



NEWS

The Family Support Group for Children with Cri du Chat Syndrome

December 2003

President's Message

by Greg Abbruzzese

Hello again everyone. I hope you all had a healthy and happy Thanksgiving! As the August 5th-8th Philadelphia conference draws closer, we are gradually getting everything pulled together. Holly Gattone is doing an excellent job coordinating events and soliciting help from area families. The majority of the speakers are all lined up to mirror what was reviewed at the Memphis conference. We are excited about the prospects of learning more about Estate Planning/Family Trusts, Independent Living for adults, Physical/Speech Therapy, and Early Intervention. In addition, we are looking to have the same style game room that we had at the previous conference. Hopefully, we can get drug companies to donate some toys or sponsor the space. On the T-shirt front, Tracy Copeland has graciously volunteered to donate T-shirts again for the conference. Thank you Tracy! We are still working on group passes at a reduced rate to Sesame Place (roughly 20-25 min. away from the Adams Mark Hotel), along with a list of hot attractions in the Philadelphia area.

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5p- Society Calendars

2004 Calendars are still available from the 5p- Society office. They are \$10.00 each and the Society receives the full amount for each one sold.

Sponsors and pictures for 2005 Calendars are now being taken. Please contact the 5p- Society for more information.

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.

President Greg Abbruzzese Executive Director Laura Castillo
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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.

Family Sponsored Events

The 5p- Society would like to thank the many families who have dedicated themselves to the 5p- Society by sponsoring events that increase awareness about the syndrome.

The 5p- Society gets a new laptop computer thanks to the fundraising efforts of grandparent Gloria Griffin's jewelry sales. Over \$5,000.00 has been raised. The new laptop replaces an old and out of memory one purchased in 1997. THANK YOU VERY MUCH GLORIA!

Halloween Benefit brings in \$2,155.00. Matt and Sheryl Klebenow and several other families from Yorkville, Illinois area held a Halloween Benefit for the 5p- Society. A fun time was had by all who attended.



A couple of cute "Characters"

(L to R) Ryan Kiersh, Anna Herposheimer and Sydney Klebenow

A VERY BIG thank you goes out to all the members of the 5p- Society who made their annual donation in December. Over \$3000.00 was received.

We've had a remarkable year with such wonderful members contributing to the Society to assist in their mission and also to the many volunteers that give their many hours throughout the year.

THANK YOU AND MAY YOUR HOLIDAYS BE MERRY AND THE NEW YEAR FILL YOU WITH JOY AND HAPPINESS

Laura Castillo, Executive Director

Life Jackets-Adapted PFD-A

If you're looking for a life jacket for your child/adult with Cri du Chat, this company has come highly recommended. Life Jackets-Adapted PFD-A is a North American company which specializes in life jackets for people with physical disabilities. They provide outstanding stability (resists involuntary reflexes and uncontrollable movements) and, through their unique design, help maintain the face completely out of water. To find out more about the life jackets please visit them online at <http://www.pfd-a.com/index.html#lifejackets> or you can email the representative at danl@pfd-a.com.

Parent Panels

In response to our request in the recent newsletter, some of our parents are informing us of their willingness to be of assistance by notifying us of their expertise. Sheryl Klebenow has a 4 1/2 year old daughter Sydney with CDCS Sheryl is an occupational therapist. She is willing to help on the parent panel. Her phone number is (630)553-7330 and her email address is msklebenow@msn.com.

Dr. Rick Rothwell has been a past president of the society and he has a 22-year-old daughter with Cri du Chat syndrome. He is a dentist and is willing to serve on a parent panel for questions regarding dental care. His number is (215) 233-3503, and his email is rrothwell@comcast.net.

Also, Linda Karr O'Connor has indicated a willingness to help on a parent panel. She is an expert in implementing PECS. She has worked with her non-verbal daughter with Cri du Chat Syndrome, Siobhan, for six years. Her phone number is (310) 399-1443. Her email is oconnor@law.ucla.edu.

We appreciate each one who is willing to help. We know that there are many more with the desire and ability to help our children. Please do not hesitate to email me at Georgia@richey.cc. I am currently compiling a list of individuals who would be willing to help in any way possible. Living with a child with Cri du Chat makes each one of you an expert!! Thank you so much,

Georgia Richey

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President's Message

We are in the process of contacting several pharmaceutical companies, along with Toy manufacturers to see if they would like to help defray the cost of the conference. In addition, we have been sending out several of Renee's fundraising DVDs to various organizations in the area soliciting funding as well. Hopefully we will hear something before the New Year.

In early February the Board will be visiting the St. Louis area to secure a location for the 2005 conference. The Renee & Joe Eickmeier are hosting the 2005 conference and we look forward to giving everyone an update on our tour of St. Louis. If there are any families in the area that would like to help Renee, please contact any of the Board members and we will put you directly in touch with Renee.

Looking ahead to 2006, we are targeting the West Coast. We have narrowed the choices to Northern California, Nevada and possibly Colorado.

I hope everyone has a happy and healthy holiday season and New Year!

--Greg

If there are any West Coast families interested in hosting a conference in 2006 please contact Laura at 888-970-0777. Thanks.

Philly 2004 -- August 5-8 -- Adams Mark Hotel -- Philadelphia, Pennsylvania

Our slate of speakers is almost set and we'd like to share with you who we have scheduled and what types of topics we have so you can start preparing your vacation/trip to Philadelphia. We are very excited to have an array of speakers and topics that should appeal to most of our members.

Special Education

Early Intervention and IFSP

Deb Daulton, Training Director
Pennsylvania Early Intervention Services

IDEA and the IEP and Transition from School to Adulthood

Wanda Poole, Director
Advocacy and Family Services
The ARC of Philadelphia

Dionne Beaman, Associate Director
In-Home and Community Services
Philadelphia Developmental Disabilities Corporation

Skill Building

Positive Behavior Strategies

AmySue Reilly, PhD
Associate Professor
Department of Rehabilitation and Special Education
Auburn University

Oral-Motor Therapy Techniques

Sara Rosenfeld-Johnson
Innovative Therapies International

Augmentative and Alternative Communication

Cynthia Cohen, MS, CCC-SLP
Edward Mysack Speech, Language and Hearing Center
Columbia University

Introduction to Sign Language

Laurel Daniels Abbruzzese, MSPT, EdM
Parent

Sensory Integration Strategies

Jennifer Rosinia, Med, OTR/L
Kid Links Unlimited, Inc.

Life Plans

Family Trust/Guardianship/Estate Planning

Maria Smith
The Family Trust, ACHIEVA

Housing for Individuals with Disabilities

Barbara Prince, Housing Program Manager
Liberty Resources

Ed Cohle/Patty Scott
Self Determination Housing Project

Understanding Medicaid/SSI/SSDI

Julia Grant Barol, Benefits Specialist
Transition to Employment Program
Pennsylvania Protection Advocacy

Dental Care Issues for Individuals with 5p- Syndrome

Dr. Angela Stout
(associate of Dr. Rick Rothwell)

Self Determination and Person Centered Planning

Bonnie Miller, Coordinator
Pennsylvania Self Determination Consumer & Family Group

CDCS BASICS

CDCS 101 and Research Update

Dennis Campbell, PhD
Associate Professor, Department of Special Education
Arkansas State University
Parent

Grandparent Discussion Group

Art & Pat Strong, Grandparents
Millie Wiegand, Grandparent

Sibling Workshop and Sibling Mixer

Parent Break-out Groups

*** We'd really like to have a Father's Workshop. If anyone knows of a contact for this please contact Laurel Abbruzzese at (201)287-1569 or ldabbruzz@aol.com.

There is also the possibility of Kim Cornish, PhD coming to our conference to discuss her latest study on Adults with Cri du Chat Syndrome.

We will be updating the schedule in the next newsletter. The registration form will also be in the next newsletter. Scholarships will be available for the Philly 2004 conference. Please contact the 5p- Society for more information.

Return Service Requested



Professional Advisory Board News

Dennis Campbell, PhD, Chairman of our Professional Advisory Board has prepared along with his colleagues and with the support of both the Professional Advisory Board and the Board of Directors an online journal that will be added to our current website at www.fivepminus.org. Check for periodic updates. Dr. Campbell along with AmySue Reilly, PhD. will be presenting some of their data regarding their study on Cri du Chat Syndrome that was done at the Memphis 2003 conference, at the end of February in San Diego, California.

Antonie Kline, MD, one of our current Professional Advisory Board members will be presenting information on Cri du Chat Syndrome at the World Congress on Chromosome Abnormalities conference, to be held June 27-30 in San Antonio, Texas. For more info please go to www.chromosome18.org/worldcongress

Dr. Kim Cornish of the United Kingdom Cri du Chat Syndrome Support Group is interested in doing research on Adults with Cri du Chat Syndrome. The 5p- Society will be sending letters to all families who have an adult with the syndrome. It would be the goal of the Society to see 90% of you participate in this study. The information gathered could be beneficial to all of us. Dr. Cornish is planning on presenting some of her material to the members of the Society at the Philly 2004 conference. Dr. Cornish has recently relocated to Canada and is very interested in becoming a member of the 5p- Society's Professional Advisory Board.