

# 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

Walker Accessory—[www.palzomine.com](http://www.palzomine.com)

5p-Society, PO Box 268, Lakewood, CA 90714-0268 (562) 804-4506, toll free (888) 970-0777, fax (562) 920-5240 email: [lc5pminususociety@aol.com](mailto:lc5pminususociety@aol.com)

## President's Message *by Jolene Towers*

New families join us on a regular basis. New babies are being born with the syndrome, families with older children are getting diagnosed, or just finding us for the first time on the web. The internet has been a fantastic tool for not only these families, but also for all our existing families. It's nice to chat with another family going through the same thing, who REALLY understands! The message board on yahoo/groups has been a fantastic avenue, allowing families to post any question and get useful answers and suggestions of ways to help. Thank you to everyone who has taken the time to answer someone's post, to communicate with another member of our 5p-family. Facebook has been another avenue to keep our friendships going, make new friendships, and get those much needed

questions answered from the experts... other Cri du Chat parents. Once again, I want to thank all of those who have offered their support to those in need. That's what this is all about. Thank you!

The 5p- Society continues to maintain a database of families who have a child with the syndrome. I would ask that if it has been awhile since you have updated your information, please do so. Make sure that we have your current phone number, address and email address, since we are sending the newsletter out electronically to as many members as possible to help save on expenses. This way if someone within the Society needs to contact you, we will have the most up to date information.

As you know, our main event each year is our National Conference. For those of you who have been lucky enough to attend a conference, I am sure you would agree that they are fabulous! For those who have not been able to attend yet, 2011 is in Columbus Ohio and 2012 is in Denver. The society does offer a couple of scholarships each year to help with cost for those that need assistance to be able to come. Many states also have local funding that you can apply for to be able to attend conferences. Check with your local DD office. This year, I get to help host the conference here in Ohio, and we are looking forward to fantastic speakers and a great family event along with a fun sibling outing. We hope to see many of you here the end of July.

## Inside this issue:

Host Family Wanted	2
Feeding Program for Jacob	2
Welcome to Ohio, Other News	3
"You Don't Know What You're Missing" Conference Info	4,5
Schedule, Fundraising Events	5
Conference Registration Form	6,7
T-Shirt Order Form	8

## Cars4Causes

The 5p- Society has partnered with Cars4Causes; a vehicle donation organization. You can donate a vehicle or boat to the organization through the 5p- Society's special link. You can find that link on the 5p- Society web page, or by phone at (800)766-2273. Follow the directions and someone will be calling you within 24 hours. The 5p- Society will receive 70% of the resulting sale of the vehicle (after repairs and any other costs). Help us out and donate today.

## Host Family Wanted

Hello, my name is Ana Ramiro. I am from Barcelona, Spain. I am the proud aunt of a 6-year-old little girl named Irene. Irene has 5p– Syndrome. I am also a professional photographer. I have been studying English for over three years. I would like to learn more and would like to spend my holiday in July/August for three weeks in the United States learning more English by studying abroad. I would like to stay with a family who has a child with 5p– Syndrome to help the family. I am really hoping to stay with a family who will be attending the conference in Ohio so that I can also attend. I am willing to offer my professional photography services to the family and to the organization.

I love my niece and help my sister, Manoli, with her children. If you can host me in your home please send me an email at [ana\\_ramiro@hotmail.com](mailto:ana_ramiro@hotmail.com).

## Feeding Program for Jacob *by Michelle Gilbert*

My son, Jacob, is almost 3 years old and he has never really eaten by mouth. When he was born he couldn't suck, swallow and breathe all at the same time, so he had an NG tube. Although we would try to feed him by mouth he never ate enough for the doctors to be comfortable removing his feeding tube. As he got older we transitioned to a G tube. Once he got the G tube he refused to eat by mouth at all. We kept trying, at one point he would eat a little baby food, but still never enough. We make progress, we regress, we make progress, and we regress. It has been very frustrating.

Jacob suffers from severe reflux, so one reason we want him to eat by mouth is to help with his reflux. But we seem to have a chicken and egg problem. His speech therapist says he probably won't eat by mouth as long as he is throwing up all the time and he is probably going to continue throwing up all the time until we can get him to eat solid food. So what do we do?

A few weeks ago Jacob's behavioral therapist suggested we try the Feeding Disorder Program at the Kennedy Krieger Institute. KK helps children with all types of disorders, from sleep disorders to brain disorders. The institute is located in Baltimore, Maryland and is known throughout the world for their work with disabled children.

The feeding disorder program is 6-8 weeks long and can be either in-patient or out-patient. The institute uses an entire team of medical professionals to create a plan of care specific to each child. The team includes Pediatric gastroenterologists, behavioral physiologists, speech/language pathologists, occupational therapists, nutritionists, and nurses. For Jacob's feeding program we have already done a 30 minute phone in-take interview to determine his eligibility. Once it was determined he was, in fact, eligible for the program we were sent an intake packet to fill out that describes his entire feeding history, current situation, including behaviors during feedings and what we hope to accomplish through this program.

Families need to provide all applicable medical records and therapy evaluations to give the institute as thorough a picture as possible of their child's situation. Next we will go to Baltimore to do an in person evaluation and set up Jacob's personal plan of care. Then we are on the wait list. We haven't been told how long the wait list is or what to expect. I try to keep my expectations low, but KK has an 82% success rate getting children to eat. And you leave the institute with the proper training to keep the feeding going once you get home.

I have no idea if KK will be able to get Jacob to eat by mouth, but I am willing to try anything. Especially if it means he'll stop throwing up. Jacob's evaluation is scheduled for March 3<sup>rd</sup> and we'll go from there. Hopefully by the time we see everyone at the conference this year my little man will be eating just like the rest of us!

## Welcome to Ohio!!

I cannot believe that the 5p- Society's Annual Conference, in Ohio, is coming up in about 4 months. July 28<sup>th</sup> is coming up fast. This year is really flying along. I am getting really excited about getting the opportunity to meet some of you for the first time, and reconnecting with those we have met before. We have a lot of things planned for this conference, and I would like to fill you in on some of the things we have in store for you. I am not going to tell you everything, as we plan to have some surprises. If you don't keep your eyes open this year, you might miss something, hence our theme You Don't Know What You're Missing.

We are in the process of confirming our slate of speakers for this year's conference. If you have never been to a conference before, I suggest you sit in on, our founder, Kent Nicholls' New Family Orientation session. This session is held Thursday night and is a valuable session to attend. We will once again be blessed by two of our most devoted speakers Amy Sue Reilly, and Dennis Campbell. Just those two alone could make the conference sessions wonderful, but we have more. A few of the sessions we will have at this year's conference include: Feeding, Trusts, IEP's, Alternative Therapy, Curbing Adverse Sexual Behaviors, The Pros and Cons of Respite Living and Group Home Living, and several other sessions. I am really pleased with our lineup, and expect it will provide a wealth of information to all.

The siblings are going to have a great outing this year as well. They will be going to COSI. The Center Of Science and Industry (COSI) is a hands on museum that is fun for all ages. The siblings will be able to see all of the regular exhibits, but will also be able to experience Adventure in the Valley of the Unknown! This exhibit has been compared to an Indiana Jones movie. To learn more about COSI and Adventures, visit: <http://cosi.org>.

The Family Fun Luncheon Event is going to be a blast. We will be featuring four areas that we Ohioans take pride in. The four areas we will be featuring will be music (The Rock & Roll Hall of Fame), sports (Ohio State and our Pro Teams), aeronautics (The Wright Brothers, John Glenn, and Neil), and the Columbus Zoo. We are excited to announce that we will be having Dance Heads return this year. They were a big hit at our conference, in Norfolk, VA., we had to bring them back. We will also be visited by some wild animals, and I do not qualify as a wild animal, for those of you who were thinking it. Yes, the Columbus Zoo will be bringing animals for us to learn about, and possibly have an opportunity to touch.

So, as you can see, we have a lot of great things planned for the conference, July 28<sup>th</sup>-31<sup>st</sup>, 2011. I know that reservations and registrations have already been received. This is not a conference you will want to miss. I can't wait to see you all there.

Nick, Angie, Allie, and Nate Wallace

## Other News

It is with much sadness that the 5p- Society has learned that Angela Jackson of Jacksonville, Florida passed away on Christmas Eve. Angela was 27 years old and passed away from complications from pneumonia. Angela was such an inspiration to me personally when I met her for the first time, I imagined my daughter growing up to be just like her, especially in her communication abilities. Angela's mom, Deborah, welcomes phone calls or cards. She can be reached at 904-704-2442. Please contact the 5p- Society office for her address.

## iPad with Proloque2go Donation

The Fernandes family of San Ramon, California has donated two iPad's with the Proloque2go software. They have requested that the iPad's go to two 5p- Society families whose child/adult with Cri du Chat Syndrome can benefit greatly from the device, but who does not have the means to purchase the iPad. The Board of Directors is in the process of preparing a Grant Application for interested families. The Application should be available by April 20, 2011. Applications can be requested by contacting the 5p- Society either by phone at 888-970-0777 or by email at [lc5pminusociety@hotmail.com](mailto:lc5pminusociety@hotmail.com). Application deadline will be May 31st. A committee consisting of several Board Members and donors Robert & Erin Fernandes will review all applicants. Applicants must be willing to document the progress of use of the iPad on a quarterly basis. Applicants must supply Letters of Recommendations from therapist, case workers, doctors and/or teachers explaining why they feel the child/adult would benefit from the iPad.

The 5p- Society would like to thank Robert & Erin Fernandes for their gracious donation.

## *"YOU DON'T KNOW WHAT YOU'RE MISSING"*

**Location:** The Annual conference of the 5p– Society will be located at the Columbus Airport Marriott, 1375 North Cassady Ave, Columbus, Ohio 43219. Hotel phone number (614) 475-7551. The 5p– Society's group rate is \$99.00 per night. You can make your reservations by calling the hotel's toll free reservation line at (800)491-5715 or online at <http://www.marriott.com/hotels/travel/cmham?groupCode=F5PF5PA&app=resvlink&fromDate=7/28/11&toDate=7/31/11> (you can also access this reservation link on our conference page on our website at [www.fivepminus.org/annconfX.htm](http://www.fivepminus.org/annconfX.htm)). Our online group code is F5PF5P 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 AT (888)970-0777.

**Transportation:** The Columbus Airport Marriott offers a complimentary shuttle from the airport to the hotel.

**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 fill in-form at the 5p– Society website at [www.fivepminus.org/annconfX.htm](http://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 Jolene Towers at (937)427-2709 or [gnjtowers@aol.com](mailto:gnjtowers@aol.com). Volunteers will be given a complimentary lunch on Saturday afternoon.

**Conference Scholarships:** The Board of Directors of the 5p– Society has approved five (5) scholarships to be funded for the conference. If you are interested in obtaining an Application for the scholarship, please send an email to Laura Castillo at [lc5pminusociety@hotmail.com](mailto:lc5pminusociety@hotmail.com). The scholarship will pay for three nights at the Columbus Airport Marriott Hotel and also for the basic registration fee of \$150.00 for up to two adults and two children. Deadline to submit your scholarship application will be May 1st.

**Speakers:** The following speakers and topics have been confirmed:

Dr. Dennis Campbell	(1) Cri du chat 101 (2) Transition
Dr. AmySue Reilly	(1) Behavior Applications (2) Transition
Shanida Mathieu	The IEP Process
*Dr. Scott Pentiuik	Feeding Issues in Children with Cri du Chat Syndrome
Cindy Arroyo	Augmentative Communication
Renee Cassaday	Hippotherapy
Joyce Pete	Sensory Strategies
Natalie Folino	Sex Education for students with moderate-severe disabilities
Marty Fagans, CRSI	Group Homes
Scott Hayes	Future Planning/Trust
Fundraising Committee	Fundraising for the 5p– Society
Kent Nicholls	New Family Orientation

\*Dr. Scott Pentiuik graduated from the University of Cincinnati School of Medicine in 2002. He then entered pediatric residency at Cincinnati Children's Hospital Medical Center. Dr Pentiuik became interested in children with feeding problems and completed a pediatric gastroenterology fellowship in Cincinnati where he remains as a faculty member. Dr Pentiuik currently works as the primary gastroenterologist on the Cincinnati interdisciplinary feeding team. His other interests include general gastroenterology and medical education.

## Conference Schedule

### Thursday, July 28, 2011

5:00 PM to 10:00 PM Registration  
 7:00 PM to 9:00 PM New Family Orientation  
 7:00 PM to 8:00 PM Sibling Mixer  
 5:00 PM to 11:00 PM Hospitality Suite Open

### Friday, July 29 2011

7:30 AM to 9:00 AM Child-care Check-in  
 8:30 AM to 9:00 AM Welcome Session  
 9:00 AM to 10:30 AM 1st Break Out Session  
*3 tracks running*  
 10:30 AM to 12:00 PM 2nd Break Out Session  
*3 tracks running*  
 9:00 AM to 11:30 AM Sibling Supportshop  
 12:00 PM Child-care Check-out  
 12:00 PM to 3:00 PM Family Fun Event  
*A Taste of Ohio*  
 4:00 PM to 6:00 PM Grandparents Supportshop  
 8:00 PM to 10:00 PM Board of Directors Meeting  
 7:00 PM to 11:00 PM Hospitality Suite Open

### Saturday, July 30 2011

7:30 AM to 9:00 AM Child-care Check-in  
 8:30 AM to 9:00 AM General Session  
 9:00 AM to 10:30 AM 1st Break Out Session  
*3 tracks running*  
 10:30 AM to 12:00 PM 2nd Break Out Session  
*3 tracks running*  
 12:00 PM Child-care Check-out  
 12:30 PM—1:30 PM Volunteer Lunch  
 12:15 PM—1:45 PM Professional Advisory Board Lunch  
 12:00 PM—2:00 PM Lunch on your own  
 1:30 PM—2:00 PM Child-care Check-in  
 2:00 PM—3:30 PM Parent Panels  
 3:30 PM—5:00 PM Professional Panel  
 5:00 PM Child-care Check-out  
 5:30 PM to 6:30 PM Family Photographs  
 6:30 PM to 10:30 PM Banquet, Family Dance,  
 General Meeting of the  
 Membership and Raffle  
 9:00 PM to 11:00 PM Hospitality Suite Open

### Sunday, July 31, 2011

10:00 AM to 12:00 PM Closing Session, Picture Session  
 Time to Say Goodbye  
 2012 in Denver, Colorado Info

## Fundraising Events

If you live in the Granite City, Illinois area and love to bowl, Jason & Michelle Myatt are having their 1st Annual 5p– Society Bowling Benefit.

April 17, 2011  
 AMF Bowland  
 5050 Nameoki Rd (hwy 203)  
 Granite City, IL 62040

Cost: \$15 for adults, \$10 for kids ages 2-8  
 Includes bowling, appetizers & soda

For more info contact: Jason or Michelle Myatt at (618) 931-1538

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2nd Annual 80/20 Raffle is now in progress. Ticket prices are \$50.00 each; the 5p– Society’s goal is to double the amount of tickets sold last year. You can help us reach that goal. If you received tickets in the mail, please try to sell them to your family or friends. If you did not receive tickets but would like to help, please contact the 5p– Society at (888)970-0777 or you can contact Gloria Griffin at flyingggi@insightbb.net. Raffle will be held at the 2011 Annual Conference. Thank you so much for your continued support.

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Did you ever think that a child with *Cri du Chat Syndrome* would be cast as a character in a fictional book? Well it happened. Joanne Harris, author of the book “A Girl with No Shadow,” a sequel to the “Chocolat” series has given little Rosette the Syndrome. When asked what her inspiration was to deciding on her character, she said “I find my inspiration all over the place, and I was intrigued by Cri du Chat initially because of the name, and then because of the people whose children were affected by it, to whom I talked whilst researching the book . . . “



2011 Annual Conference and Get Together  
 Columbus, Ohio  
 July 28—July 31, 2011

“You Don’t Know What You’re Missing”

**CONFERENCE REGISTRATION FORM**

Yes, I plan to attend the 2011 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 \_\_\_\_\_

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

\_\_\_\_\_  
 \_\_\_\_\_  
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Names of All Children attending conference Relationship to 5p– Syndrome Child/Adult Age Childcare Sibling Event

Names of <u>All</u> Children attending conference	Relationship to 5p– Syndrome Child/Adult	Age	Childcare	Sibling Event
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

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 this information will not guarantee you a high chair, however for planning purposes we will alert the hotel of the amount of highchairs needed for the event.)

**Sibling Event:** This year's sibling event will be at COSI, a hands on science center. The cost will be \$9.25 for Admission, sack lunch and a special Adventure exhibit. For more information contact [www.cosi.org](http://www.cosi.org). Please indicate if your sibling child will be attending on page one of the registration form. If you or an individual from your party is interested in chaperoning the event please indicate that here: \_\_\_\_\_

**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 2011 5p- Society Annual Conference and Get-Together in Columbus, Ohio 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 2011 5p- Society Annual Conference and Get-Together.

\_\_\_\_\_  
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](mailto:director@fivepminus.org).

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

Page 2, conference registration



PO Box 268  
Lakewood, CA 90714-0268

Return Service Requested

## 2011 CONFERENCE T-SHIRT ORDER FORM

The 2011 T-shirt will be black or grey with the Ohio logo on the back. 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 the opposite attendees shirt with the Ohio logo. Please indicate if you need a volunteer or attendee shirt. If you have any questions, please send an email to [director@fivepminus.org](mailto:director@fivepminus.org).

SIZES	QUANTITY		
	Attendee	Volunteer	
YS	_____	_____	Name: _____
YM	_____	_____	Address: _____
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	_____	_____	Credit Card Information: _____
AXXL	_____	_____	Expiration Date: _____ Total Amt Charged: _____
Total:	_____	_____	