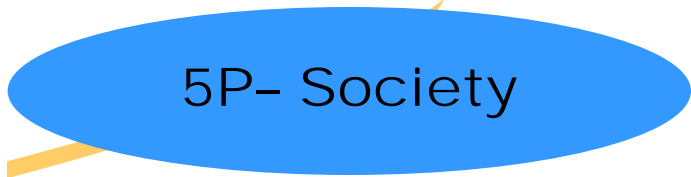


5P- News



5P- Society

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Summer 2008

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

Volume 23, Issue 3

President's Message—Jolene Towers

Dear Friends,

Once again, it's time to send out the newsletter; and once again, the challenge of penning a coherent "President's Message" rears its ugly head. No, it's not really that bad, but it is a bit daunting thinking about all of the families out there, each with its own divergent needs, desires, and experiences. Still, there is one thing that ties all of us together – the fact that each one of our families is touched in some way by some very unique and amazing individuals who enrich our lives through their innocence and exuberance. Yes, there are many challenges with having a 5P- family member, but if we look closely, there are also many rewards.

Our family, recently reunited following Geoff's tour

in Afghanistan, took a bit of a vacation, driving south to Florida. On the way, we were able to see our good friends, the Vadens, and took advantage of their hospitality for a day. These are people we would not have known, friends we would not have made, save for Taylor; and we're truly blessed to have them in our lives. Even better, these are not the only friends we have made through our children – indeed, they are too numerous to mention them all by name at this writing. Almost everywhere we go (and we go a lot), it seems we know someone with whom we can share our triumphs and trials, challenges and fears; someone with intimate knowledge of what it's like to have an exceptional family member such as ours, and

with whom we can truly be ourselves.

Such is the nature of the conferences we hold on an annual basis, and I fully anticipate a similar fellowship in Virginia Beach this year. So many people contribute so much – in time, talent and material substance, or simply by their presence. Our host families especially have done a lot of work to make this conference fantastic. Thank you also for all who work so hard to provide monetary support and donations. Your generosity and sheer effort in fundraising continue to ensure that we can provide this event for a nominal fee.

For those who haven't attended a conference, please consider coming. I think you'll find that there is a world of people out there with a unique understanding of YOUR life, and we look forward to meeting you. It was certainly a big step for us to take, coming to our first meeting. Now, this is a highlight of our year. For those who are returning, we look forward to renewing friendships.

See you in Virginia Beach!

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Resources:

- Message board:
http://groups.yahoo.com/group/Cri-Du-Chat_Syndrome/
- Specialty Toys:
<http://www.schoolspecialtyonline.net>
- Advocacy—
www.protectedtomorrows.com
- Fundraising:
www.goodsearch.com

Thank you for the Stories

I'd like to take this opportunity to thank the families that submitted stories for this issue of the 5P- News. I invite all of you to submit stories and pictures. As is the message board, this newsletter is a forum for you to share information, provide opinions and

sometimes to vent.

Welcome to all the new families to the 5p- Society. Thank you for renewing your membership.

Story of Inspiration by Alyssa Galvagni

My inspiration in life is my younger sister, Isabella Gillian. Bella has a mental disability, and she goes through every day with a smile. Before Bella came into my life, I was the type of kid to stare at the people who were “different”, or what I thought to be weird. But having a sister who was one of the “different” people, opened my eyes. I realized that being mentally challenged isn’t weird. I realized that people who are mentally challenged are just like me, except the way their brain develops, and the way they think is slightly different. I figured out that being different isn’t all what people make it out to be.

My hero, Bella boo, goes throughout her life with out a care in the world that she’s different. When people look at people who are mentally disabled, and they see the way they act, that’s all they think about and they judge them on that one aspect. My sister is bubbly, energetic, loving, caring, and happy. She is always concerned about me and my family, and hates to see us physically or mentally hurt. She understands

emotions, and knows when something bad is happening or when something fantastic is happening. She can talk, walk, and feel just like everyone else.

Stinky makes me realize that the problems I face in my life aren’t even a third of what my sister faces, but she still has the biggest smile on her face. She has gone through so much in her life. Even when I get mad that she hits me or pulls my hair, I just calm down and realize she can’t express herself quite as easy as we can.

Whenever I think about my sister, I start to cry because she goes through so much, and tries so hard. It makes me want to become her. That willingness to try everything, that smile that lasts forever, that spunk, that exciting personality, the way of not caring about being the different one. My sister is my hero, my star, my inspiration. This I know to be true:

The twinkling star in my life,
My very own celebrity.
The one I know who would give her life,
For her family.
Bella, Izzy, Bella Boo.
How much I love you.
From your smile to your laugh,
From the way you care so much,
To the way you laugh at anything.
You are my everything.
My sister, my inspiration, my hero, my strength.
My will to do better, my passion for life.
My way out of the rain, my umbrella.
I love you Isabella.



Is your child too big for Lil’ Swimmers? Is there an alternative when your child gets too big? Has anyone found a product to satisfy this need? One parent has contacted Kimberly Clark and voiced her concern about needing larger sized Swimmer Diapers. If you would like to also voice your opinion and hopefully make this happen please call 888.525.8388.

Employer Matching Brochure

Attached to this newsletter is a Matching Brochure for Charities. It lists all the companies that match donations that its employees make. Please look at the list and if your company is listed consider a donation to the 5P– Society. For more information please contact your Human Resources Department. Your friends and families that work for these companies can also donate to the 5p– Society and have their donation matched.

We currently have several families that participate in this program and we are very grateful to them for their continued support of the 5p– Society.

If you get this newsletter electronically and would like a copy of the brochure please send an email to director@fivepminus.org and your name and address and we will get one right out to you.

CONGRATULATIONS TO
BOARD MEMBER AND GRANDPARENT

GLORIA GRIFFIN

GLORIA WAS THE WINNER OF THE
RAFFLE FOR THE NAGS HEAD
RENTAL HOUSE FUNDRAISER FOR
THE 2008 CONFERENCE

To New Families by Charlotte Walleisa

Well, hopefully you found the 5P- Society website. When my son was born in 2003 I only knew that it was called Cri Du Chat Syndrome. The information that Genetics gave us at the hospital was very grave. When you read this 5P- site it is a much more positive experience.

Our special son, David, was diagnosed at birth. He had a high pitched cry like a cat.

I loved hearing his cry, because it was different – I knew it was my baby! The doctors thought it was DiGeorge's syndrome or Cri Du Chat. David's blood was drawn and it was Cri Du Chat. My husband and I were both tested and it was not genetically passed down. What a fluke – but you just have to deal with the cards that were drawn for you. Please look at it as a positive experience – that God chose you and your husband to take care of a special child. The Lord knew that only you could take care of that child. Yes, you will cry a lot and ask, "WHY?", but there is a purpose for everything.

David was born 2 weeks premature at 6 lbs. and 3.2 oz., and he had 2 holes in his heart. He had a PDA hole and a VSD hole. From 6-14-03 to 7-10-03 our lives were completely turned around. I wanted my baby next to me like all the other mothers in the maternity ward. No, I had to go to a special room where my child is in an incubator. I was only allowed to hold him for a certain amount of time. I was all prepared to breast feed him, but due to his small chin he was not able to. Then he was wisked away to another hospital. They didn't even allow me to ride in the ambulance with him. My heart was so torn and the hospital never gave a straight answer as to why I was not allowed to go with him. I had to wait patiently for my husband because you are not allowed to drive after giving birth. He went to a hospital where I couldn't sleep there with my child. I had

to rely on friends and family to take me to the hospital because my husband had to go back to work and could only visit at night. I have to admit I didn't follow the doctor's instructions about no driving – I felt like I was starting to annoy people for rides to a hospital that was 45 minutes away. Thank God the price of gas wasn't as high as it is now!

Did this happen to you? Is your mind reliving your past experiences while reading this?



David was in this second hospital hoping that the PDA hole would close by itself. It did not – so they finally sent him home with us. Life seemed more normal then. Ah, the baby was home safe in our arms. We were in a normal routine with our baby. Then David had labored breathing and he had to go back to the hospital 9-6-03 to 10-3-03.

This is when genetics got involved – gave us all the information that they had on Cri Du Chat – and stated, "We don't recommend surgery due to the quality and quantity of life for David." Wow – we both rode home sobbing our eyes out! I am 40 years old – this may be my only baby I screamed to myself. As fate would have it – I was diagnosed with cervical cancer and had to have a complete hysterectomy. I had to live to take care of my child for the rest of my life. Therefore, David is my one and only. My husband has two children from a previous

marriage, so at least David has older brothers. Sorry, I got a little side tracked!

Of course there was no choice in our eyes – yes doctors – please do the surgery and save our son's life.

He had to gain weight in order to have surgery. They were going to close the PDA hole with sutures and the VSD hole with an Amplatzer device. This device was used in Europe, but had not been approved yet in the United States.

We had to wait three weeks for the Amplatzer device to be approved and shipped over from Europe. He had the most wonderful heart doctor and had the surgery at CHOP hospital in Philadelphia. Yeah – one of the most respected hospitals in the East Coast for children. I was able to stay at the hospital in the same room. Of course they had a great cafeteria where I ate all my stress away and gained 20 lbs. Now who was suppose to gain weight – oh yes, David, not me! Oooooops!

We are so glad that we decided to have the heart surgery. Yes, David requires a lot of hard work, but he is such a loving child. We try not to think about the future at this moment. This is too hard to deal with mentally. Yes, the hard facts about what will happen to him in the future when we are gone nags on our minds, but we can't dwell on this fact.

The best thing CHOP Hospital hooked us up with is a social worker. She gave us all the information about Early Intervention. We feel that this is the best thing we ever did. With the help of Early Intervention and a lot of repetition and hard work, he rolled over at the age of 8 months. He sat unsupported at the age of 19 months. He crawled at the age of 20 months. He pulled to stand at the age of 19 months. He walked around the furniture at the age of 21 months. Now there was a great delay, and at the age of 4 ½ years, he just started to take 10 – 12 steps independently. He is at the stage of – should I crawl or walk to that destination?

Now parents please pay attention. Do not assume that your child is mentally challenged and can't learn. Yes, they are mentally challenged, but they can learn. I always am a very descriptive person and I say, "that is the yellow bus or that is green grass." He must have been paying attention to the descriptions and understanding. When he was at Easter Seals, they asked me if I knew David knew his colors. I was so surprised and said "No!" They would ask where all the colors were in a book. He would point to the correct color 80 to 90 percent of the time. Wow, I was so excited! I never thought he could do something like this.

The genetic doctors told me that David's fifth chromosome, in which the majority of the short arm of this chromosome has been deleted, is missing in all the cells examined. The doctors told me it would be severe mental retardation. I thought there would be no chance of him actually learning. He proved them wrong and so can your child. You are now your child's teacher and advocate. It is a lot of paperwork - always filling out papers and IEP meetings and SETT meetings. I think the hardest thing is filling out the paperwork every year to get qualified for assis-

tance. I have to relive all the events in David's life in my mind. I actually put it on the table and send it in at the last moment when it is due. Now mentally you may be able to handle it better than I do. I cry at the drop of a hat and filling out this paperwork uses a lot of tissues.

I just started to go back to work part-time after almost 5 years. You have a full-time job with your child. That child has to come first if you want them to have a more "normal" life in the future! Now I am not saying that you shouldn't go back to work right away! If you can afford living on one person's salary - then be there for your child. We were very lucky to have most of David's clothes passed down to him and family that would buy him interactive toys. We would only buy something if it was on clearance or at the flea market. The Lord is good and has supplied all our needs!

The State has been wonderful paying for diapers, doctor's visits, a wheelchair. I certainly need this just to keep him seated while filling out paperwork or else he would crawl and knock over a plant or pull down the mini blinds in the office. You have to have four eyes and eight arms just to watch him.

With this syndrome, Cri Du Chat, children have a tendency to head bang and self-mutilation. He is just starting to

head bang, but only for attention or to get his way. He has not started self mutilation, but he pulls and chews on his clothes. There is no hope to pass down his clothes anymore. I have given up the fact that the new jacket will be new for only a few hours and then ruined. He has to always chew. The doctor who I used to work for gave me his used leather couch. I thought that would be wonderful because I could just wipe it down. Well, David loves it too! He loves to bite it and get the leather in his mouth. All along the trim there

are teeth marks and holes in the leather.

David also loves books! He loves to look at the pictures, but he also likes to destroy, pull, and tear the pages. He definitely needs hand over hand assistance with books if you want them to last more than a day!

David doesn't understand the word no. If you tell him, "No!", then he does it even more. We have to redirect him and get him interested in something else. That is why it is so hard to go to a friend's house. They have not certainly David proofed the house and put away all the knick knacks. I would just be chasing after him and saying, "No David". I know this is great exercise, but it is very wearing on the nerves. I can't even have a normal conversation. I would get interrupted many times and wonder where I left off. That is why I keep in touch with friends on the phone and David in his David proofed room with gates so he can't get out. If he didn't have this room, I would go nuts. I wouldn't be able to get anything done. I have to watch him at all times. Thank God for his favorite program, "Jay Jay The Jet Plane!". I can put this on and at least do my laundry downstairs in the basement.

These are just some experiences that I thought I would share and let you know you are not alone. That, yes, these things may happen to your child. I am literally shaking and cold writing this information on paper as I relive the past experiences. I would love you to learn from my trials and failures. Please, I implore you to love and teach your child all you know. You will then feel blessed knowing you did your best! Your child is capable of loving and needing you. David has said DaDa for awhile, but just the Christmas of 07 David said MaMa. Oh, what joy to hear it! He can also say "Eat" and everything else is "Ba". He knows many signs also. If David can do it, then your child can too!

God bless and take care of your special "gem"!



Allow Me to Introduce My Son, Kevin Vaughn Jedi by Sherri Coulter

Allow me to introduce MY Kevin. On the day of his birth, snow skirted cross the roadway, dancing, twirling with the wind. Small whirlwinds full of power, gaining momentum, then being released only to begin again, to start anew. On this day he came, fully, completely, young and old at the same time, forever waiting to get on with it, but waiting patiently for someone to ask the right question. He always has the answers. He entered the world as a preemie when Medical Technology was just beginning to save those tiniest ones. He was to be named Kevin Vaughn Coulter. Kevin meaning "gentle" and "loving", Vaughn meaning "small" and "bold". At the age of three he was diagnosed with Cri-du-chat syndrome, better known now as 5pminus syndrome-he is missing a portion of his fifth chromosome. They told me he would never walk, never talk, or be able to care for himself.

Also at the age of three he discovered "guns", and claimed to be a soldier. He has never backed down from that claim. He claims to be a Jedi Knight (hopefully not the last of his kind). He has proven this claim to the many who know him. A guy who definitely knows what he likes-has a passion for old war movies and of General Patton he says, "that guy cusses really really good". He knows what he doesn't like. A few weeks back I turned off the sixth street viaduct into the alley behind Lopez Restraunt, his arms flew into the air and he screamed "you stupid ho---AND I SAID, "so now your're calling me names?" He laughed and said "no mom, not you, that ho back there, that stupid pot ho.!" He has been complaining about the condition of "our" streets since he let me "off the hook over the trains." A couple of years now! When he graduated from High School, he told me that he knew "his life work was to have a toy store and take care of babies." For the past few years he has been selling toys on EBAY (toys he collected from the age of five when he started walking) and he takes care of babies whenever and however possible. He tells me "I am the Master of my Ship" on a regular basis, least I forget, and on a daily basis he begs me to "leave him alone and quit messin' with him"-meaning, I don't have time for this hygiene stuff -I have a war to fight. That would be STAR WARS BATTLEFRONT II-(PSII). TALK ABOUT PAS-

SION. Between flight missions and head shots the only things he asks is that I supply his energy source-Oreo cookies. I believe he was a soldier before he came, he will be a soldier when he returns-and he chose his destiny in the form of a developmentally disabled (so say we) person to complete the blessings (his life work) that he is to bestow upon this world, as each we do, in our own way.

I am honored that he chose me as HIS mother, I do not/have not always do/done him justice in our years together, but I am committed to do my best with everyday that I am still given the opportunity to do so. He is a blast and believes WARP SPEED is the only way to go! One day coming home from Leavenworth he looked at me so seriously and asked, "Are you engaged?" He pushed the "wrong" button because my reply was, "YES, I AM ENGAGED, I'M DOING 75 WARPS IN A 65 WARP ZONE AND IF THAT'S NOT FAST ENOUGH FOR YOU, YOU NEED TO FIND YOURSELF ANOTHER MODE OF TRANSPORTATION!" He reached across the vehicle and rested his hand on my shoulder and said "calm down, no.1, SSHEESH!" This is MY Kevin-the same who (when seeing the little crosses at Benedictine Grade School representing babies deaths due to abortion) said as we drove by, "Oh, somebody's having a party, or something." When I explained their purpose he rolled down his window and screamed with so much passion it shook me to my core, "you stupid women, you stupid Doctors." When he was 12 he was watching Gilligan's Island-that great Hamlet scene--he turned to me and said, "hey, mom, to be or not to be, that is the question, what does that mean?" In many such moments as this I am humbled, feel small and so developmentally disabled. At this time the school was telling me he functioned at a three year level-right-so I answered wrong-my answer was more in line with the schools level but then some. Still, no Doctor or Psychologist would ever believe me unless they heard it themselves. Unfortunately, it took me several years and the help of a magazine featur-

ing Christopher Reeve and Stem Cell Research to do it right. We sat on his bed and I told him what the article was about and when I was through I said "so, maybe now you can answer that question you asked me once, to be or not to be." He sighed so heavy and said "it is better to be than not to be, always, but IF (one of his favorite words) we cannot be it is better to help superman fly." We were both crushed when he passed away. IF. If I had listened to the diagnosis and believed that to be so, would it have been so? Or is it that I chose not to believe and so it was not? One day when I was frustrated at his incessant if's about the girl of his dreams, I snapped and said rudely to say the least, "I don't know Kevin, they say IF is the biggest word in the dictionary" to which he replied without skipping a beat, "what about 'or'?" At these times I feel the hand of my GOD gently slap my cheek and I hear his voice, "so what do you think of that?" That's my Kevin, forever showing me another perspective.

Continued on page 6



Kevin and his favorite past time

The following poem hangs in the Orthopedic Clinic of CMH along with a picture of Kevin as JEDI

A JEDI KNIGHT

A JEDI KNIGHT I WAS BORN TO BE
HONOR AND COURAGE WERE GIVEN TO ME
I STRIVE TO BE STRONG, TO LIVE LONG.....I HAVE MUCH TO GIVE
TO THIS WORLD I BELONG
A JEDI KNIGHT ON A JOURNEY NEVER ENDING
PEACE AND LOVE ARE THE MESSAGES I'M SENDING.
HOLD FAST THE DREAMS OF YOUR HEART
LIVE LIFE TO THE FULLEST
RIGHT FROM THE START
A JEDI KNIGHT I WILL ALWAYS BE
BOTH GOOD AND EVIL INSIDE OF ME
A DAILY STRUGGLE TO DO MY BEST
UNTIL THE DAY I FOREVER REST.

Now approaching 28 years, I have witnessed the ebb and flow of his momentum, skirting through my world as the snow on the day he came. When he is released from his dancing, I pray that I be strong, to let him twirl away, to begin again, to start anew. But my road on which I have been led has not ended, so I continue on, celebrating life, his life, and I anticipate crossing many more bridges.

I thank you for letting me take this opportunity to share who Kevin is and a very small part of what he's all about.

Conference Update

It's not too late to register for the conference. We will accept registration forms at the conference. If you have any questions please email Laura Castillo, Executive Director at director@fivepminus.org. Here is the update to our speakers and topics:

Cri du Chat 101—Dr. Dennis Campbell, Southern Alabama University
Planning for the Future and Transition—Mary Ann Elhert, Protected Tomorrows
Effective Communication—LaVerne Johnson
Reflux—Michael Konikoff, MD
Sleep Disorders—Edmund Cornman, MD
Behavior Applications—Dr. AmySue Reilly, Auburn University
Hippotherapy—Renee Lynn Casaday, specialist
Developmental Profiles of Cri du Chat Syndrome—Dr. Dennis Campbell and Dr. AmySue Reilly

Change to Sibling Outing: The sibling outing will be held at the Oceanbreeze Waterpark in Virginia Beach, Virginia. Transportation, the entry fee and lunch will be provided by the fundraising efforts of the Blount and Zettlemoyer families.



The First Hailey's Haggin Oaks Classic is a Hole in One!!

Held on a breezy and sunny day on May 3rd at Haggin Oaks Golf Course in Sacramento, California we had a triumphant turnout! Rounding out at about 80 golfers for our first swing at hosting such an event, we were needless to say, pleased. Getting there at 6:00 am was a little rough, but once we started selling balloons as mulligans and trying not to lose them to the wind, measuring the height of someone in raffle tickets and getting everyone involved in Par 3 Poker (at every par 3 a golfer who bought in would draw a card, the best hand wins), the rush of the event just continued on throughout the day!

It couldn't have been what it was without all the volunteers, golfers, donated prizes, generous sponsors and the amazing staff at Haggin Oaks! It takes a great group of people to be thoughtful and willing to participate and support the cause toward advocacy and awareness of 5p-; and it looks like we were lucky enough to have that great group of people standing right beside us.

With an ambitious goal of \$3,000-5,000 we actually were able to raise a grand total of \$8,400! To everyone who even donated a dollar, we are equally grateful. It was an absolute blessing to be able to put the time and energy into this golf tournament and be able to give something back to the society which we all have valued tremendously over the years. We have higher hopes for next year, especially with all the support we have been given and people telling us they would do it again next weekend! Our mission was to give back and we think this should be inspiration to anyone else out there who has never planned something like this but wants to make a difference. From our family to yours, you can do it! Get out there and try something like this! As we like to say, keep swinging!

With mountains of gratitude and all sincerity,
Todd, Kaila and Hailey



Thank you to our sponsors:

Sierra Printing and Office Supply
Empress Events
Smith Moore & Associates
Signature Reprographics
Digital Ink
CCPOA
Mindful Meetings
Robertson Ranches
The Gift Basket Stop
City Bicycle Works

To All Those Who Participated,
Thank you!!!!

KEEP SWINGING—Thank You, Love Hailey

5P- Society

PO Box 268
Lakewood, CA 90714-0268

Return Service Requested

We're on the web, visit us
at www.fivepminus.org

Conference T-Shirts

Last Chance to Pre-order your conference T-shirts. Design is shown to the right. Attendees t-shirts will be in a Jade color and the volunteer t-shirts will be in Natural.

	Attendees	Volunteers
	Qty	Qty
YS	_____	_____
YM	_____	_____
YL	_____	_____
AS	_____	_____
AM	_____	_____
AL	_____	_____
AXL	_____	_____
AXXL	_____	_____

Name: _____

Address: _____

Phone #: _____

Email: _____

Total # of T-shirts ordered: _____

X \$10 each: _____

Shipping fee (if not

Attending conference) \$5 _____

Shirts will be available for pickup at the conference.

Preorder deadline is 7/1/2008; shirts will be available for purchase at the conference in small quantities.



July 31 - August 3, 2008