

5P- News

Family Support Group for Children with Cri du Chat Syndrome

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.

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 Greg Abbruzzese*

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://comtechlab.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

Dear Five P Minus Society

I hope everyone is well and enjoying this warm Spring/Summer weather that we are experiencing. With the Minneapolis conference only a few weeks away, things are shaping up quite nicely for the conference.

Laura Castillo has once again done an excellent job coordinating everything on the Society's behalf. Paul and Alison Bakken and the local Minnesota families have done a wonderful job fundraising and preparing for the conference as well. Once again we have an impressive group of speakers, lined up - Dennis Campbell, AmySue Reilly, Joan Henley, and Dr. Towers, along with some local speakers. Gloria Griffin and Jim and Fran Bodle will be running the grandparents workshop. In addition, WE STILL NEED VOLUNTEERS FOR CHILD CARE!!! Anybody willing to help out for an hour or so to cover a shift will be greatly appreciated! Please sign up upon arrival at the conference. Also, it's still not too late to sponsor a room or an event for the conference. If you wish to sponsor a room, or make a donation toward an event for the Minneapolis conference, then please

contact Laura, Paul or myself. I greatly appreciate everyone's contributions thus far to the conference and the Society. Without all of your support, we could not offer the current services that we provide.

As we approach this year's conference, it is important to hear feedback from the members. I have heard from several of you with regard to some improvements on the web site that you would like going forward, PDF files of the conference brochures (for those of you who cannot attend), etc. As we are working on some of these initiatives, we would still like to hear more from you. Please e-mail me (gabbruzzese@converse.com), or any other Board member with your suggestions.

Looking ahead to 2008 in Virginia Beach, Christy Blount and Anne Zettlemoyer are well ahead with preparations. They are almost done with fundraising and have coordinated several races, raffles and food drives on behalf of the Society. Thank you both for a GREAT start! We are very grateful for all of Christy and Anne's (and their families)

continuous efforts!

In 2009, we are heading to Dallas and we are working hard to finalize a site. With the assistance of Mylenda Commiato, Jessica Gomez, and Laura Castillo (who will revisit Dallas), we will finalize a location in the next few months. Any local families in and around the Dallas area who wish to assist with the conference, please feel free to contact Mylenda or any of the Board members.

I look forward to seeing you all in Minneapolis!

Greg Abbruzzese

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CONFERENCE
REGISTRATION
AND T-SHIRT
INFORMATION
AVAILABLE IN THIS
ISSUE OF 5P- NEWS

Cri du Chat Research Project *by Dr. Dennis Campbell*

You ask, "Why do I need to participate in this research project"?

There are several research projects that are supported by our 5pminus Society which will benefit our children with Cri-du-chat Syndrome. Some highlights of the results and outcomes from these various research projects include:

* Set of growth charts specific to our children with Cri-du-chat Syndrome. These growth charts have had a profound impact on the "quality of life" of our families. Prior to the creation of these growth charts, many of our children with Cri-du-chat Syndrome were diagnosed as "failure to thrive". This was commonly due to our children's small stature size and slow weight gain. In actuality, our children were developing "typically" for someone with Cri-du-chat Syndrome. In the past, families spent too much time and a lot of money on supplements for weight gain that we now know is not necessary.

* *The article Cri-du-chat Syndrome: A Topical Overview, available free on the society website. This is a composite picture of Cri-du-chat Syndrome that was unavailable to professionals in the past. This overview provides professionals and others who are working with our families information about our special children without having to go to medical school.*

** As an update of the most current research project that many of you have participated in with Drs. Campbell, Reilly, and Henley we are continuing to collect various overall assessment information on many of our children. The purpose is to begin to develop a composite picture of communication and language skills (verbal, using sign language, gestures and/or augmentative devices) and then relate our children with Cri-du-chat Syndrome's communicative process to their development and differing behaviors. There is little argument that communication is one of the major if not the greatest challenge faced by our children.

As of this writing we have some interesting findings. We have found a strong relationship between parent report and formal assessment results. Basically this suggests that you, as parents, are able to describe your child's abilities very well and quite accurately. The formal assessment instruments we used matched very closely with your report of your children's abilities. We will have a paper published July 2008 in the *Journal of Education and Training in Developmental Disabilities* on these findings.

We have found that although this group we evaluated has all of the typical Cri-du-chat Syndrome behavioral traits, the frequency and intensity of those behaviors are

very low. A review of the literature of past research published does not indicate this. This is an interesting finding; we want to look further into it to collect and gather more specific information.

As part of the formal assessment process we did not stop at the prescribed ceiling for the instruments. Results from the Battelle Developmental Inventory showed an average of 12 splinter skills for these individuals that would not have been reported if the ceiling rules were followed. In a standardized assessment a beginning score is determined which is usually called the basal. The assumption made is that the individual would get credit for every item in the instrument before the basal. Likewise a ceiling or top score is also reached. The assumption being that the individual would not be able to perform the skills past this point. We are currently looking at the skills demonstrated above the usual ceiling in the assessments we have completed. We want to see if there are patterns in the data. With the data we collected this last summer we have over 100 assessments completed.

*** So at our **2007 Minneapolis conference** we would like to review your child's IEPs from the past three years and also the one for the upcoming year. We would like to talk with you about your child's IEP in regards to how it was developed and how it was finally written. We would like to discuss the input that you provided in the IEP's development as well as who were the IEP team members. We would like to seek your input on the IEP overall process and about the various services your child is receiving across the various IEPs. In looking at IEPs from many of you we hope we can use the data we have collected to compare what we are seeing from your children with what is actually happening in the schools. Our intent is to provide all of you with information to help your IEP teams develop good programs.

As many of you have heard before it is only by systematically collecting information from you, that we are able to help professionals understand Cri-du-chat Syndrome and not sell our kids short. The information on Cri-du-chat Syndrome in the literature is better now, but we still run across professionals who assume poor outcomes.

We welcome you to join us in the research project at the 2007 Minneapolis conference where we will be interviewing families about their child's education programs. We will be scheduling a time to talk to you. Please bring copies of your child's IEPs from the past three years and for the upcoming year.

If you are not able to attend the 2007 Minneapolis conference and would still like to participate, contact me and I will send you a packet of information to complete with a self addressed envelope to return to me. We can set up a

time to talk about your child's IEP where I will call you at a time that is convenient for you.

We look forward to seeing many of you in Minneapolis. If you would like more information, please feel free to email me at campbell@usouthal.edu, or call me at my office at 1-251-380-2877, or if you prefer drop me a note at:

Dr. Dennis Campbell
 Department of Leadership and Teacher Education
 UCOM 3130
 University of South Alabama
 Mobile, AL 36688

Parent Supported Fundraising *by Eric McNett*



Alec relaxing with his family

On June 16, 5p- Society member Eric McNett hosted the first State of Maine Outrigger/Surfski Championship in Portland, Maine. The weather, the organization and the course were all fantastic. The only aspect of the event that let it down was the attendance. Proceeds from the event are to benefit the 5p- Society. Eric has a 13-year-old son, Alec, who has Cri du chat Syndrome. Alec loves to ride in the outrigger canoe so that he can participate in family outings. Eric has a two man canoe where Alec rides in the front. Donations are still being accepted to support the event. If you are interested in donating please send your donation to Eastern Outrigger, 77 Barrows Drive, Topsham, Maine 04086

Eric's course started from Portland's Eastern Prom with a 3 mile up-wind section to the bottom of Cushing Island. The remnant swell (from the lingering low pressure off New England) bounced between Cushing and Ram and made life interesting for a while. But it was worth pushing through for the 10 miles of sweet quartering rides that remained of the course up to Harpswell.

The course went further from the shoreline than most other New England races but a coast guard boat and two volunteer support vessels covered the divided field very effectively.

Eric put on a superb race. Downwind and open water races let the boats do what they were made to do - make sure you have this classic marked on your calendar for next year.

Thank you Eric for your fundraiser to support the 5p- Society.



Eric chasing the leader

WELCOME TO MINNEAPOLIS 2007

Hello again from Minnesota! We are in the final stretch preparing for the annual conference, and are looking forward to having you all visit!

We wanted to give everyone a few updates on the upcoming conference. Some of this information reflects a change from the information available in the last newsletter:

1. Once again, the information about the hotel and area attractions are on the Society website (www.fivepminus.org). The Society website also has a link to the hotel reservation website – if you haven't made your room reservations yet, please do so.
2. The details of the Friday family Event have been finalized. We will have a “state fair” style meal with burgers and hot dogs. To the side of the meal area will be a carnival for kids of all ages to enjoy. The carnival will have an “Adventure Jump” inflatable jump house and a ball pit for those craving physical activity. For those who wish to try their hand at games of skill and chance, we will have the following games: duck pond, milk can toss, can smash, gopher golf, basketball toss, ring-a-pop toss, hi-striker, and believe it or not something called a “potty toss.” We will also have a separate tent with a face painter and a chance to do spin art projects. This event will run from 12:30 PM until about 3 PM.
3. We have also finalized the details of the Saturday Sibling Outing. This full day sibling outing will be to the Mall of America, where the kids will take advantage of the Park at the Mall, which is an indoor amusement park. The cost per child is \$25. This fee includes unlimited rides and because we were able to get a good rate, it does include a voucher for lunch! Kids will still need extra spending money for snacks and souvenirs, however. Right now, the plan is for the kids to depart from the hotel by bus at about 9 AM and be back at the hotel no later than 5 PM. We are still looking for parents or other adults who can act as chaperones for this event. If you are able to help, please send an email to paulbak-ken@comcast.net.
4. We have confirmed a photographer for those wishing to sit for family portraits before the Saturday dinner and dance. We will have two photographers from a nearby ProEx available, who will offer a choice of packages. They use digital photography, so you will be able to review your shots and make your selections at the same time you select your package.
5. Once again, please take advantage of pre-registration. Not only does pre-registration help us better plan for an effective conference, it will save you some money! Please also indicate if family members will be participating in the sibling workshop or outing, using the childcare rooms, or purchasing T-shirts.
6. Finally, we would like to thank the following people for sponsoring specific activities at the 2007 conference. Their generous support makes our conferences possible!

<u>Friday Fun Event:</u>	Paul and Terry Arango Paul and Alison Bakken	in honor of Oliver Arango in honor of Amanda Bakken
<u>Welcome Reception:</u>	Stephen and Kate Jensen	in honor of Janine Jensen
<u>Hospitality Suites:</u>	Fuller, Seaver, & Ramette, P.A.	in honor of Sarah Seaver
<u>Friday Breakfast:</u>	Rob and Cathy Vaden Friends & Family of Abigail Vaden	in honor of Abigail Vaden
<u>Saturday Breakfast:</u>	Friends & Family of Amanda Bakken	in honor of Amanda Bakken

See you all at the conference!

Paul & Alison Bakken

2007 CONFERENCE INFORMATION

DATES: July 26-29, 2007

LOCATION: Sheraton Bloomington Hotel, Minneapolis south, 7800 Normandale Blvd, Minneapolis, MN 55439. (952) 835-7800.

RATES: The Society has been able to obtain an excellent room rate of \$105.00 per night (+ applicable taxes). When you call to make your reservations tell them you are with the 5p- Society. Reservations must be made by July 1st to get this great rate. Room reservations can be made either by calling the hotel directly (952) 835-7800, the toll free reservation line at (800) 325-3535 or online by clicking the online reservations button for preferred online booking on the 5p- Society website at www.fivepminus.org/annconf07.htm. At the writing of this newsletter all Cabana rooms have been booked. Remaining guest rooms are available. If you have any problems with your room reservations please contact the 5p- Society office at 888.970.0777 and we will help you in making your reservations.

REGISTRATION: See attached registration page for rates.

T-SHIRTS: See order form for T-shirts on page 8 of this newsletter.

SPEAKERS: The following speakers have committed to the 2007 Annual Conference:

Dr. Dennis Campbell — Cri du Chat 101, IEP's, Study Overview

Dr. AmySue Reilly — Behavior Modification, IEP's, Study Overview

Dr. Joan Henley — IEP's, Behavior Modification, Study Overview

Dr. Geoff Towers—Puberty

Mary Ann Ehlert, Protected Tomorrows—Planning for the Future and Transition

Dr. Monica Bessler — Tert Gene Study, What's Next

Carla Kress, Recreation Coordinator—Recreation Inclusion and Your Special Needs Child

Kelsie Williamson, Advocate with ARC—Advocating for your Special Needs Child

Officer Liam Duggan, Burnsville Police Department—Keeping you're Child Safe

SCHEDULE (times are approximate and subject to change)

Thursday, July 26, 2007

Registration 5—11 PM

Welcome Reception — 5—7 PM

New Family Orientation — 7—9 PM

Sibling Mixer — 7—8 PM

Hospitality Suite Open — 7—11 PM

Friday, July 27, 2007

Child Care Registration 7:30—9:00 AM

Registration 8—9 AM

Opening Session 9—9:30 AM

Breakout Sessions 9:30 AM —12:30 PM

Friday Fun Event—including lunch 12:30—3 PM

Grandparents Session—4—6 PM

Dinner on your own

Board of Director's meeting 8—10 PM

Hospitality Suite Open—7—11 PM

Saturday, July 28, 2007

Child Care Registration 7:30—9:00 AM

Registration 8—9 AM

Opening Session 9—9:30 AM

Morning Breakouts 9:30 AM—12:30 PM

Sibling outing 9:00 AM—5:00 PM

Lunch on your own

Afternoon Parent Panels—2:00—5:00 PM

Dinner, Dance, Photos, Raffles, General meeting — 6:30—11:00 PM

Hospitality Suite Open— 8:30—11:00 PM

Sunday, July 29, 2007

No Childcare on Sundays

Closing Session—10—11:30 AM

SEE YOU IN NORFOLK, VIRGINIA IN 2008

THANK YOU TO ALL OUR 2007 DONORS

Many thanks to the 2007 Conference Committee for their many hours in planning and preparing the upcoming conference. In particular the numerous donations that they have received from their families, friends and businesses — these are in addition to the donations listed in the March 2007 newsletter. Because of the additional earmarked donations there will now be a Continental Breakfast made possible by the Vaden family; and the Welcome Reception made possible by the Jensen family.

Richard Morris
 Michael Nelson
 Dorothy Harchanko
 Steve & Katherine Jensen
 Steven Rothmeier
 Edward Monser
 Randy Seaver
 Alice Peterson
 Philip Rogers
 Kraig Grivette
 Marty Anderson
 James Pierce
 Robyn Jagler
 Ronald Schomber
 Bert Neagbour
 Richard Dunstan
 Donald Grivette
 Janet Weber
 Robert & Cathy Vaden
 Heather Bui
 The Rosenberger Family
 Carol Schaffer
 Virginia Hopkins
 Kathleen Burns
 Lori Weaver
 Mariette DeMorett
 Greg & Laurel Abbruzzese
 Albert Starshak
 Judith Kopenen
 Laura Ventrella
 Pamela Amundson
 Christopher Weber
 Jackson Parish Therapy Center
 Warren Weber
 The Latawiec Family
 St. Agnes High School
 Independent Radiation Therapists of Florida
 Marta Nunez
 Plant Sale proceeds from Bethel Lutheran Church
 Med City Chapter of Thrivent Financial for Lutherans

Over \$30,000.00 has been raised to help offset the conference expenses.

Our Grandparents have begun their own fundraising campaign called Grandparent's Angel Fund. The fund is to be used by the 5p- Society to assist in all areas of need. The biggest need right now of the 5p- Society is getting new brochures made and hopefully being able to get those in Spanish as well as English.

So far the 5p- Society has received over \$2500.00 from the fund. Donors are Grandparents, friends and families of the 5p- Society. We'd like to thank all those who have participated in this endeavor. If you are interested in donating to the Grandparent's Angel Fund, please contact Gloria Griffin (Grandparent of Landen Griffin) at flyinggigi@insightbb.com or by calling her at (502) 895-9279

Dorothy Galatz
 Cecilia Preston
 Deborah Wolflok
 Dorothy Wade
 Teara Osterhage
 Denise Tonini
 Gloria Griffin
 Dale & Joann Huffman
 Eileen & Peter Abbruzzese
 Ann & Donald Fluer
 Patrick O'Shea
 Ruth & Ed Germscheid
 Rita & Frank Torre
 Jane & Robert Willock
 Annette & Robert Becker
 Lucy & Dale Shampoo
 Pat & Arthur Strong
 Lynn & Judith Larson
 Joanne Boel

Check out your local WalMart for a donation to the 5p- Society.

Many thanks to Georgia Richey for letting us know that individual WalMart stores will donate to various charities \$500.00. We've already received three \$500.00 donations from different WalMarts. If you'd like to assist with fundraising this would be an easy and great way to help. Contact Georgia at Georgia@richey.cc for more information.

Picture Gallery – send your favorite pictures in



Allan Dawson's 17th Birthday doing what he loves most . . . Watching sports, especially the Angels



Beautiful Girl – 4-year-old Angela Sweazy

Welcome to Holland

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never go away... because the loss of that dream is a very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

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2007 ANNUAL CONFERENCE AND GET TOGETHER MINNEAPOLIS, MINNESOTA July 26—29

Registration form

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

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

Non-Members—Registration fee \$200.00 USD (two adults and two children) _____

Each Additional Adult—\$50.00 USD each (banquet cost) _____

Each Additional Child—\$25.00USD each (banquet cost) _____

No, I am unable to attend, please accept my donation to help offset the cost of the conference _____

Total Enclosed _____

Name _____ Phone Number _____

Address _____ Email Address _____

City, State, Zip _____

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

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

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

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

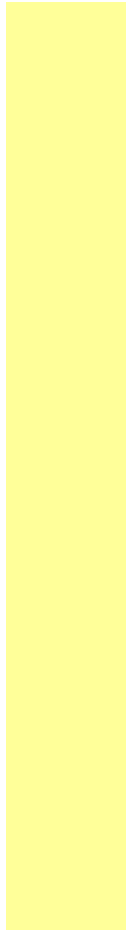
Will you be needing a high chair for the banquet? Y/N

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



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

Return Service Requested



T-SHIRT ORDERS

Pre-order your 2007 conference t-shirts. Order before July 1 to guarantee your shirt size. Volunteers of the 5p-Society, including Board Members, Conference Committee members, Welcome Committee and child care volunteers will have a different color t-shirt. Please indicate your size and color below. T-shirts are \$10.00 each. If you want to order them and have them shipped to you please add \$5.00 shipping fee (for up to 5 shirts). Please call the office if you want to have more than 5 shirts shipped.

	White	Volunteer
YS	_____	_____
YM	_____	_____
YL	_____	_____
AS	_____	_____
AM	_____	_____
AL	_____	_____
AXL	_____	_____
AXXL	_____	_____

No. of Shirts _____ x \$10.00 = _____
Shipping fee (if any): _____ Total Amount enclosed _____

Name: _____

Address: _____

Phone Number: _____

Paid by ___ check ___ credit card Visa/Mastercard (please circle)

Card # _____