learning disabilities and early-onset Alzheimer's disease, as well as a greater risk of blood disorders and heart defects.

Gene therapy, which uses genes to treat illnesses, has been attempted for problems caused by a single defective gene. But until now, the idea of being able to silence the effects of a whole chromosome had appeared beyond the realms of possibility, even in the lab. Now scientists at the University of Massachusetts Medical School have shown that, in theory, this might be possible but would take decades of research.

A team led by Dr Jeanne Lawrence inserted a gene called XIST into the stem cells of a person with Down's syndrome grown in the lab. The gene plays a role in normal cell development by switching off one of the two X chromosomes present in female embryos, ensuring daughters avoid a double dose of X chromosome genes. The experiments showed that the gene was able to silence the extra copy of chromosome 21, helping correct unusual patterns of growth in the cells.

Dr Lawrence told BBC News: "The research means that we have a new way - right away - to study the cellular basis for Down's syndrome, that could help identify drugs for Down's syndrome. At the same time we have made it conceivable - not necessarily possible or effective, that still needs to be proven - but conceivable that you could use just a single gene to correct the over-expression of the whole chromosome. So it makes genetic therapy for Down's syndrome more conceivable where it really wasn't before."

Commenting on the study, Carol Boys, chief executive of the Down's Syndrome Association, said it was exciting new research from a very well-respected team. "The findings could have serious implications for future work that may be of real benefit to people with Down's syndrome," she said. "We are a very long way from understanding how these findings might translate into clinical applications but it could be that they will be of great assistance in the search for conventional treatments for some of the health conditions that affect people with Down's syndrome."

Dr Lucy Raymond, from the department of medical genetics at the University of Cambridge, said the group had demonstrated an important proof of concept. "This is an exciting breakthrough, but this process is still at a very early [cellular] stage and we are nowhere near seeing this procedure being used in the treatment of Down's syndrome in people."

YOUR BOARD AT WORK

I want to say a huge thank you to all our board members, and am happy to do it publicly. Our current Chapter Board is one of the best working boards with which I have been involved. We are a *working board,* not an *advisory board.* We have people working on membership, website, finances, newsletter, social events, baby/toddler events, PR, Buddy Walk. These people are committed and consistent in their work, making things run very smoothly. We meet just once a month, with connections in between via email. On top of that, we have a little fun social time at meetings. Interested in joining? There are other jobs to do or committees for sharing the work. We are currently thinking about a video project....but more about that in the next newsletter! Please call me or email me if interested in joining on creating the future of our Chapter.

Donna Davidson 694-2545 dkdavidson@gci.net

Rose Fitch, mother of Reilly, has started organizing some activities for our kids who are 5 years old and younger. If you would like to be a part of this activity group e-mail list, please contact Rose at 297 - 9671 or by e-mailing her at rosemariem@gci.net Rose has also organized a Facebook group called AKDS Playgroup for Babies and Toddlers. It is private and if you are having difficulty finding it please let her know and she will invite you. The group has been attending the weekly "Toddle Time" sessions at Spenard Rec Center on Thursdays. They have also played at H2Oasis and attended story time at the library together.

Are you in the valley? There is a new group for you on Facebook!

Mat-Su Valley Down Syndrome Support Group
Supporting those with Down Syndrome in the Mat-Su Valley, Alaska

Our Annual Summer Picnic in June was a Blast!

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