

A Little Something Extra

Volume 2, Issue 9

November 2004

www.pcdsmi.org

Parents of Children with Down Syndrome

Opening a World of Opportunity For Children with Down Syndrome

Mark your Calendars for the PCDS Holiday Party!

We will be having our annual PCDS holiday party on Sunday December 5th at The Cross of Christ Lutheran Church 1100 Lone Pine Road (NW Corner of Telegraph and Lone Pine). This event is open to all members of our organization and their families. Please see the page inserted in the newsletter for details and to RSVP. We always have a great time so don't miss out on the fun!!

Better Late Than Never—How David Finally Learned to Use the Bathroom, By Linda Moran, Ridgewood NJ.

“Don't worry. He won't be in diapers when he enters high school.” We've all heard this advice as it pertains to typical kids. It's intended to help us relax— and it's true. But what about our children with Down Syndrome? Our son, David, took so long to train that he threw this advice into question. If you have or work with a child with Down Syndrome, you know what it means to adjust expectations.

Although many children with Down Syndrome are trained completely by age five, the range of what's typical is quite broad—some say anywhere between three and 11. Those numbers gave us some comfort, until David turned 11 and there was still no end in sight. We had tried the standard method, suggested by a specialist, or putting him on a schedule. David likes schedules and memorizes his school schedule each year. But, starting in kindergarten, whenever we tried to put him on a schedule for using the bathroom, he would rebel, and withhold His urine all day until he went to sleep. Since our doctor advised this was not good for David's health, we had to quickly give up. - continued on page 4 -

High Frequency Hearing Loss

High frequency hearing loss is probably more common in people with Down Syndrome. One aspect of this loss is the reduced ability to distinguish different consonant sounds. Therefore, the person with Down Syndrome may be hearing the sounds but may have difficulty discriminating what is being said. This leads to problems with misinterpreting what is being said. Therefore, what may appear to be defiance or oppositional behavior or even a decline in intellectual skills may actually be impaired hearing.

It is important to speak clearly to a person with high frequency hearing loss. It is also beneficial for the person with the hearing loss to be able to see the person that is speaking to him or her. Crowded or noisy rooms are places where the person may find it particularly difficult to discriminate what is being said.

Hearing aids may also be indicated for some people with high frequency hearing loss.

(from NADS news, July 2004)

Who We Are

Parents of Children With Down Syndrome was formed in 1982. It is a group of families primarily in Oakland, Macomb and Wayne counties who share common concerns and provide mutual support to parents and their family members.

PCDS Playgroup News

Our next playgroups are scheduled for :

Saturday November 6 10:00-11:30

At:

The nursery at The Cross of Christ Lutheran Church 1100 Lone Pine Road (NW Corner of Telegraph and Lone Pine).

All mothers with new/young infant/toddler children are welcome to come with their siblings or friend they would like to bring.

For additional information contact:

Annette Liike (248)624-3046/
aliike@comcast.net



Calendar/Important Dates

Saturday November 6, 2004 8:30 A.M.-3:00 P.M. 5th Annual Michigan Fathers Conference, at Birmingham Covington School, 1525 Covington Rd.(corner of Quarton and Covington), Bloomfield Hills.

www.dadsempowered.org for additional info,
Note: we think this would be a very worthwhile conference for all dads

Wednesday November 10, 2004 at 6:30 P.M. "How Special Education Law Supports Inclusion" featuring Laura Athens, Special Education Attorney. Meeting will be held at the Bloomfield Hills Library, Bloomfield Hills, MI.

November 12 & 13, 2004 Las Vegas Night at the Waterford Elks club. Proceeds will benefit Oakland County Special Olympics

November 16, 2004 9:00 A.M. - 4:00 P.M. Self-Advocacy, Self Employment, ADA (Location TBA through the Washtenaw Association for Community Advocacy)

Sunday December 5, 2004, PCDS Holiday Party (details to follow)

January 27, 2005, 2:00-8:00 P.M. Healthy Living Fair at Oakland Schools. Contact Michele Harmala (Michele.harmala@oakland.k12.mi.us) for additional information.

April 22, 2005, Band of Angels Starry Night Gala at the Birmingham Townsend Hotel (details to follow)

PCDS General Membership Meetings on Tuesdays

in classroom #7 at the Cross of Christ Church from 7:00-9:00 pm on the following dates:

December 5 Holiday Party (details to follow)

January 11

February 8

March 8

April 12

May 19

PCDS Board Meeting

Tuesday, November 23 9:00 A.M.-11:00 A.M. at Paulette's house 3805 Quarton Road in Bloomfield Hills. Please RSVP attendance to Paulette

BOARD MEETING

Board meetings are open to **ALL** PCDS members. Your presence is welcome and appreciated. Please contact Paulette with any questions you may have at 248-646-0819 or Dugginsp@comcast.net.

Beautiful Faces Calendar

We have our supply of the 2005 calendars featuring beautiful pictures of many local children who have Down Syndrome. The calendars are \$15.00 and make a great gift as well as providing an opportunity to support PCDS from the sales of the calendars. Please contact Paulette for the Beautiful Faces calendars.

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What We Do

Our group meets regularly throughout the year, both formally and informally, socially and informational including:

- Sharing and parent social gatherings
- We provide a library containing a wide range of materials on Down syndrome and community group services and programs
- A newsletter that covers current legislation, articles on education, health, child development, estate planning, and a calendar of upcoming events, seminars and conferences.
- Occasional expert speakers who present topics of vital interest and concern to parents of children with Down syndrome.
- A website (pcdsmi.org) with up-to-date information on articles of interest to our members

PCDS MISSION STATEMENT

*Parents of Children with
Down Syndrome*

is a parent and family support group. Our goal is to share information about available services and programs in the areas of health, education, guidance counseling, advocacy, and other related matters.

PCDS is a 501 ©(3) non-profit organization. All donations are tax deductible. If you would like to help us in our mission of serving people with Down syndrome and their families, we welcome your contributions.

PCDS is an affiliate of the National Down Syndrome Society.

To reach NDSS write:
666 Broadway
New York, NY 10012-2317
or call 1-800-221-4606

DISCLAIMER POLICY:

The editor of this newsletter writes as a non-professional. This newsletter reports items of interest about Down syndrome in an effort to educate and to promote awareness and positive attitude. PCDS does not support or endorse any particular regimen, treatment or religious view, Inclusion of items does not necessarily imply promotion or recommendation of its sponsors. Articles from this newsletter may be reprinted but proper credit must be given to its source.

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New Parent/Hospital Liaison

Better Late Than Never—Continued from Page 1

Over the years, we read books, tried various approaches, and consulted psychology, special education and medical experts. We were perplexed, and spent long months doing nothing at all. Some experts felt we had started too late. Others felt that David was just “not ready.” But what does that mean? Looking back, perhaps David was just not ready to give up control. That condition could reinforce itself forever.

Now he was 11, had outgrown night-time pull-ups, and was wearing adult diapers. The school psychologist and special education teacher were befuddled. And we, his parents, were exhausted and resigned. The school called in a behaviorist, but we didn’t have much hope. We were in for a surprise.

Jacqueline Dubil-Craig, with her master’s degree in Applied Psychology, and a background working with children with autism, was, it turned out, just what the doctor ordered. Dubil-Craig concurred with us that this was not a potty issue any more. From our point of view, David’s power struggle with us was akin to that of a teenage girl with an eating disorder. According to Dubil-Craig, it all came down to reinforcers. “I look at everything in terms of reinforcement,” said Dubil-Craig. “The highest reinforcer is the control he is exerting over you.” She explained that all the positive reinforcers we had tried (stickers, favorite foods and his interest in schedules); and all the negative reinforcers we had tried (no computer use in school), had less meaning to him than the power he was holding over everyone.

What she prescribed was so simple. It seemed, at the surface, to be something we had already tried, but we actually had not. She told us we were to show no interest in whether David used the bathroom. On the other hand, his toys would care deeply about it. All his favorite toys were to climb up on a high shelf, which would come to be known as the deprivation shelf. Each time he wanted a belonging, the toy would inform him (in my flat voice) that it would be happy to come down after he pees. For three weeks, those toys didn’t budge, just as Dubil-Craig had predicted.

As we were instructed, never once did we, his parents or siblings, say a word about the toys or the bathroom. Then one day David got fed up. He wanted his favorite toy, a Madeline doll. We heard a flush, and then David emerged from the bathroom with a grin and reported, “I Peed.” Down came the Madeline doll, with no words of praise.

The power struggle had now shifted to David and the Madeline doll. We were out of the loop. But what was next? When would the doll return to the shelf each time? Could we direct David to “go” before a long car trip? We made it up as we went along, but stayed strict about one thing—we ascribed all enthusiasm and control to his Madeline doll. She was in charge now. Sometimes we would have to go behind closed doors to shout for joy.

After about six weeks, we sensed it was time for underwear. In David’s mind, pull-ups get changed when wet. Since his pull-up was never wet, he would wear it until the elastic wore out. One day his gym teacher noticed a wad of bulk down around his knees inside his pants. It was an old, stretched out, dry pull-up.

Would he do any better changing underwear every day? We solved that problem with a laundry marker and the day of the week printed on each pair of underwear. Now, David was happy to match the correct underwear to the correct day of the week. It was four weeks short of his 12th birthday, and six weeks since the deprivation shelf was created. David was now in underwear, even at night. We extinguished the shelf.

In the final analysis, this method capitalized on David’s social strength by creating a relationship between himself and a doll, and then later, between David and his underwear. We would say, “Your underwear wants to stay clean and dry.” It was never, “We want your underwear to stay clean and dry.” The wording is subtle, but it worked. The focus now away from his relationship with us. “By acting as though you did not care whether he used the bathroom or not, his control reinforcer was removed,” says Dubil-Craig. “suddenly, depriving him of his favorite toy became meaningful again.”

Today, upon reflection, what finally worked was both the easiest and the hardest. It was the easiest because we didn’t have to go with him or be controlled by a schedule. It was the hardest because we had to stifle all enthusiasm. Had we shown excitement, we would have unwittingly recharged the power struggle. According to Kim Casey, M.S., Special Ed., all children, regardless of age or disability, need to have a say in their own lives. “If we constantly are battling with our children to gain control,” says Casey, “then everyone loses and nobody really has any power. If you have the last say in every battle the child does not learn from the situation.” David now was enjoying having control over his own toileting.

Now that David is trained, he still holds it for a long time. We hope to proceed cautiously with shifting him to a reasonable schedule. For the moment, trying to convince him to go before a long trip, means he holds it even longer. We have had to leave him alone and trust him to know what he needs—that is appropriate for an adolescent. Some things about David are quite on target.

..... continued on page 5.....

Better Late Than Never— Continued

We may never know whether David could have trained years earlier than he did. However, his lack of fine motor coordination plays a role in his ability to use the bathroom independently. According to Marlene Targ Brill, author of *Keys to Parenting a Child with Down's Syndrome*, physical readiness for toileting includes fine motor skills. Even at age 12, he needs to wear elastic waist pants with no zipper. Had he trained earlier, he would have been dependent on our help. Given his strong dose of stubbornness, coupled with our preoccupation with three younger children, it's possible the timing could not have been different.

As is often true with our wondrous children, the question of whether the ending of this story is neat and tidy is a matter of perception. When it comes to David doing his "number two," he awakens at night, changes his own dirty underwear, finds a plastic bag, carefully wraps up the mess, and leaves it in the kitchen for us to find in the morning. He awakens no one. Honestly, I can't complain.

From *Down Syndrome News*. Additionally, an editor's note to the article adds that David has progressed to using the toilet for "number two".

Additional toilet training help can be obtained locally by contacting the **Toilet Learning Clinic (TLC) for families of Children with Developmental Disabilities at the Beaumont Center for Human Development**, 1695 West Twelve Mile Road, Suite 120, Berkley, MI 48072-2122 (248)691-4744

Gastroesophageal Reflux (GER) and Down Syndrome

By Len Leshin, MD, FAAP (Parts 1 and 2)

Gastroesophageal Reflux (GER) is probably the most common gastrointestinal problem in childhood. GER is defined as the movement of contents of the stomach (solids or liquids) into the esophagus. Commonly, this results in children "spitting up" or even forcefully vomiting. While some spitting up in infants is common and may even be called normal, it becomes abnormal when it causes either distress in the child or complications to the child's health such as pneumonia, esophagitis or slow growth.

The cause of GER is most often a decrease in muscle tone of the lower esophageal sphincter (LES), a muscle that lies at the junction of the esophagus and stomach. Another contributing factor to GER is how much the stomach holds and how fast it empties out into the small intestine, as infants with smaller stomachs and slower emptying times tend to reflux more than any other age group.

Whether or not GER is more common in children with Down Syndrome (DS) than in the general population has not been determined. At least one major pediatric textbook states that this is the case, but only one study on the topic has been published to date. But it would make sense for GER to be more common since infants and children with DS have lower muscle tone, so the tone of the esophageal muscles may be lower as well.

Signs and Symptoms

The most obvious signs of reflux are frequent spitting up and/or vomiting. While normal infants may spit up occasionally, the infant with reflux will spit up or vomit after almost every feeding. The difference between spitting up and vomiting is one of force: vomiting is more forceful, usually due to spasms of the pylorus muscle. 85% of all infants with GER will show signs by 7 days of age, with another 10% showing signs by the 6th week of life.

Some infants and children will have GER but the stomach contents won't come up all the way to the mouth. Others will have just enough contents come up that they will have to swallow again, but not spit up or vomit. One condition called Sandifer syndrome presents with swallowing actions and an unusual head tilt, and reflux that may or may not be obvious. Any infant that seems to be continuously choking, gagging or making swallowing noises should be evaluated for GER.

For reasons that aren't entirely clear, GER can produce apnea in infants. Apnea is the temporary absence of breathing, usually lasting 10-20 seconds, and sometimes accompanied by a bluish color of the face. ...Continued on Page 6

Gastroesophageal Reflux (GER) and Down Syndrome

.....Continued from Page 5....GER can also cause respiratory symptoms when stomach contents coming back up the esophagus trickle over into the airway. This can cause a chronic cough, a hoarse noise during breathing (“stridor”), wheezing, and repeated cases of pneumonia.

GER also can cause chest pain, often referred to as indigestion or heartburn. This is because the stomach contents become acidic after exposure to the gastric acid, and the lining of the esophagus isn’t meant to be exposed to stomach acid. In some infants this discomfort is registered as prolonged fussiness or crying, and may be one cause of infant colic. If untreated, the GER can eventually cause esophagitis, which is an irritation of the walls of the esophagus. Severe esophagitis may lead to bleeding and scarring of the esophageal lining.

Diagnosis In most cases, the diagnosis of GER is fairly obvious. For less obvious cases, the usual means of diagnosis is through radiological tests. One test, the Upper GI, involves the infant or child swallowing barium, a radio-opaque liquid. (“Radio-opaque” means that the liquid shows up as white on X-rays, not that the substance is radioactive.) Several X-rays are taken as the infant swallows to see if any liquid comes back up, and how far up it comes in the esophagus. However, because GER is an episodic event, the Upper GI test may not always catch the reflux; so a negative test does not prove the child doesn’t have GER. (Note that an Upper GI is not the same as a “Barium Swallow” test. The Barium Swallow only looks at esophageal function and may not catch episodes of reflux that an Upper GI test will.)

Another X-ray test is Scintigraphy, also called a “gastric-emptying test” or a “milk scan.” In this test, the infant or child is fed a liquid that has a very small amount of technetium, a compound that can be seen by special equipment. While this test takes longer to do than an Upper GI, it involves a smaller amount of radiation exposure to the infant. This test has the advantage of observing the child over a longer period of time and may pick up cases of GER that the Upper GI might miss.

In more difficult cases, the esophagus may need to be looked at directly for signs of irritation to the lining. This is done by endoscopy, in which the doctor puts a fiber-optic tube down the sedated child’s throat to examine the esophagus. If necessary, biopsies can be done at this time, which is the removal of a small piece of esophageal lining to be looked at under a microscope later.

Finally, in cases where a definitive diagnosis is elusive or when surgery is being planned an esophageal pH probe may be done. In this situation, the child is observed in the hospital overnight with a probe placed in the child’s esophagus. This probe will measure the pH of the contents of the esophagus, looking for the acidic characteristic of stomach contents being refluxed up the esophagus. The probe may also be used to measure pressures in the esophagus (“manometry”) to help determine the usefulness of surgical treatment.

There are other causes of frequent spitting up or vomiting in the infant and child besides GER, such as metabolic or allergic conditions. Should the above tests show that GER is not the cause, then the child’s physician may do other tests to isolate the cause.

Treatment of GER The first line of treatment is usually a combination of positioning and diet changes. In positioning the infant the refluxes, it is best to elevate the head above the level of the stomach. In the 1970s and 1980s, it was common to have the child lie on his stomach (the “prone” position); however, studies in the early 1990s showed that there was an increased risk of Sudden Infant Death Syndrome (SIDS, or “crib death”) associated with babies sleeping in the prone position. At the present time, it is best to have the refluxing infant lie on his/her side with the head of the bassinet or crib elevated at a 25 to 30 degree angle. For refluxing infants taking formula, the formula can be thickened in order to decrease the total volume that the infant takes at a feeding and to make it harder for the stomach to reflux the thickened liquid. Dry cereal is most often used to thicken the formula, starting at 1 tablespoon for every ounce of formula and going thicker if necessary. Thickening the formula tends to reduce the total volume of contents refluxed as well as increasing calories.

For children or infants that do not respond to these conservative measures, the next step is using medications. This group of drugs are called “prokinetic” drugs. Bethanechol was the first drug used for GER and acted to increase the muscle tone in the esophagus, but was never an approved indication for this drug in the US. It has the significant side effect of increasing bronchospasm in children prone to asthma, and was not that effective in reducing GER symptoms. Metocloperamide (Reglan) is the most common drug used for this condition currently, as it increases the tone of the LES as well as increasing the speed at which the stomach empties into the small intestine. Metocloperamide works better than bethanechol, but still gives mixed results at relieving symptoms. Also, there is a narrow margin between the dose needed for effectiveness and the dose that causes side effects such as sedation and movement disorders. Cisapride (Propulsid) had been a fairly good antireflux medication, but had to be pulled off the market in March 2000 due to side effects involving the heart rhythm. A new drug called domperidone (Motilin) may be more useful for GER but is not approved for use in the US yet.

For many infants and children with severe GER, acid-reducing products that protect the lining of the esophagus may be useful at decreasing pain. Antacids such as Maalox may be effective, but large and frequent doses are required. More commonly, “anti-secretory” drugs which reduce the amount of acid produced by the stomach are used such as cimetidine (Tagamet), ranitidine (Zantac), and omeprazole (Prilosec). These are given together with metocloperamide or cisapride. Surgery is used for infants and children with severe GER resistant to medications. These are most often needed in children who reflux so much that they have failed to grow sufficiently or there is chronic respiratory problems such as repeated aspiration pneumonia. Another group of children who often need this surgery are those who have gastrostomy tubes, as the presence of gastrostomy tubes greatly increases the incidence of GER. Fundoplication is the most reliable way to surgically prevent reflux, and is successful more than 90% of the time in published studies. In this procedure, the top of the stomach (the “fundus”) is wrapped around the LES; this increases LES pressure and also serves as a valve in preventing GER.

From DSA Press, September and October 2004.

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Happy Birthday to everyone with a birthday in November!

Scissors icon
DID YOU KNOW?
The Department of Treasury says that when you pledge to give to United Way this year, you can designate your contribution to PCDS.
Image of PCDS logo
Please pledge to direct your gift to PCDS by writing this name and number on your pledge card:
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or "PCDS" and the number "121194"
Cut out and save this information to put in your purse or wallet for when you sign up and be sure to pass the word to your friends and family who are giving to the United Way.
Scissors icon

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This newsletter goes out to over 250 families each month. Would you like to advertise your business with us? The monthly rate for a business card size ad is only \$20.00. If you would like to advertise for 6 months the cost is only \$100.00—for a year \$200.00. Think about it. Many people read this and may be able to use your services. Call Tricia Dewar for further information. (248)554-9191

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