

# 5P- News

## Resources

Message board: Post a message or respond to another parent's questions at [http://groups.yahoo.com/group/Cri-Du-Chat\\_Syndrome/](http://groups.yahoo.com/group/Cri-Du-Chat_Syndrome/) Need to join group to participate. New members joining this active group daily.

Clothing: <http://www.special-clothes.com/>

Supported Living Services [www.supportedlife.org](http://www.supportedlife.org)

Sign Language Vocabulary <http://commtechlab.msu.edu/sites/aslweb/brower.htm>

Signing Videos and DVDs: <http://twolittlehands.com>; <http://www.signingtime.com>

Speech Therapy ideas: <http://www.speechtx.com/index.htm>

Speech/Language and Feeding tools: <http://talktoolstm.com>

Specialty toys — Abilitations: <http://www.schoolspecialtyonline.net/>

Yellow Pages for Kids with Disabilities— State by State resource for therapists and other services. [www.yellowpagesforkids.com](http://www.yellowpagesforkids.com)

Advocacy — [www.protectedtomorrows.com](http://www.protectedtomorrows.com)

Fundraising for the 5p- Society through: [www.igive.com](http://www.igive.com) — online shopping mall and through [www.goodsearch.com](http://www.goodsearch.com) —search engine that gives .01 per search to the 5p- Society

5p-Society, PO Box 268, Lakewood, CA 90714-0268 (562) 804-4506, toll free (888) 970-0777, fax (562) 920-5240 email: [lc5pminussociety@aol.com](mailto:lc5pminussociety@aol.com)

## "YOU DON'T KNOW WHAT YOU'RE MISSING" by Nick Wallace

The 5p- Society will be hosting its 26th Annual Conference and Get Together in Columbus, Ohio, and Angie and I, as well as the other Ohio Families, are really getting excited for this event. We have a lot of great things planned. So we are writing this article so you will know what you are missing if you don't attend.

The conference will be held at the Columbus Airport Marriott. The room rate per night will be \$99.00. You can make your reservations at the [Columbus Airport Marriott](http://www.marriott.com/hotels/travel/cmham-columbus-airport-marriott/?to-Date=7/31/11&groupCode=F5PF5PA&fromDate=7/28/11&app=resvlink) website: <http://www.marriott.com/hotels/travel/cmham-columbus-airport-marriott/?to-Date=7/31/11&groupCode=F5PF5PA&fromDate=7/28/11&app=resvlink>

You can also call the hotel at 1-800-491-5717 and reference group code F5PF5PA. The room rates will be

good for three days before and three days after the event, so that you can [experience Columbus](#) and the various activities Columbus has to offer. The Marriott has a free shuttle to/from the airport and also to the [Easton Town Center](http://www.eastontowncenter.com/) (<http://www.eastontowncenter.com/>).

cess at our Virginia Beach conference. Also joining us for our Family Fun Event will be the Columbus Zoo. The zoo will be bringing several animals for our kids to learn about. There might be an opportunity to touch one of these animals.

We are also excited to let you know that our Sibling Outing will be held at COSI. COSI is a hands on museum for science and industry that is fun for all ages. You can find out more at: <http://cosi.org/>

More information will be posted on the 5p- Society website regarding the conference, including information about our Slate of Speakers. So you had better check back or you won't know what you're missing, and trust me that could be bad.



The Family Fun Event this year will showcase four things that Ohio is known for. Those four things are music, sports, flight/space, and the Columbus Zoo. We are pleased to announce that Dance Heads will be joining us again this year at our Family Fun Event. They were a huge suc-



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## My Daughter, Briana *by Lori Passerelli*



It's one of the hardest things to deal with, having a child with some sort of disability, facing the reality of lost dreams. Picking up the pieces of a puzzle that has broken to pieces and trying to fit it all together again. The picture that emerges is not the one we imagined it would be but eventually a beautiful mosaic sketch emerges. One that matures as our child does and as we ourselves do. We realize that although we thought our aspirations crumbled, a tower built of strength has emerged, and realized dreams, although altered, have flourished in unimaginable ways.

The birth of my daughter twenty seven years ago was a lesson in reality. I was stunned to learn she may not walk or talk. I refused to believe any of it and forged forward as a soldier preparing for a battle against a tremendous enemy. The internet was a baby then so I marched to the library pulling my oldest daughters wagon behind me and checked out hordes of books. I read anything I could get my hands on about child development, the brain and how it works, nutrition, chromosomes. I immediately enrolled my daughter in speech therapy, infant stimulation, and occupational therapy. She was only ten days old and the battle had begun.

Time is a great healer. Briana is twenty seven years old now and I can honestly say that I appreciate and love her just the way she is. So many things I had hoped for have not been achieved, but I've grown to accept that reading and writing are not that important in the whole scheme of things.

She has so many things going for her in her life that will be useful to her. Her personality and ability to get people to notice her is a gift. She knows how to make people laugh. Cleverness is her middle name.

Recently I asked Vicky, her job coach, to video tape her on an outing with her boyfriend. I was curious to see the interaction between the two of them. What do they talk about? I wondered. My husband and I eagerly anticipated watching the video as if we were at a premier movie. Briana was very excited and decided we should make popcorn for the event. As we crowded around the television her laughing escalated with so much excitement I had to calm her down. Phillip and Briana have been meeting every Friday and both have declared that they are officially boyfriend and girlfriend. One day several months ago I found a letter written in a childish hand, professing love for Briana. The note was signed by Phillip. Imagine the rush I felt! I immediately called Vicky and she told me that this little fling had been going on for a while now.

As the movie played I watched my daughter holding hands and walking with Phillip into the bowling alley. Later a glimpse of adoration was captured and my heart quivered. My sweet Briana has succeeded in finding her own little piece of heaven. And I can confirm that my shattered dreams didn't really break into a million pieces. My dream has been realized through her in a way I never could have conceived. Her happiness is so large and her positive energy so big no one near her can help but to catch it. She has a purpose, there is a reason she is here living amongst us and I for one am so very happy to be a part of it.

## Bella and her iPod and iPad *by Jacqueline Galvagni*

It all started with Bella being obsessed with Justin Bieber.

She wanted his videos on the computer, on the TV and my family and I were tired of listening to only Justin Bieber; not that we're not a fan because we are. On her birthday, last March, we decided to get Bella her own iPod. We started with the Nano. It was great because we had a break from watching him on the TV and computer.

But it wasn't as easy to use, someone always had to help her find what she wanted. And I was afraid to get the iTouch. I thought she would crack the screen or break it because she loves to throw things when she is mad.

After being at the conference this year in Orlando, I decided I wanted an iPad. Of course I convinced my husband David it was really to help Bella; even though, in reality, I desperately wanted one. The plan was: if I was to get the iPad, then Bella would get my iTouch.

Well needless to say, I did get the iPad for my birthday. It's mainly used for Bella in helping with her speech and learning.

She is doing great on both her iTouch and the iPad.

I put Justin Bieber apps on both of them for her entertainment and many other apps for her learning.

Her speech therapist, Lisa Pugliese, who spoke at the Orlando conference, uses the iPad for her speech and language therapy.

When using the iPad we make Bella a deal: after she works with Lisa on her speech and language, her reward is to watch Justin Bieber videos.

The iTouch is so much easier for her to use, that when she bothers me for the computer or the tv, I just tell her you have your iTouch go ahead and watch it on there; she does and she knows how to work it. Much Better than the Nano. But I am glad I started with the Nano to get her started on learning how the iPods work. The abuse the iTouch gets is beyond what you would think, it has no cover because she will not keep it on, and it is still working. But Bella and all of us are so HAPPY there is such a thing as an iTouch.

I put the same apps on her iTouch that are on the iPad because when we are out there is no Internet and it keeps her busy and content. We also have music, music videos and her favorite tv shows on it.

All I have to say is how amazing her language is now since she started using both the iTouch and iPad. All the things they tell me at school she doesn't do like counting to 20, saying her ABC's, or trace her letters with a pencil; She knows it. She knows all her letters and numbers. She recognizes words. She traces letters with her fingers; I could go on and on.

I thank God everyday that we invested in the iTouch and iPad.

I believe that there are no boundaries for our children and with this new technology my daughter will soar!!!!!!!



## Bella's iPad and iTouch Apps

Here is a list of apps received from Bella's speech therapist that she received from Bella's ESE contact from her middle school. She is now a freshman in high school.

- iLearn ABC lite
- iLearn ABC
- Sight Words
- Toddler Counting
- ABC Trace
- iPaint lite
- Picture Pusher
- ABA Flashcards – Actions
  - Alphabet
  - Emotions
  - Sports
  - Science
  - Musical Instruments
  - Receptive Identification by Class
  - Vegetables

Picture pusher is great because it makes Bella take her time when tapping and bringing the picture into the box. It helps with using the iTouch/ iPad.

### Restricting access to deleting apps

1. Open the Settings app on the home screen
2. Tap General, then Restrictions
3. Enable Restrictions by entering a passcode
4. Turn Deleting Apps Off
5. Click the home button, then tap and hold on a 3rd party app (e.g. Brain Pop) until your apps pulse. You can now move the apps but not delete them

To update iOS, sync your device to iTunes and check for update on the summary screen. Click to download and install 4.2.1 update.

More iPad/iTouch Apps . . .

At July's conference, Dr. Campbell talked about the Proloquo2go app for the iPod touch. Many families have emailed the Society who attended the conference to tell about the success of the iPod touch and iPad use and the Proloquo2go app.

Share your success stories and pictures with the many apps available!!!

The 5p- Society flower site has been temporarily disabled. Unfortunately the grower that produces the flower arrangements has gone out of business. The coordinator of the program is looking for a new grower and will advise us when the program is up and running again.

## QUICK GLANCE AT GOVERNMENT BENEFITS *by Mary Anne Elhert*

If you're the relative of an individual with special needs, that person may be eligible for government benefits. However, many of these options are often confusing. Some families believe their relative or child is not eligible for benefits, or that everyone is turned down the first time they apply. While the process of applying for these benefits can be arduous, they are worth looking into. Here is a brief explanation of government benefits that your loved one may or may not become eligible for, but you may want to investigate:

- **SSI** - Supplemental Security Income. A Federal income supplement program funded by general tax revenues (not Social Security taxes). Its purpose is to help the aged, blind and disabled who have little or no income. It currently provides a maximum of \$603 per month to be used for basic needs such as food, clothing and shelter. Not everyone receives the same amount. The assets an individual or family can own are limited, in order to qualify for this benefit. Basically, the allowable assets for a person applying are a home, one car, a pre-paid funeral, and \$2,000. Of course, understanding what is an asset is important, as well as which is the appropriate asset for your own family member to own.
- **SSDI** - Social Security Disability Insurance. Social Security Disability Insurance is a federal cash benefit that may be available if a person is disabled. It pays benefits to the individual and certain members of the individual's family if you are "insured," meaning that you worked long enough and paid Social Security taxes. Every year, each insured individual should receive a statement from Social Security, explaining their status of eligibility.
- **Medicare** - A federal health insurance program. Medicare is for people 65 years of age or older, certain younger people with disabilities, and people with End-Stage Renal Disease (permanent kidney failure with dialysis or a transplant). Medicare does not cover everything, and it does not pay the total cost for most services or supplies that are covered.
- **Medicaid** - This program provides medical assistance for certain individuals and families with low incomes and resources. Medicaid eligibility is limited to individuals who fall into specific categories. Although the Federal government establishes general guidelines for the program, the Medicaid program requirements are actually established by each state. In addition to paying for some medical services and prescriptions, Medicaid may also pay for residential facilities, workshops and other programs. This program has asset limitations similar to the SSI limitations. When exploring government benefit options, it's important to evaluate your family member's entire picture and take a few more things into consideration:
  - If you are dealing with a child at this time, what do you see for him/her in the future? Supported employment? Workshop employment? Residential living?
  - Does your existing health insurance remain in effect when your child turns 21 and is no longer a full time student?
  - What assets are presently in your relative's name? Example: savings bonds, life insurance, stocks, mutual funds, homes, etc.
  - Is there a possibility of inheriting any money or assets? Once you've answered these questions, you can then look at what benefits he/she may be eligible to receive and how to best position his/her assets and income.

*Mary Anne Elhert is the founder and president of Protected Tomorrows, Inc., the leader in enhancing the lives of families with members who have special needs. By guiding families through its comprehensive, proprietary planning process, Protected Tomorrows helps ensure the well-being of a loved one by creating a Future Care Plan™. Through their work with clients and the family's advisors, and alongside of other advocates and legislators, Protected Tomorrows addresses many concerns of families with special needs such as: future care funding, government benefits, legal considerations, residential options, employment opportunities, recreational choices, education options and family communication. For questions, contact [info@protectedtomorrows.com](mailto:info@protectedtomorrows.com) or visit [www.protectedtomorrows.com](http://www.protectedtomorrows.com).*



PO Box 268  
Lakewood, CA 90714-0268

Return Service Requested

### UPDATE YOUR INFORMATION

It is very important to keep your information with us current. The Post office will provide us with updated addresses as long as you've put in a change of address, but we don't always get your telephone number or email change. Please take the time to update your information.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City, State, Zip: \_\_\_\_\_

Telephone: \_\_\_\_\_

Email: \_\_\_\_\_

Name of Child/Adult member with Cri du Chat Syndrome: \_\_\_\_\_

Birthdate of Child/Adult member with Cri du Chat Syndrome: \_\_\_\_\_

If you haven't already done so, this would be a great opportunity to update your membership dues of \$25.00.

Check or Credit Card (Visa or MasterCard)

Credit Card # \_\_\_\_\_ Expiration \_\_\_\_\_ Amount \_\_\_\_\_