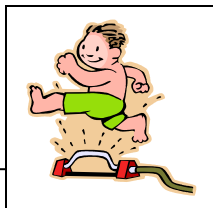




Down Syndrome Development Council FORUM- March 2007

volume 6



Please contact us at:

DDC
PO Box 906
Mundelein,
IL 60060

Our Meeting Place:
Community Protestant Church
418N. Prairie
Mundelein,

Second Mondays of the month

Our Mission:
To promote a greater acceptance and understanding of Down syndrome, by enlightening the broader community to recognize the individuality, uniqueness and capabilities of individuals with DS.

March Monthly Meeting:

Monday, Mar. 12th, 7pm.



The March meeting will give us a chance to do a little "maintenance" on our group. We have so many topics to discuss. It will give you a chance to discuss any topic you want to bring to the group. Many of us are currently struggling with the same issues, and we can find some piece of mind by openly discussing what is going on. So please take a break from the dishes and the kids and become an active member or **your** support group. Or you could just come for the cookies.

SUMMER IS COMING!!

On April 9th, Theresa from Special Recreation Association of Central Lake County (SRACLC) will be presenting information for summer programs available for children in this area. These programs vary from day camp to programs providing a couple of hours of entertainment for the kids. Learn more about this wonderful group of volunteers and what programs your child may wish to participate.

UPCOMING DDC EVENTS:

3/10 Sat. Playgroup is CANCELLED (For March Only)

3/12 Monthly Meeting, 7pm -- "It's IEP Season Again"

3/15 Thurs. Playgroup, 5:30 - 7:30pm

3/31 Movie Lovers Club, Teenage Mutant Ninja Turtles, Sat 9:45am

4/9 Monthly Meeting, 7pm "SRACLC"-Summer programs.

5/5 - PECs Workshop with Pat Bryant

5/14- Amber Petersen- Special Olympics

Other Interesting Events:

3/2 Handwriting without Tears - Pre-K workshop

3/3 Handwriting without Tears - Printing and Cursive workshop

3/6 The Parent's Emotion Journey- 7pm @ JCYS

3/13 Strategies for Important Meetings - 7pm @JCYS

3/30 Handwriting without Tears - Print Tool workshop

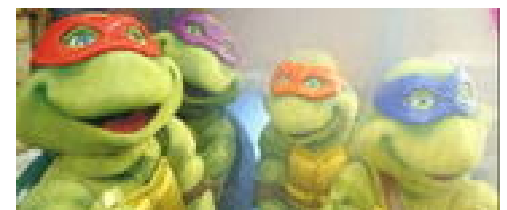
(For info on these workshop go to the Handwriting without tears website.)

MOVIE LOVER'S CLUB PRESENTS:

Teenage Mutant Ninja Turtles

This full feature film will be shown at the Libertyville Theater on Saturday March 31st at **9:45am**.

The theatre is located at 708 No. Milwaukee Ave. in Downtown Libertyville. The doors will open for us at **9:30am** and popcorn and drinks will be available for purchase. The DDC will again provide for our tickets and we encourage all kids to sit together as much as possible.



What Do You Think?

Associated Press

Published December 31, 2006

WASHINGTON -- The American College of Obstetricians and Gynecologists

this week begins recommending that every pregnant woman, regardless of age, be offered a choice of tests for Down syndrome. Until now, testing for the common birth defect hinged on whether the woman was older or younger than 35. The main reason for the change: Tests far less invasive than the long-used amniocentesis are widely available, including some that can tell in the first trimester the risk of a fetus having Down syndrome or other chromosomal defects. The change promises to decrease unnecessary amnios while also detecting Down syndrome in moms who otherwise would have gone unchecked. The new guideline is published in January's issue of the journal *Obstetrics & Gynecology*.

Age 35 was always a somewhat arbitrary threshold for urging mothers-to-be to seek testing. The older women are, the higher their risk of having a baby with Down syndrome. But it's a gradual increase in risk--from 1 in 1,200 at age 25 to about 1 in 300 at age 35.

"It's clear there's no magic jump at 35," said Dr. James Goldberg of San Francisco Perinatal Associates, a member of the American College of Obstetricians and Gynecologists committee that developed the guideline.

"We've done away with age 35 because the screening tests have gotten much better." The original age-35 trigger was chosen years ago when doctors had less information about the risk of Down syndrome and the only choice for prenatal detection was an amnio, using a needle to draw fluid from the amniotic sac, he said. Amnios occasionally cause miscarriage.

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The National Down Syndrome Congress (NDSC) has publicly condemned this recommendation by the American College of Obstetricians and Gynecologists (ACOG) that convey tacit approval for termination pregnancies where the fetus has Down Syndrome. Among the NDSC's concerns are:

- The primary medical reason for first trimester screening is to encourage earlier diagnostic testing in at risk pregnancies, in order to facilitate early terminations. Other reasons for prenatal diagnosis, such as hospital selection and delivery management, do not require first trimester testing.
- Based on ACOG figures, the recommended screenings will produce numerous false positives, potentially leading to unnecessary patient distress and possible termination of pregnancies where medical concerns do not exist.
- All screening or diagnostic tests need to be fully explained to patients, who should be provided the opportunity to decline or give their informed consent for testing. If patients decline certain tests, physicians and other medical personnel should respect the individual's wishes and not overtly or covertly pressure patients to undergo undesired screenings.
- Recent studies by Dr. Brian Skotko, published in the *American Journal of Obstetrics and Gynecology* (2005) and *Pediatrics* (2005) note that many doctors are inadequately prepared to deliver a diagnosis of Down syndrome, and often use negative language or out-of-date information. ACOG recommendations do not address this situation, nor how it will be corrected.
- Studies have shown that parents and siblings of children with Down syndrome overwhelmingly report that having a family member with that diagnosis has been a good situation. Early intervention and inclusive education have led to largely positive outcomes for children with Down syndrome. It is unacceptable that many obstetricians present negatives -- and seem to emphasize pregnancy termination -- rather than reporting the facts, which paint a much more positive picture.
- Parents who receive a diagnosis that their fetus has Down syndrome should have the opportunity to meet a family that includes a person with the syndrome, a move in keeping with the spirit of the Kennedy-Brownback bill.

NDSC Executive Director David Tolleson notes that Down syndrome is a serious diagnosis; however we have seen families thrive. We empathize with obstetricians who fear wrongful life lawsuits, Tolleson adds, but the cure for that problem is tort reform, not preventing the births of a whole class of people.

What Do You Think? Continued

Bridget's letter to the Editors of the Chicago Tribune and Time Magazine:

Dear Editor;

I am a young woman with Down Syndrome. I am so sad to hear about all the babies with Down Syndrome being aborted. I am so grateful that I was not aborted because I have a full and wonderful life!

I do not "suffer" from Down Syndrome. I believe in the sacred dignity of all people and most people I know with disabilities have full and productive lives.

I learned about what Hitler did during the Holocaust. He killed many people he did not think had the right to live. A He learned how to kill by killing people with disabilities first. My heart broke when I learned about this at the Holocaust museum.

It seems to me we are doing the same thing to children with disabilities today in our country. I think this is like genocide - the systematic killing of a whole people or nation.

I wonder why we think Hitler was so horrible when we are doing the same thing he did?

My heart breaks again when I think that I might be the last generation of people with Down Syndrome. The world will never again benefit from our gifts.

I will hold hope for people with disabilities and for all the people who think we don't have the right to live.

Bridget Brown
Self advocate



Here Is Someone You Should Meet

Patrick is an 18 year old senior at Warren Township HS in Gurnee. He is the 3rd of four children, Bill and Jason are away at college and Brittany is in 5th grade. Patrick faced the challenges common to other DS children including heart surgery 1 week before his 3rd birthday. He is a caring, happy, religious, and conscientious and a friend to many. He is kind, forgiving and compassionate and has a way of knowing and responding to others when they are down or troubled. He is a big help at home assisting with his chores and we learn from him daily from his positive outlook on life. We were fortunate to be introduced to DDC soon after Patrick was born for which we are grateful. DDC was invaluable in providing support and the guidance to resources to aid us in Patrick's early development.

Patrick was involved with speech and physical therapy as well as play groups right from the start. He has attended Gurnee public schools throughout his school years and has been blessed with many dedicated teachers and support staff. He also attended religious education and received the Sacraments of First Communion and Confirmation. Most summers he attends summer school as a reinforcement tool. As part of his high school junior and senior year curriculum he has been involved in a daily work-study program. During his junior year he worked at Paris Presents in Gurnee in labeling and packaging beauty care products. He recently began training at a Senior Center in Lindenhurst in food service. He enjoys his work and the interaction with other people.

His interests include sports, playing both baseball and basketball. He is a big fan of Chicago and college sports teams. He is looking forward to this years NASCAR season and he loves to play cards and dice games. He looks forward to having his own laptop computer, cell phone and motorcycle. He is excited about high school graduation and will continue in an educational and training program until age 21. We look forward to Patrick's continued development and meeting the challenges and opportunities that come his way. This was written by Patrick's proud parents, Bill & Brenda Rygiel.

The DDc Sports Page

Calling all boys and girls.....



BATTER'S UP!

Hi, I am Andrea O'Donnell and I am the Challenger Division Director for the Libertyville Little League and I am looking for more players for my team. What, you don't know what the Challengers are? Well, the Challengers is a Little League sanctioned special needs baseball team available to kids as young as 6 years old. We Practice once a week starting in late April and have games on Saturday mornings. We play against other special needs teams. Our home games are played at the Little League fields at Butler Park in Libertyville. The away games will also be on Saturdays. This year, for the first time, we will have on home night game, playing on the Major's field under the lights!!! Each player receives a uniform and hat. The players are responsible for their own baseball mitt and shoes. Each player needs to have a sibling or parent at every practice and game. We need each "buddy" to help out the player, not play for them, but to be there to assure the player does not get hurt. Our coaches run the practices like regular baseball. There are warm ups, hitting practice (using both pitching and a batting tee), and fielding practice. If you are interested in joining our team or need more information, please call me at 847-949-1975.



Special Olympics

Special Olympics

Join us on Monday, May 14th for an informative presentation by Amber Petersen of Special Olympics-Illinois. Learn about the wonderful opportunities for every special needs child, and volunteer opportunities for family and friends. Special Olympics are really for everyone!

Our friend Zachary Lincoln, a DDC member since 1986, participated with the Wauconda High School Special Olympics Basketball team Sunday Jan 28th. The team took first place and will be competing downstate on March 17- 18th for the Gold Medal competition of Area 2. Last year they took the Silver medal but now they will "go for the Gold"! Way to go Zachary, we are so proud of you and your teammates.



The YMCA SWIMMING PROGRAM IS GREAT!

There is a fantastic program for our children to learn to swim at the Central Lake County YMCA in Vernon Hills. The modified program runs from 4/16 to 6/3 and is taught by a group of YMCA coaches and a registered Pediatric Therapist. The cost for the 8wk program is only \$75 and registration begins on April 2. Several DDC kids have tried this program and given it thumbs up. Call Mary Craig at 847-367-6797 for dates and times, or for questions about how the lessons are modified call Debbie Morettini at 847- 573-9486 ex. 11. The YMCA is located at 700 Lakeview Parkway in Vernon Hills (behind the Target store).



Picture Exchange Communication Workshop – May 5th

The Down Syndrome Development Council (DDC) is pleased to offer a full-day parent involvement make-and-take workshop on Picture Exchange Communication (PECS) facilitated by Pat Bryant, SLP and AIMEE Solutions, Inc. The workshop will be held on May 5th, 2007 at the Grayslake Area Public Library from 10:30am to 4:30pm. There is a \$20.00 fee for the workshop that covers all materials and lunch. If you are unable to afford this fee please contact RaeAnn Collins for available scholarship information.

Each participant will learn how PECS is used in schools and how it can be customized for your child to enhance communication at home and in the community. Picture communication can grow with your child's needs as their language and communication skills develop. PECS has many applications and can be helpful for kids with emerging language and communication skills, for kids who have a good grasp of language but are difficult to understand, for kids whose first language is not English, for building sentence structure and for kids who are non-verbal...the possibilities are limitless.

During the workshop participants will make a file folder communication system with several laminated communication symbols AND a set of essential communication cards on a ring holder that your child can carry with them to communicate wants and needs while they are on the go. Time permitting you will be able to laminate some of your own images to be incorporated into your Picture Exchange Communication System. Please watch in upcoming newsletters for a more detailed description of the day's activities.

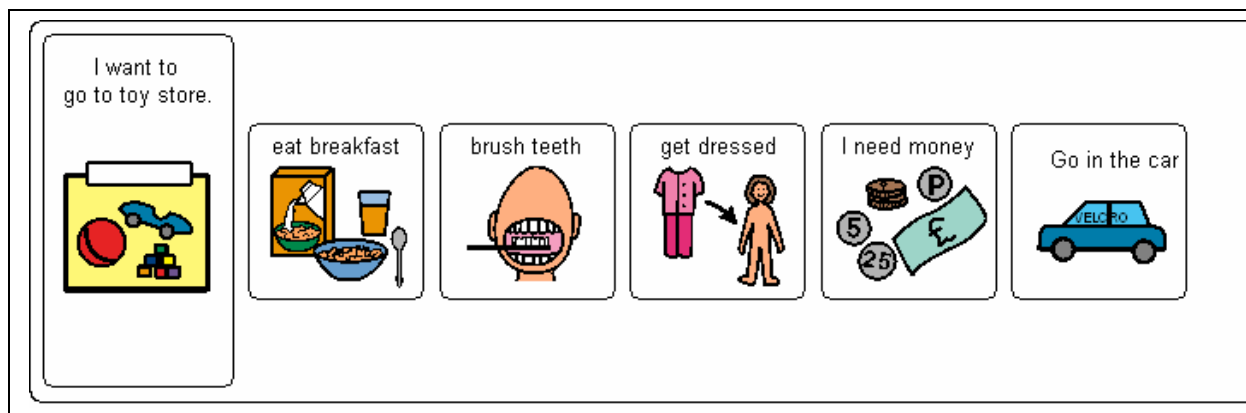
This is an ADULTS ONLY workshop. Due to the length of the workshop and available space, babysitting will NOT be provided.

The basic picture communication symbols will be available in both English and Spanish versions and a Spanish interpreter will be provided for the workshop. Please request the version of your choice on the registration form.

Space is limited so please make your reservation early. Application deadline is April 16th, 2007.

If you have any further questions please contact RaeAnn Collins at 847.265.8482 or rjohncol@comcast.net

Here is a sample of PECs used for reinforcing a day schedule:



The **Down Syndrome Development Council (DDC)** is pleased to offer a full-day parent involvement "Make and Take" workshop on Picture Exchange Communication (PECS) facilitated by Pat Bryant, SLP and AIMEE Solutions.

Date: May 5th, 2007
(please RSVP with your completed application form and check before April 16th, 2007)

Time: 10:30am-4:30pm (box lunch will be provided)

Location: Grayslake Area Public Library (meeting room ABC)
100 Library Lane
Grayslake IL

For directions please call the library at 847.223.5313

Cost: \$20.00 per person (includes lunch and all materials)

Please bring a pen/pencil for notes (handouts will be provided), **scissors and a ruler to the workshop**

You may also bring close-up photos of specific items that are important to your child (ie a favorite toy, family members, self etc). Time permitting, your images can be laminated and incorporated into your take home PECS communication system.

Please make checks payable to **DDC**.
Send your check and the below registration form to:
RaeAnn Collins
2945 Farmington Drive
Lindenhurst IL 60046

For more information please contact RaeAnn Collins at 847.265.8482 or rjohncol@comcast.net (put PECS in the memo)

For information in Spanish please contact Belinda Hidalgo at 847.838.4398

Please keep this half as your reminder

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Please send this half in with your check to reserve your space or go to the DDC website for a printout of this application.

If you are unable to print this application from your email newsletter, call RaeAnn.

Please reserve my space for the
PECS parent involvement make-and-take workshop

Name(s) _____

Address,
phone/email _____

Number of persons attending _____ (no children please)

_____ I want my PECS materials in English.

_____ I want my PECS materials in Spanish.

_____ Yes, I will need a Spanish interpreter.

Amount Enclosed \$ _____
Make checks payable to DDC.

Let's get together and make friends!!!



The "Playgroups" are therapist coordinated group sessions, geared toward preschool aged children with Down syndrome, but all ages are welcome. It is also a great chance for families to socialize and ask questions. Siblings are welcome. There is a Spanish translator at each session. Please RSVP if you would like to attend by calling Belinda Hidalgo at 847-838-4398 or Kris Murray at 847-630-4991

Thursday Playgroup is on the 3rd Thurs. of the month at 5:30-7:30pm. Location will be announced when you RSVP.

A light dinner will be served.

Saturday Play group is on the 2nd Sat. of the month from 10:30am - 12:30pm. Location will be announced when you RSVP.



Welcome to our group!!

Ghita Mueller and Keith Johns live in Libertyville with their 2 daughters, Hayden was born on Oct. 5, 2007.

Marisol and Sean Rasmussen live in Mundelein with their 3 children, and their daughter Giada was



March Birthdays

1	Jacob Shimanek	11 yrs old
2	Carl Stahl	8
4	Alex Allwardt	18
11	Elizabeth Foresta	33
11	Carlie Reuter	12
17	Derek Clarke	14
20	Carly Ziesemer	21
22	Douglas Rostron-Jansen	47
24	Grace Uhwat	4
26	Justin Bychowski	12
27	Lance Fry	37
27	Makayla Olson	6
30	Jasmine Carmona	7



We now have a website:

www.TheDDC.org It is a beautifully designed site that will provide current news, upcoming events, listings of books in our library, as well as hyperlinks to other groups and info. Edwin and Mary Lou Paff have worked hard to bring us out of the Stone Age and we can help them by making suggestions on what we would like to see on our new site. Check it out!



LAST MONTH IN THE DDC:

“House Full of Hormones” – Puberty & Down Syndrome

Speaker: Dr. Cathy DiVincenzo

At the February meeting, we were fortunate to have pediatrician Dr. Cathy DiVincenzo speak to our group about how the overwhelming process of puberty can affect our kids with Down syndrome and how we as parents might help our kids to cope with these changes. In general, kids with Down syndrome seem to be right on schedule when it comes to the onset of puberty, with most of the same initial signs (growth spurts, increased penis size, developing breast buds, appearance of additional body hair, etc.) that occur in their typically developing peers. For boys, these changes often appear between ages 12-13, while for girls the signs may appear earlier with no cause for concern (with growth spurts here typically slowing down once menstruation has been regularly established). Around the time that puberty starts to kick in, it’s important to keep an eye on thyroid levels, as changes in both directions (higher or lower), often reflected in changes in weight gain, can be problematic. As with all kids, moodiness goes hand in hand with puberty, and the presence of mood swings, or of unusual depression, can serve as a strong indication that puberty is under way!

Dr. DiVincenzo reminds us that puberty can be very challenging for both the parent and child, and that above all, we should emphasize to our kids that what’s happening to their bodies and to their emotions is completely normal, “just a part of growing up.” One advantage of puberty is its relatively slow pace, giving kids time to adjust to the changes in their bodies (though, of course, parents often see these changes as happening all too abruptly!). A key disadvantage, however, lies in the fact that this is often the time when kids with Down syndrome start to become more keenly aware of the differences between themselves and other typically developing peers. Over the course of the MANY discussions you will have with your kids pertaining to puberty, Dr. DiVincenzo suggests that we provide information on a need-to-know basis, using “official” school discussions as a springboard; it’s important to be attentive to their questions but also to try not to overwhelm them with the details of what’s happening now and what to expect in the future. While modeling appropriate behavior is always a good idea, more blatant conversations may need to occur (regarding boundaries of physical affection, “good” vs. “bad” touching, etc.), in order to make sure our kids understand what’s ok and when and with whom (e.g., hugging doesn’t “work” in all contexts!); kids need to be aware of the possible dangers they face as maturing adolescents and young adults and learn the importance of telling a parent or an adult at school if anything inappropriate should occur. It’s a fine line between being overprotective and being overbearing, but the same “common sense” rules that you establish for your family’s safety apply here as well (e.g., knowing your child’s circle of friends, being watchful of any changes in your child’s behavior, being knowledgeable about the threat of Internet predators).

Although we tend to see our kids as chronically younger than their peers, Dr. DiVincenzo emphasized the fact that they DO grow up, complete with all the desires and emotional depth that accompany adulthood, and that your pediatrician or family doctor can offer assistance in helping your kids come to terms with all of these issues (including decisions about birth control). In addition, Ups for Downs is sponsoring an upcoming workshop on puberty – watch the newsletter for more information! Thanks to Dr. DiVincenzo for answering so many of our questions and thanks to all the parents who participated in the discussion!

- Jennifer Jenkins, Secretary

DDC Board Members 2006-2007

President	Patrick Collins	847-265-8482	rjohncol@comcast.net
Vice Pres	Mary Lou Paff	847-548-4852	mlpaff@aol.com
Secretary	Jennifer Jenkins	847-970-6797	only_connect@msn.com
Treasurer	Janis Kern	847-548-4417	Janiskern@comcast.net
Past Pres	Andrea O'Donnell	847-949-1975	odonnella@sbcglobal.net
Playgroups	Belinda Hildalgo	847-838-4398	Hidalgob@comcast.net
Board	RaeAnn Collins	847-265-8482	rjohncol@comcast.net
Newsletter	Terri Christolini	847-267-1169	christoliniben@comcast.net
Foro (Spanish Issue)	Anna Roeser	847-362-0980	roeser1984@yahoo.com

UPCOMING MEETINGS AND EVENTS:

Special Kids, Special Families is a support group for parents of children with special needs of all ages and from all school districts. For information or to RSVP for either of the following meetings please call Marilyn Green-Rebnord at 847-821-7740 or Chris Eng ant 847-913-1812.

On March 6 there will be a meeting with Pamela Kaplan on “**Parenting a Child with Special Needs: The Parent’s Emotional Journey**” beginning at 7pm at the JCYS in Buffalo Grove.

On Tuesday, March 13, 2007 at 7 – 9pm there will be a informative meeting presented by “Special Kids, Special Families” called “**Strategies for Important Meetings: IEPs, Mediations and Transition**”. The speaker will be Charlie Fox, a special education attorney, who will discuss how parents need to develop an overall plan that will serve as a guide for all advocacy activities. Discussion will focus on transition planning: beginning with the first IEP; setting priorities for goal writing and for advocacy; creative thinking as a part of the process; and time management for the IEP meetings.

The JCYS Northwest Family Center is located at 1700 Weiland Rd. Buffalo Grove.

Wrightslaw From Emotions to Advocacy Training with Pat Howey, Paralegal and Advocate Downers Grove, Illinois, March 17, 2007

From Emotions to Advocacy, a [Wrightslaw training program](#) with [Pat Howey](#), is part of the "All About Your Family Series" being brought to you by [Easter Seals DuPage and The Fox Valley Region](#). This program is being sponsored by Burke, Mahoney & Wise, LLC, in conjunction with the Topfer Family Foundation. The program will be held at: Aramark 2300 Warrenville Road Downers Grove, IL 60515.

Program Description In “From Emotions to Advocacy” training programs (one day, 6 hours), parent advocate Pat Howey teaches you how to take an active role in managing your child's special education, the gentle art of disagreeing, and how to maintain healthy working relationships with the school.

You will learn:

- how to assess your child's strengths and needs
- how to prepare a Parent Report for the IEP team
- how build healthy working relationships with school personnel
- how document information that may prevent or resolve disputes
- how to participate as an equal member of your child's IEP team

[Wrightslaw programs](#) are designed to meet the needs of parents, educators, health care providers, advocates and attorneys who represent children with disabilities regarding special education. The program is not disability specific.

Your registration includes choice of turkey or veggie wrap box lunch, along with [Wrightslaw: From Emotions to Advocacy, 2nd Edition](#) (\$19.95 retail value). No outside food or drink is permitted.

Registration	Fee
Parent/Professional	\$30.00

To Register by Mail: Easter Seals DuPage and The Fox Valley Region
Attn: Sharon Pike
830 South Addison Avenue
Villa Park, IL 60181

Questions? Please contact [Sharon Pike](#) at (630) 282-2036 or [Cara Long](#) at (630) 620-4433.

Downs (Down Syndrome) Development Council, DDC, is a not-for-profit t 501(c) (3)organization and volunteer support group established in 1978 by parents of children with Down Syndrome.

Please note: The Forum newsletter is written on a volunteer, non-professional basis. Information presented should not be construed to be objective or definitive, but represents the opinions and understanding of the editor and it's contributors. Your contributions are welcome. Please contact Terri at christoliniben@comcast.net

For every newsletter we email, the DDC saves money. Please send Terri your email address so she can forward the news to you directly. Thanks for helping.
www.christoliniben@comcast