

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/ 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
- 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/>
- Living Spaces — Architectural www.lifecaredesignstudio.com
- Advocacy — www.protectedtomorrows.com
- Fundraising for the 5p- Society through: www.igive.com — online shopping mall and through 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 director@fivepminus.org

President's Message *by Jolene Towers*

I love summer. I enjoy that I no longer have to nag my children about doing their homework, and I love sleeping in! Taylor still has her weekly therapy, and we still have her "homework" assignments from therapy, but most of these are fun. I thought I would share our latest assignment with all of you.

A few months ago, we heard about an application for the I-pod touch (and the I-pad) called proloquo2go. It is an assistive communication application, one like the programs on people's talkers. It has categories and pictures and you scroll through the pictures, press the buttons and it talks for you. We had the regional center here come do an assessment and they brought an i-pod touch out for Taylor to try. She did great with it and so, we spent the money and invested in it. We have been working with her at home and at therapy for the last

few weeks on this program. Her homework this week is to use the I-pod to ask for a snack. Easy, fun homework!

Taylor talks and we understand her, as do her teachers at school. The problem is, when she is around other people, they have a hard time understanding her. This is where the I-pod will come in handy, since she can use the I-pod to help her communicate. We have used it out in public when Taylor is ordering food, when she is with her friends, and places like that. It is great because it is so small and portable, and it even has an available case with a speaker. If anyone is interested in researching this to see if it would be useful for you, here are some websites: www.proloquo2go.com <<http://www.proloquo2go.com/>>; and www.imaingo.com <<http://www.imaingo.com/>>; (the imaingo2 fits the i-pod touch)

In other news, our 25th Annual Conference is only a few weeks away! Those of you coming to the conference can see Taylor's I-pod touch with the application in person and see how it works. We have a fantastic conference planned for this summer with great speakers and wonderful activities, and of course we are excited to see as many of you as possible. Come join us and experience the Magic of Orlando!

As usual, we are looking for parents or grandparents who are willing to serve on the board of directors. If you are interested please let us know. We announce the Board of Directors at the conference the end of July.

Have a wonderful summer and enjoy a few months of Little to No Homework!

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Discount DisneyWorld Tickets

DisneyWorld has set us up with discounted tickets for the 5p- Society Conference. You can visit the following link to get more information: <http://www.disneyconventionear.com/FPS>

What's so Special About Special Needs Planning? *By Mary Anne Elhert*

When you first learned that your child had special needs, you probably began analyzing your home life, your child's education and other immediate concerns. In time, you realized that your child's needs would continue to evolve. How would you pay for medical expenses that insurance didn't cover? What types of programs would your child qualify for as an adult? Where would your child live if something happened to you?

There are so many things to take into consideration that you may feel overwhelmed. You need a solid financial plan to help you make sense of a complex situation. Here are some reasons why working with a financial planner trained in special needs situations is not only a good idea but is also necessary.

Brings objectivity to a very emotional topic: A financial planner can look at a situation from a "big picture" standpoint. Traditional planners will look at the hard data, but a special needs planner will, more importantly, understand the story beyond the numbers and how all those pieces fit together to make a whole. The first step of every plan is to create a vision of what you want for your child and talk about what keeps you awake at night. Knowing those two things can make the difference between a plan consisting of only numbers and graphs and a plan that creates a map to your child's future.

Identifies options and provides guidance: A great planner will present you with more than one option and provide sound direction. She breaks down the pieces and explains them in easy-to-understand terms. She has a knowledgeable staff to help with special needs situations and an efficient system already in place. When you walk into her office, she knows both your time and your money are precious and always remembers the sensitivity of the topics at hand.

Focuses on legal options: It is essential to have the appropriate legal documents written by a legal source. You may need a special needs trust or even a payback trust. As a parent of a child with disabilities, you also need to make sure your estate plan is solid. If you aren't prepared, then your child's care may suffer as a consequence. Special needs planners do not give legal advice, but they excel at providing a practical view of how an appropriately written trust will factor into your plan. A poorly written trust can jeopardize your child's eligibility for benefits.

Maximizes benefits and programs: A special needs planner has a benefits department, which specializes in the myriad government and local benefits programs your child may be qualified to receive. This specialized area plays an essential role in your planning. Your planner can appoint a specialist to your family to work with you through the application process, which allows you to focus your attention and time on other things.

Understands that transition is the key: Once your child reaches adulthood, benefits can, and will, change. A planner will be able to guide you through this process utilizing not only financial options, but program options to make the transition as easy as possible for both you and your child.

Remains accessible: Unlike traditional financial planning, where graphs and numbers are followed, a special needs planner is accessible for the many developmental and situational changes your child will go through. Some planners work on an hourly basis, while others require a yearly retainer. Each option has its place depending on the complexity and nature of the situation as well as your preferences. A planner should be available to answer questions throughout the duration of your engagement.

Gets involved with the community: A planner who is involved with special needs organizations is informed about the issues that his clients face. Another benefit of being an advocate or activist in the special needs community is her knowledge of non-financial programs, support groups, recreational opportunities and many other resources your family might be interested in.

Financial planning is an essential part of providing the future care of your child. Every parent wants to know that their children will be safe and happy when they are not able to be there, lead a life as independently as they are able to and to have lives of their own. A financial planner who focuses on special needs can provide objectivity, guidance, knowledge and, most importantly, empathy to your family. Working together to create a solid financial plan, you and your planner can make your dreams for your child a reality.

Mary Anne Elhert is the founder and President of Protected Tomorrows®, an advocacy company that provides comprehensive life planning that addresses the educational, residential, financial, legal, health care, government benefits, employment and recreational needs of the individual with special needs. For more information on becoming a Protected Tomorrows® Advocate, or working with an Advocate near you to help out with life planning, contact info@protectedtomorrows.com or visit www.protectedtomorrows.com. If you have specific questions, please feel free to e-mail Mary Anne at mehkert@protectedtomorrows.com, or call Protected Tomorrows at 847-522-8086 and the receptionist will direct your call to the appropriate individual.

Meet Deborah Jan Demone *by Harold W Demone, PhD, Father & Legal Guardian*

Who is Deborah Jan Demone? Debbie was born on June 22, 1950 in Boston, Massachusetts. Deborah's (Debbie) physical health is good, overall. She has no speech or language skills, she is deaf in one ear and is hard of hearing in the other. Her IQ has been tested at 50; she has zero depth vision, a dental overbite, severe gum problems. She is obese (post menopause) with high blood pressure, cholesterol problems and constipation issues.

When she was young she was moderately hyperactive and to this day she still bites her nails. Debbie is now an outgoing, warm, friendly, caring, unselfish individual with a keen sense of humor. She is curious, adventuresome, finds pleasure in small things; always wants to help and can defend herself.

Debbie was diagnosed as MR at 3 ½ months old. Her pediatrician referred her to the chairman of Pediatric Neurology at Harvard and Boston's Children's Hospital because of the circumference of her head and cry. Conclusion: she had "a pea head," commit her to state school, likely a genetic problem. In the next five years she twice went through a State specialized diagnostic procedure. Conclusion: genetic, hyperactive, commit to a state school. (We disagreed with both her hyperactive diagnosis and her prognosis.)

Social care and quality of life: For the first 50 years she lived with her parents until we decided to phase Debbie into her next adventure, "shared living," rare then, common now. After 3 years we designed and built a three bedroom/bath home, for two MR clients and house mother. Debbie spends weekends and holidays with us. A non-profit agency manages the 7/24 home and staff under contract with the State. Both function very well.

The Survivor: according to the Five P Minus Society Debbie is the oldest **known** adult with Cri du Chat Syndrome in the U.S. and Canada. She has great genes (well except for that 5th one), an extraordinary mother, a supportive family, outstanding health, social service support, she's our 1st born, only child and we've had lots of luck.



Debbie Demone *photo by Kathy Fedus*

Highs & Lows: The major low was at 3 ½ months. Debbie's first organized activity was at age 8; long wait for mother and daughter. Two wonderful highs were a front page story in 1993 and ten years later was Debbie's painting exhibit at Cotuit Center for Arts including newspaper stories and photos of both Debbie and her work. (Strangers introduced themselves to meet the artist.) Debbie loved it.

Genetics: When the cream of Boston's MR diagnostician's suggested we were carriers, we searched eleven genealogies without finding any clue of another Debbie. Yes, there were loyalists, scoundrels, wheat farmers, fishermen, businessmen and MR, we also found leaders in our families – on my wife's side was the great Irish leader Daniel O'Connell; on my side – President Eisenhower.

Both of Debbie's grandmothers lived to their mid 90's and her grandfathers to their mid 70's.

In 1986 we discovered that Debbie had Cri du Chat Syndrome and that we were NOT carriers.

Debbie Demone continued from page 3

*And then there is Debbie's mother, Marguerite Frances (Peg) Demone. Family and friends credit MOM for all of Debbie's success and the case is very strong. She went her own way. She was our leader. She never gave up. She never will. I doubt that a day passes when Debbie's well being is not considered. She is still our tiger. In late 1950's she and allies began a local MR Assn., pre-school program, first local public school program, summer activities and other. Peg was and still is *relentless & tenacious*. Debbie's grandparents were always supportive, as were her aunts and uncles, and several of her cousins.*

The professional care giving system was exceptional from mentors to friends, in medicine, the law, social services and accounting, we had access and support for 50-60 years. One example, our obstetrician was the Kennedy family obstetrician. Now retired to Cape Cod, in succession, we found two fine young internists.

Our unique experience was a decade of work when Debbie was in her 20's using cognitive development procedures, pairing signs with spoken language by the Millers, one a clinical psychologist, and the other a speech and language pathologist.

One system failure was the hearing test. The Boston group specializing in rehab work found normal hearing at age 9. We were sure results were wrong but not until age 34 did we discover the Auditory Evoked Response Lab at Mass. Eye and Ear.

For Debbie's first 14 years Peg was our leader (and still is). In 1962 I became the Director of both the Massachusetts Mental Retardation Planning Project and the Mental Health Planning Project. Thus, in 1966, the Governor asked our Legal Council and me to draft enabling legislation for both conditions. Following 8-9 months of political battles (both political parties wanted the credit) the bill was signed on 12/30/1966. Now in 2010, there are two departments with our 1966 Legislation and regulations largely intact. For MR, Massachusetts has a well established and managed community based program.



Peg and I are now "Leaders and Followers" of Mass. ARC. At the policy/appropriations, Federal and State levels, we continue to send e-mails, make phone calls and meet directly with state legislators.

That Debbie was our first born, we believed that we were carriers and the decision was to take care of Debbie at home is what led us to a one child family. Since it has been a lifetime experience it was a wise decision for all of us.

In conclusion, we believe that we are better people because of Debbie, specifically in empathy. We also feel we have learned more from Debbie than anyone else

Peg, Debbie & Harold 2010 Photo by Kathy Fedus

2010 Ohio Family Gathering

Dan and Jessica Hoover are hosting the 2010 5p- Ohio Gathering in Newark, Ohio, September 24-26. We are planning a weekend of fun at Cherry Valley Lodge and Coco Key Indoor Water Resort. We are able to offer families a nightly rate of \$119, which includes 4 passes to the water park. Check out the facilities and reserve your room at the special rate at the following link: https://reservations.ihotelier.com/crs/g_reservation.cfm?groupID=470905&hotelID=10327. We have also reserved the shelter house at our local handicapped-accessible playground for Saturday, so the kids can play and we can have a picnic. We still have some planning to complete, but hope to have a great weekend to plan and organize for the 2011 Ohio 5p-Conference. If anyone would like additional info, contact Jessica at jhoover@forkliffttrainingsystem.com or 740-507-7061.

Conference Donations

Thank you to the following for donating items for our raffle and for your financial support:

Dade Community Foundation, Oliver's Fund—General Conference
 Terry & Pat Offerle—Scholarship Donation
 Donald Vey—Volunteer Lunch
 Geoff & Jolene Towers (Family & Friends) - General Conference
 Bagety Elien—Sibling Outing and Family Fun Event
 Bill & Janet Weber— General Conference
 Stanford & Ratliff Family and Friends—General Conference
 The Family of Sophie DeLeon— Sibling outing
 Larry & Lisa Asman—General Conference
 The Sleith Family—General Conference

Jerry & Carolina Kretschmar—Annual Children's Quilt
 Frances Bodle—Annual Themed Quilt
 Frances Bodle—Commemorative T-Shirt Quilt (see photo at right)
 Gloria Griffin—Jewelry
 Nancy Greenberg— Artwork
 Kent Nicholls—Microsoft Items
 Signing Time Items
 Miranda Elien—Painting



Fundraising for the 5p- Society

80/20 Raffle Update: We need everyone's assistance to make this a successful fundraising campaign. We are really short of our goal of 500 raffle ticket sales. As of June 15 only 150 tickets have been sold. The winning ticket will receive 20% of the resulting funds raised from the sales of the tickets. This is our first major full membership fundraising campaign, its success depends on YOU. The monies raised will help fund the 2010 annual conference in Orlando.

We would be grateful to you and your family if you could send in your tax-deductible \$100 donation and one (1) ticket stub no later than July 15th. We are very grateful to those members who have sold more than five (5) tickets, awesome job and thank you. We understand and realize that times are tough right now and you may not be able to participate, but even if you could try to get four family members to kick in \$25 each for one ticket, then the winning ticket could be split four ways. If you did not receive a ticket and would like to participate, please contact the 5p- Society office at (888)970-0777 or director@fivepminus.org.

Yard Sale- President Jolene Towers, family and friends had a very successful three day yard sale. They raised over \$2300 to help with the 2010 conference.

Sounds of WWII—Thanks to the Wallace family and all those who attended this successful event. They were able to raise over \$3400 for the 2011 conference.

Wine, Beer & Cheese Event and Raffle—Thanks to the Brewer & Hutchinson family for their very successful event. They were able to raise over \$7000 for the 2012 conference.

Wine & Cheese Event—Stanford and Ratliff families from Houston, Texas are in the final planning stages for their 2nd annual event to be held June 27th. For more info go to www.fivepminus.org and click on the Widget on the home page.

Golf Tournament—3rd Annual Hailey's Haggin Oaks Golf Tournament—August 8, Sacramento, California. For more info go to www.haileyshagginoaksclassic.org.

Golf Tournament — 2nd Annual Olivia's Open — August 15, Bedford Hills Golf Club, Temperance, Michigan. For more info contact Tiffany Townsend at ttownsend@buckeye-express.com.

The Magic of Orlando

Location: The 25th Annual conference of the 5p- Society will be located at the Orlando Airport Marriott, 7499 Augusta National Drive, Orlando, Florida 32822. Hotel phone number (407) 851-9000. The 5p- Society's group rate is \$109.00 per night. You can make your reservations by calling the hotel's toll free reservation line at (800)380-6751 or online at <http://www.marriott.com/hotels/travel/mcoap?groupCode=pmspmsa&app=resvlink&fromDate=&toDate=> (you can also access this reservation link on our conference page on our website at www.fivepminus.org/annconfX.htm) Make sure you indicate that you are with the 5p- Society. **IF YOU RUN INTO ANY PROBLEMS MAKING YOUR RESERVATIONS, PLEASE CONTACT LAURA AT THE 5P- SOCIETY OR ON HER CELL PHONE AT (562)756-4123.**

Please Note: The 5p- Society has guaranteed to the hotel 80 rooms per night on the peak nights of Thursday, Friday and Saturday. **WE HAVE NOT MET THIS GUARANTEE.** Therefore, if you plan on coming to the conference BUT not staying at the Marriott, you will need to pay an additional \$100 with your registration. The complimentary meeting room space is given to us based on the number of sleeping rooms that we fill. Local Florida families that plan to drive each day to and from conference are exempt.

Transportation: The Orlando Airport Marriott offers a complimentary shuttle from the airport to the hotel. There is also a Hertz car rental onsite at the Marriott.

Conference Registration: Registration is now open. Please fill out the form on pages 6 and 7 of this newsletter, or you can download a copy of the Registration form at the 5p- Society website at www.fivepminus.org/annconfX.htm. The Members Registration fee is \$150.00 for up to two adults and two children; each additional adult is \$50 and each additional child is \$25 (non-member fee is \$200.00). Please note that these costs only include the dinner banquet on Saturday night. We are looking for sponsors to help offset the cost of the other events, including, Friday's Family Fun Event, Hospitality Suite, Sibling Event, and possibly continental breakfast and/or welcome reception.

Volunteers Needed: Volunteers are needed for our complimentary child care that is offered during the Friday and Saturday break out and panel sessions. If you have an extra adult that will be accompanying you or teenager that loves to baby sit, then please contact Cathy Vaden at (850)215-3364 or redtwin@knology.net. Volunteers will be given a complimentary lunch on Saturday afternoon.

Speakers: The following speakers and topics have been confirmed:

Dr. Dennis Campbell—(1) Cri du chat 101 (2) Transition
 Dr. AmySue Reilly—Behavior Applications
 Sandy Cooley (OT) and Brenda Martin (OT)—(1) Sensory Integration Therapy; (2) Coping Skills
 Janet Weber (PT) — Developing Fine & Gross Motor Skills (hands-on)
 Mary Anne Elhert, Protected Tomorrows—Planning for the Future
 Mike Brewer/Gloria Griffin—Fundraising 101
 Lisa Pugliese—Speech Therapy
 Shanida Mathieu—The IEP Process
 Kelly Galvagni—Dental Hygiene
 Kevin McCormick— Behavior in the School System



2010 Annual Conference and Get Together
 Orlando, Florida
 July 29 – August 1, 2010
"The Magic of Orlando"

CONFERENCE REGISTRATION FORM

Yes, I plan to attend the 2010 Annual Conference and Get Together

Members — registration fee \$150.00 USD (two adults and two children) _____

Non-members — registration fee \$200 USD (two adults and two children) _____

Each Additional Adult — \$50.00 USD each _____

Each Additional Child — \$25.00 USD each _____

***** If you are not staying at the Orlando Airport Marriott please add \$100.00 to your registration fee (local families exempt)**

(Room Guarantee must be met for this to be waived)

No, I am unable to attend, please accept my donation in lieu of attendance _____

Please renew my annual membership at this time \$25.00 _____

Total Enclosed _____

Name _____ Phone No. _____

Address _____ Email Address _____

City _____ State/Province _____ Zip _____

Country _____

Names of All Adults who will be attending the conference Relationship to 5p– Syndrome Child/Adult

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Names of All Children attending conference Relationship to 5p– Syndrome Child/Adult Age Childcare Sibling Event
 (even your child with CDCS)

_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

Please let the **hotel** know if you need specific items such as cribs, roll-a-ways or refrigerators. There will be an additional cost for the roll-a-ways and refrigerators.

Items requested directly from hotel: Refrigerators ____ Cribs ____ Roll-a-way _____

Will you be needing a high chair for the banquet? Y N

(providing us with the above information will not guarantee you the item, however for planning purposes we will alert the hotel of the amount of highchairs, cribs, roll-a-ways and refrigerators needed for the event.)

Sibling Event:

The Siblings are planning a trip on Saturday, July 31 to the Fun Spot Action Park in Orlando (<http://www.funspot.tutengraphics.com/index.php?mypage=Groups>). The cost to attend will be \$25.00 per child (in addition to the registration fee). We are looking for sponsors to help cover the cost of the bus (\$399) and lunch (\$7.00 pp). Please indicate on the registration form if you are planning on having your child attend the event. If you would like to supervise a group of siblings, please list your name and number where we can reach you: _____

Photo Release:

I/We give the 5p- Society authorization and/or permission to use any photograph and/or video tape of our immediate family who attends the 2010 5p- Society Annual Conference and Get-Together in Orlando, Florida for the purpose of promoting the 5p- Society or explaining Cri du Chat Syndrome. The 5p- Society will have ownership of the photographs and/or video tape and will not be used for any other purpose other than to promote the Society and its educational goals.

Signature date

Signature date

Two ways to pay:

Check: USD funds made payable to 5p- Society

Credit Card: Type Mastercard or Visa

Card No. _____ Exp. Date _____

Name on Card _____

I agree to charge my credit card, number listed above, in the amount of \$ _____ USD for registration fees for the 2010 5p- Society Annual Conference and Get-Together (T-shirt fee can be added here too).

Signature date

Please fill out and return both pages of this form to:

5p- Society
PO Box 268
Lakewood, CA 90714

Any questions? Please contact the 5p- Society office (888) 970-0777 or director@fivepminus.org.

If paying by credit card you can fax the form to (562) 920-5240.

Member-to-Member News and Information

IRS Changes and Social Security Benefits

Lucy Brady writes — I recently received an email which stated that there were more diagnoses added to the approve list to receive Social Security Benefits. I thought this may be useful information for families. The Cri du Chat diagnosis is #7. Here is the link for more information. <http://www.socialsecurity.gov/pressoffice/pr/cal021110-pr.html>

Nancy Hyde sent us this info — I wanted to share this info with other CDC families. After reading the article below, I asked my CPA if we could write off Stephen’s tuition to Stewart Home School and he said yes because it is considered a medical expense! He also printed off the pages 72-76 “Checklist for Medical Expenses” out of the U.S. Master Tax Guide which shows all medical expense deductions allowed. I’m sure there are many families who don’t have this information. And, do they know that they can write off the CDC conference and hotel expenses!

For more information visit: <http://www.greatschools.org/special-education/support/2009-tax-benefits.gs?content=646>

Thank you for sharing your information, keep it coming.

Amusement Park for the Disabled Opens

Jessica Gomez and Maribel Rowe, both of Texas wanted to share this news: Morgan’s Wonderland is located in San Antonio, Texas. It is the World’s First Ultra Accessible Family Fun Park designed specifically for children and adults with special needs, their family members, caregivers, friends and the entire community. This 25-acre park is a unique oasis, that through the spirit of inclusion, allows people of all abilities to play, learn and share life changing experiences together, in a fun and safe environment. Individuals with Special Needs—*free*; Person’s accompanying Special Needs individual-\$5.00; General Admission-\$15.00. Let us know how you liked it when you go!!

Visit: www.morganswonderland.com for more information.

Commemorative Conference T-Shirt

Celebrate the 25th Annual Conference with a Commemorative T-Shirt. The T-shirt will be Black with Silver writing and will list all the years and sites of the past twenty-five conferences on the back. The front will have the “Magic in Orlando” Sorcerers’ Hat and Wand. T-shirts will be \$10 each. To guarantee your size please pre-order your t-shirts no later than June 25th. Payment does not have to accompany your pre-order but is appreciated. Payment can be made at the time of pick up. The Society will have a limited number of shirts to sell at the conference. If you are not attending the conference and would like to purchase a shirt please make sure you add in the shipping cost to your order (shipped T-shirts will have to be paid upon order). All other shirts will be available for pick up at registration. Volunteer T-shirts will be Gray with Black writing. Please indicate if you need a volunteer or attendee shirt. If you have any questions, please send an email to director@fivepminus.org.

SIZES	QUANTITY		Name: _____
	Attendee	Volunteer	
YS	_____	_____	Address: _____
YM	_____	_____	
YL	_____	_____	Phone No. _____ Email _____
YXL	_____	_____	Total # of Shirts _____ x \$10.00 each = _____
AS	_____	_____	Shipping fee (add \$5.00 for each 3 shirts) = _____
AM	_____	_____	Total Amount Enclosed: _____
AL	_____	_____	Paid by ___ check ___ credit card ___ pay at conference
AXL	_____	_____	
AXXL	_____	_____	Credit Card Information: _____
Total:	_____	_____	
			Expiration Date: _____ Total Amt Charged: _____



PO Box 268
Lakewood, CA 90713

Return Service Requested