



# NEWS

## The Family Support Group for Children with Cri du Chat Syndrome

June 2005

### President's Message *by Greg Abbruzzese*

I hope everyone is enjoying the summer! We are all anxious to head to St. Louis as the Eickmeier family is scurrying around to make this year's conference the best ever. With added speakers and a multitude of activities planned, we are all excited to experience St. Louis' hospitality at its finest!

As some of you may know, if you haven't already booked hotel accommodations at the St. Louis Hyatt Union Station, we are encountering some rooming issues. What we learned from the Philadelphia conference is that the membership is growing significantly. Keeping that in mind, prior to securing this location, we blocked off a significant amount of rooms above our normal projections based on 2004's conference attendance. As it turns out, it appears that we may even exceed these projections based on the amount of reservations that have confirmed at this time. Laura Castillo and Renee Eickmeier are working diligently with the hotel to secure additional rooms or local alternative accommodations.

Regarding the conference, we are still taking on volunteers to help with day care, room/event sponsorship, and donations (toys, welcoming room, etc.). If you are interested in helping out, please contact Renee directly at: reickmeier@sbcglobal.net, or one of the other Board members (e-mail addresses available online at [www.fivepminus.org](http://www.fivepminus.org)). Even helping out for just one session helps tremendously!!! In addition, we have received confirmation from several key speakers from previous conferences and the plan is to make them available for *multiple* sessions.

I have received several communications from parents throughout the country that are very excited about the new speakers as well that will all help broaden the scope of addressing the needs of our children, as well as ourselves.

Another component of this conference is the fact that we will have some outside vendors presenting augmentative communication devices, a sensory lounge, etc. It is imperative that we visit each of these vendors so that we make it worthwhile for them to attend these conferences from a grassroots level. It is our hope that more vendors will participate in future conferences and pay a sponsorship fee to show their wares.

As for the children, there are a plethora of activities planned for the conference. We are fine-tuning the "A Day at the Fair" inning with hot dogs, hamburgers, potato salad, chips, popcorn, cotton candy, ice cream with waffle cones and cups. There will also be ball pools, a bounce dome, an inflatable slide, and an obstacle course that will hopefully tire everyone out! In addition, there are several local historical and entertainment locations directly in and around the immediate hotel area.

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5P- NEWS, published four times a year, is a publication of the 5P- Society, the national support group for families who have children with Cri du Chat Syndrome also known as Cat's Cry Syndrome or 5P- Syndrome.

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Mission Statement: To encourage and facilitate communication among families with a member who has 5P- Syndrome and to spread awareness and education about the syndrome to these families and their service providers.



## **COMING SOON!**

**By Renee Eickmeier**

The 2005 Annual Conference and Get-Together is just around the corner! We have a lot in store for you, including excellent speakers, fun events, and the return of the Parent Panels. We have been very fortunate to have received donations from The Sanger Family, The Maurer Family, Manhard Consulting Company, Millie Wiegand and the Burlington Presbyterian Church, Eileen Abbruzzese, Bob and Valeria Eickmeier, the Gannett Foundation, Maritz Inc., Kohler Printing, and the Erin Eickmeier Foundation. The kindness and generosity of these families and groups have enabled us to provide a welcome reception, two continental breakfasts, the Friday Day at the Fair Event, the Event Program, five Conference Scholarships, Friday's Sibling Outing to the Arch, and a Volunteer Luncheon. We thank these families and groups from the bottom of our hearts, for providing our conference attendees with a fabulous weekend experience!

As you can imagine, planning this conference is a lot of work. Joe and I would not be able to do this without the help of Jen Wong of Folsom, CA and her family in St. Louis, Claudia Sanger of Penfield, NY, Eileen Sherman of Skokie, IL, and all of you who have volunteered to help in childcare while you are at the conference. This conference gets bigger each year, and it would be near impossible to plan it without the help of our membership.

The Hyatt Hotel is situated in St. Louis' Historic Union Station. Union Station offers many shops, restaurants, and a food court. There is also Glow in the Dark Miniature Golf, paddle boats, and indoor trampolines for fun. There are many fun family attractions in the St. Louis area as well, many of which are FREE! Take a minute and Google the St. Louis Zoo, St. Louis Science Center, The City Museum, Grant's Farm, The Magic House, and the Anheuser Busch Brewery. There's also Six Flags nearby, complete with a water park.

We are really looking forward to "Meeting You All in St. Louis"! We have already unexpectedly exceeded our room block at the hotel, so this may be the biggest conference yet! Please contact me at [Reickmeier@sbcglobal.net](mailto:Reickmeier@sbcglobal.net) if you are interested in helping with childcare. Shifts are still available! Remember, if you are traveling by air, the Metrolink goes directly from the Airport to Union Station. Directions and tips for the Metrolink are available from Laura at the 5p- office.

See you in July!

## **New Membership Fee**

Effective August 1, 2005 and continuing each August we will now have an annual membership fee drive. To be a member of the 5p- Society and get its newsletter, research information, conference attendance, membership listing and other important information you will need to pay the annual fee of \$25.00. This membership fee is for families of children who have Cri du Chat or Cat's Cry Syndrome. If you are a family friend/relative and/or a professional your annual fee dues will also be \$25.00. This fee will keep you on our mailing list. These fees are being instituted to help offset administrative costs and costs of mailing. If you receive your newsletter via internet you will need to pay your Membership fee before the next newsletter to have access to it. Please detach form and return enclosed membership form. Any questions please contact the 5p- Society. If you do not get your September newsletter it's because you didn't pay your membership fee!!! **See form on page 6.**

## Help is Needed in Michigan for our 5P- adult/children

Michigan has been very fortunate to be the last state to education our children through public school for the handicap until their 26<sup>th</sup> birthday. But now, Michigan, Oakland County in particular, has decided to read the Medicaid/Medicare laws as stating that the State and Federal government will only pay for handicap people who can "work" and attend a job site. They want to get rid of "Day Programs" for our S.M.I. adults. Since many of our adult/children are classified Severely Mentally Impaired and cannot "work" in a normal environment, our State county, Oakland County, is saying that there is no funding money for our adult/children when they turn 26. Oakland County is saying that there is no longer Day Programs. They may give 24 hours a week of in-home hours to a paid care-giver but will not fund any program for 5 days a week.

I am asking for your help. I would like to chart what every State/County does for our "kids" after public school ends. Along with the other parents at my son's school, I will be using this information to get our State/County to rethink the Day Program issue. After I collect all the data, this information will be sent to our 5P- Director, Laura Castillo, who will distribute it to other interested parents in the future. I hope you will help our kids in Michigan who may be sitting home day after day with no Day Program in place to stimulate them after the age of 26.

Please email me any information you have on what your child does daily after public school ended. Please fill in the information you would like to share with others and email me at [lmischley1980@wowway.com](mailto:lmischley1980@wowway.com). Thank you for your anticipated help in Michigan. Linda Mischley

1. Person responding: \_\_\_\_\_

2. Adult/child name and age: \_\_\_\_\_

3. State: \_\_\_\_\_ 4. County: \_\_\_\_\_

5. Agency that helps fund programs: \_\_\_\_\_

6. Law enacted to fund the programs: \_\_\_\_\_

7. Email for Information on Laws enacted: \_\_\_\_\_

8. How your day program works: \_\_\_\_\_

9. Who administers and pays for programs: \_\_\_\_\_

10. Hours out of home daily: \_\_\_\_\_

11. Caregiver's title: \_\_\_\_\_

12. Daily activities: \_\_\_\_\_

13. College, classes taken, and funded by: \_\_\_\_\_

14. Jobs/Employment: Wage?: \_\_\_\_\_

15. How they get to jobs/daily: \_\_\_\_\_

16. Additional hours for Respite for in-home (for parents to go out): \_\_\_\_\_

17. Weekend Programs: \_\_\_\_\_

18. Respite Housing (Camp) for a Week visit or weekend stays. Who funds house? : \_\_\_\_\_

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## More Parent News . . .

Message board available for 5p- Society members at [Cri-Du-Chat\\_Syndrome@yahoogroups.com](mailto:Cri-Du-Chat_Syndrome@yahoogroups.com). You will need to join group by following the instructions. Thanks Carrie.

The Texas Center for Physically Impaired has refurbished computers available to blind and disabled people all over the world for the cost of \$50.00. These are Windows based Pentium computers with a monitor, keyboard, six-cassette tutorial, and a demo copy of Windows-Eyes Version 4.1. Bob Langford evaluates individual needs and provides the initial freeware, shareware or demos. For more information contact Bob Langford at [boblang@airmail.net](mailto:boblang@airmail.net) or call 214.340.6328. -- Thanks Nancy.

Micah Hoernig has found a calculator to help figure out the amount of money an individual with special needs might need if both parents are deceased. -- [http://www.metlifeiseasier.com/metdesk/calc\\_step1.asp](http://www.metlifeiseasier.com/metdesk/calc_step1.asp) -- thanks Micah.

# Patrick Gunnells

by Jamie Gunnells

[fiddlers3@earthlink.net](mailto:fiddlers3@earthlink.net)



Patrick Gunnells is 5 years old. He is the fourth born of five children. We suspected at birth that he had Cri du Chat because of the information given them by their mid-wife. Patrick has made tremendous progress in 5 years and his parents would like to share it with you.

Currently Patrick has a sight vocabulary of over 600 words. He can identify all shapes, colors, and hundreds of pictures. His expressive language consists of about 50 words which he began to say in March of 2005. He can identify words, pictures, or make his needs known by saying the beginning sounds of many words. He can carry out a series of 3 commands, such as touch your hair, touch your toes, touch your mouth. He is very mobile and almost to a full run. He loves Blue's Clues, Elmo, and Clifford. He loves cheeseburgers and he loves to go places. Most of all he loves books. He would have you read or write words to him all day if you could. He loves to watch his brother (8) and his three sisters (ages 3,7,and 9) play.

Patrick's fine motor skills are quite delayed as well as his speech. He cannot color or draw well and this really frustrates him. He understands everything that you tell him. He does like to "stim" on shoestrings and rubber bands. When he becomes frustrated, startled or just plain ugly he pinches.

We would like to share several of the strategies that we took early in Patrick's development. We will just highlight a few of them but if you have any questions we plan to be in St. Louis at the conference - hopefully with videos.

When Patrick was 6 months old we started him on a multi-sensory program with the National Association of Child Development ([www.nacd.org](http://www.nacd.org)) He sees a neuro-developmental, Dr. Bob Doman, four times a year in Atlanta. Dr. Doman looks globally at Patrick and identifies what neurological issues need to be addressed and gives us the specific activity to teach the brain. This over time will change the functionality of the brain. He bases the length of the program on how many hours a day we can commit to working with Patrick. From the beginning we have trained his therapists to implement this program. True progress can only occur if everyone with whom Patrick interacts uses the same approach. In the beginning and until he was age 3 we had some minor resistance for different reasons. For example an Occupational Therapist was trying to teach him to sit and she worked one day on this for an hour. Patrick would just cry and arch his back. I mentioned to her that this was not part of his program but she persisted. I called Dr. Doman and he said absolutely do not have him sit, his muscles are not ready, plus he is not developmentally ready to sit. He went on to explain that he must crawl before he sits and then you will not have to "teach" him to sit. I politely told the therapist and she quit coming to our house because she said, "That was not how I was trained." In the end when Patrick learned to cross pattern crawl he sat up perfectly on his own with such strength and stability.

Most of his therapists have been very enthusiastic to implement the program because they are relieved to know exactly what he needs at a specific point in his development. In reality there might be 50 issues that are all important that could be addressed which possibly could take 10 hours per day to address. However, Dr.Doman can prioritize which ones are urgent and most pressing and we concentrate on these. For example if we address 10 issues head on with intensity and duration for 3 months for three hours a day then we move on to more. One therapist wanted to address an issue that was important but not urgent. We explained that if she addresses that issue one time a week for 10 minutes there will be no progress. That's why it's vital that we all work together on the same issues.

In a nutshell some of the issues that Dr. Doman has addressed are proprioceptive sense, vestibular sense, tactility, mobility, strabismus of his left eye, oral motor, and cognitive development. Our school system currently rules him homebound at our request. We feel that his environment needs to be free from stimuli that sensory sensitive children can not handle. All of his instruction needs to be deliberate and purposeful. We also knew that this program would not be implemented to the fullest or not at all in the school system.

Patrick also receives a service called Community & Home-Based Waiver Program from the State. He receives a certain amount of hours for a care-giver of our choosing to come into the home and help with his day to day needs. This is a real positive for the state of Mississippi. Patrick has to re-certify every three years by undergoing a complete battery of tests. This year at his evaluation he totally amazed all the staff and doctors. Many were overcome with emotion. The psychologist gave him an IQ test and his score was 70. Her comment was that she knew he could go higher but his language stopped him. She was so disappointed because she could not get a true score. I think it's interesting that the man who created the IQ test said that there could be a margin of error of 40 points in either direction. And this is the test the schools use to "label" our children?

There are many aspects of his multi-sensory program that we could talk about, but we want to address one more vital component in Patrick's progress. From the beginning we gave Patrick vitamins and supplements. We have been fascinated with how some doctors are successfully treating Down's and autistic children with supplements. A big question to us was how did the break in the chromosome affect his ability to metabolize his food and could it have made his immune system quirky? We read about the PKU test that is given to our babies at birth and how there is a protein connection and if it's not treated the result is mental retardation. Could there be a protein connection with Cri du Chat? After having Patrick's urine tested 7 or 8 times we found that he was not effectively metabolizing proteins, fats and carbohydrates. At 2 years old we started him on doctor prescribed supplements to target this. We saw great improvement in focusing, concentration, and overall well-ness. You can count on one hand the number of antibiotics that Patrick has been on even though his father is a pharmacist. In Patrick's five years he has only had 1 diagnosed ear infection. We were still not 100% satisfied and felt there was still a piece missing. Summer of 2004 we read about Dr. Jeff Bradstreet in Melbourne, FL. He specializes in treating autistic and Down's children by testing their urine, blood and stool and treating them accordingly. We did our research and he has an awesome track record and we had our first appointment last October. Patrick had 2 amino acids that were out of wack (which are the building blocks to the proteins) and extremely high ammonia levels and extremely low zinc just to name a few. Dr. Bradstreet started treating each issue one at a time. Patrick started the supplement regiment in December and in three months he had gained 6 pounds and had recognizable language. He is so much thicker and stronger and is making tremendous strides cognitively as well. Dr. Bradstreet will be speaking at the conference in St. Louis. You will not want to miss him. I am looking forward to seeing you in St. Louis and learning from you as well. There are many more details that I would love to share with those who are interested.

## ***President's Message continued . . .***

Next year, for the 2006 conference, we have confirmed host city of Santa Clara, CA, and the Santa Clara Marriott. There are several flight options available for people who wish to fly in to the conference (the San Jose airport-20 min. away, Oakland and San Francisco airports-45/80 min. away respectively). Beyond the activities planned at the Santa Clara Marriott, we are excited about the prospects of the amusement park directly across the street as well as a local entertainment center down the road. As for 2007, several members of the Board will be visiting the Bloomington area of Minneapolis, MN, with Paul Bakken to finalize the site. Paul has done a wonderful job planning for 2007 in the midst of everything that he has going on with the new addition to his family. Looking even further ahead to 2008, we are still looking for some families in the Northern VA/Washington D.C. area that are interested in hosting a conference.

In response to the positive feedback received from parents, friends of the Society and Board members, we have decided that adding a 5p- membership fee would assist in moving the Society in a positive direction. We will begin a \$25 dollar membership fee starting at the St. Louis conference. Please apply through Laura Castillo or one of the Board members.

Lastly, I have received several recommendations on how to improve the Society going forward. For example, providing video conferences, CDROMs available for families that could not attend the conference, etc. Again, we are looking at goals within the next 3-5 years. Please keep those recommendations coming! Again, we encourage open dialog on how to best improve the Society and we would like to hear from you directly. Please contact me at: [gabbruzzese@converse.com](mailto:gabbruzzese@converse.com), or any other Board member, with any thoughts or suggestions for the Society.

Thank you all for your continued support of the Society.  
Greg Abbruzzese



All members of the 5p- Society, extended families and professionals are invited to our Annual Conference and Get Together scheduled for July 28-31, 2005 at the Hyatt Regency St. Louis at Union Station in St. Louis, Missouri. Registration application is on page 7 of this newsletter.

**Site:** Hyatt Regency at Union Station, One St. Louis Union Station, St. Louis, MO 63103.

**Room Rate:** A reduced rate for 5p- Society members is \$110.00 per night. To make your hotel reservations please call (314) 231-1234 or (800) 233-1234 and tell the operator that you are with the 5p- Society to get your reduced rate. If you encounter any problems when making reservations please contact Laura at the 5p- Society office at (888) 970-0777 or director@fivepminus.org. All suites are currently occupied.

**SOLD OUT**

**Alternate Hotels:** One good thing about St. Louis is that there are a lot of hotels in the area. Unfortunately all hotels within walking distance of the Hyatt Regency are also sold out due to a city-wide event. The good news is that there are hotels down closer to the Gateway Arch that are still available at decent rates. We do not have a block of rooms available, however you can call the following hotels for rooms: Hampton Inn St Louis - Gateway Arch at (314) 621-7900 or the Millennium Hotel St. Louis at (314) 241-9700. At the printing of this newsletter they still had rooms available.

**Transportation:** The hotel is just 20 minutes from the Lambert St. Louis International Airport. There is a MetroLink Light Rail that can take you from the Airport to the Hotel for less than \$3.00 each. The MetroLink can also take you from the Hotel to many attractions including the Gateway Arch. Trans Express provides transportation to and from the airport and the Hyatt Regency every 25 minutes for \$13.00 per person one-way or \$21.00 per person roundtrip. If you are driving to the conference please contact the hotel for directions or go to the hotel's website at [www.stlouis.hyatt.com](http://www.stlouis.hyatt.com).

**Child Care:** Complimentary child care will be available during meeting times. Please indicate on your registration form if you will be needing child care. Thank you to Susan Donnelly for heading up this part of the conference

**T-Shirts:** T-shirts will be white and have the St. Louis Conference Logo above. They are \$8.00 each. Please pre-order your T-shirts (recommended) on the order form on page 8 of this newsletter. A limited amount of shirts will be available at the conference. All volunteers of the conference, including child care, board of directors and welcome committee please order your shirts in pastel yellow (on order form). **Deadline for Pre-orders July 1, 2005.**

**Speakers:** Unfortunately Dr. Bradstreet has just informed us that he is unable to come. However, we look forward to having a superb slate of fantastic individuals ready to provide you with needed information. Research will be taking place with a couple of the speakers.

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## Membership Form

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

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

\_\_\_\_\_

Phone: \_\_\_\_\_ Email Address: \_\_\_\_\_

Enclosed (circle one)

\$25.00 Family Membership

\$25.00 Relative/Friends/Professional Membership

New Member or Existing Member

**Detach and Return to:**

**5p- Society, PO Box 268,  
Lakewood, CA 90714-0268**



# Registration Form

\$125.00 Two adults/two children same family \_\_\_\_\_  
*(after July 1st \$150.00)*

35.00 Additional adult \_\_\_\_\_

25.00 Additional child \_\_\_\_\_

50.00 Professional fee - *professionals only* **not** attending family events \_\_\_\_\_  
*(see page 5 for more information on how you can waive this Professional fee)*

Sponsorship Opportunity -- Please consider a donation to assist in sponsoring one of the following events:

Continental Breakfast, Welcome Reception, Sibling Outing, Volunteer Lunch, Friday "Inning" *World's Fair Carnival*, Speaker Expenses \_\_\_\_\_

Total Enclosed \_\_\_\_\_

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone: \_\_\_\_\_ Email Address \_\_\_\_\_

Names of <b>all</b> Adults attending	Relationship to Cri du Chat Child/Adult
_____	_____
_____	_____
_____	_____
_____	_____

*use additional page for more than four adults*

Names of <b>all</b> Children attending	Relationship to Cri du Chat Child	Daycare Y/N	Age
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

*use additional page for more than four children*

Requesting directly from the hotel:  
 Cribs \_\_\_\_\_ Rollaways \_\_\_\_\_ Refrigerators \_\_\_\_\_ Will you need a high chair for the banquet y n

Please attach your check or money order (in US funds only), fill out and return this form to:

5p- Society  
 2005 Conference  
 PO Box 268  
 Lakewood, CA 90714

Any questions please call (888) 970-0777



P.O. Box 268  
Lakewood, CA 90714

Return Service Requested

T-Shirt Order Form

This year's T-Shirts will have the **Meet Us In St. Louis** logo on the back and 5p- Society logo on the front left pocket area. T-Shirts will be in white. All conference and 5p- Society volunteers including host families, welcome committee members, board of directors and child care provider's T-Shirts will be in pastel yellow. Please indicate below the quantities and sizes that you would like. T-Shirts are \$8.00 each. Please make checks payable to the 5p- Society and send your order form and money to 5p- Society, PO Box 268, Lakewood, CA 90714-0268. If you are not planning on attending the conference but would still like a T-Shirt (pre-orders only) please add \$5.00 for shipping up to 3 shirts (\$5.00 for each additional 3 shirts). There will be a limited number of T-shirts available at the conference. Pre-ordering will guarantee your shirts. Any questions please contact the 5p- Society office at 888-970-0777. **Deadline for pre-orders July 1, 2005.**

Sizes	Quantity	
	White	Yellow (volunteers only)

Youth Small	_____	_____
Youth Medium	_____	_____
Youth Large	_____	_____
Youth XL	_____	_____
Adult Small	_____	_____
Adult Medium	_____	_____
Adult Large	_____	_____
Adult XL	_____	_____
Adult XXL	_____	_____

Name: \_\_\_\_\_  
 Address: \_\_\_\_\_  
 Phone: \_\_\_\_\_

No. Shirts \_\_\_\_\_ x \$8.00 = \_\_\_\_\_

Add for shipping: \_\_\_\_\_  
 (if not attending conference)  
 Total Enclosed: \_\_\_\_\_