

The Joubert Syndrome Foundation & Related Cerebellar Disorders is an international network of parents who share knowledge, experience and emotional support. The group offers a networking list, newsletter and a biennial conference. The Joubert Syndrome Foundation & Related Cerebellar Disorders plays an important role in educating physicians and their support team and in increasing public awareness.
www.joubertsyndrome.org

The RAINBOW

Volume 18, Issue 3

Summer 2009

July, August, September

Past President's Letter

Dear Friends:

All good things must come to an end. Summer is almost over. Some kids are already back to school and some will be back in school shortly... The 2009 JSF & RCD conference was a huge success - it seems to have ended too quickly... Many board member terms are over and my term as JSF & RCD President and Board Member is over as well!

On behalf of the JSF & RCD I would like to thank each of you; the outgoing officer (Treasurer) and board members, many who have served the Foundation for years:

Janet Gundling (Treasurer) Era Hall Luise Reading Eric Rosenthal Alison Ender William Hine

Your hard work and dedication to the Foundation over the years is greatly appreciated. The Foundation could not have moved forward without your help.

It takes team work and dedication to make the Foundation go. And with that I am very proud to announce the JSF & RCD new Officers and Board of Directors for the years 2009 – 2011. You may recognize a few names who were previously part of the board, and have returned to serve the Foundation.

JSF & RCD Officers

Karen Tompkins – President Nadine Phillips – Vice President Jonathan Morgan – Treasurer Kelly Seymour – Secretary

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This is an amazing group of people that have many talents that will benefit the Foundation. They will be working together and will continue moving the JSF&RCD forward.

The 2009 JSF & RCD Conference this past July was a HUGE success. For some it was their first conference; for others, it was another chance to get together with friends they'd met at prior conferences. We certainly hope that everyone enjoyed their experiences with such great families from all over the world.

There were 61 families that attended the conference. Some traveled from countries as far as The Netherlands, Australia, India and Canada.

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The RAINBOW

The Joubert Syndrome
Foundation &
Related Cerebellar Disorders

www.joubertsyndrome.org

Regular Features

Can You Help? Helpful Hints

An opportunity for parents to share problems that other parents can respond to by sharing solutions. Send Q & A to newsletter editor to share with members.

Family Updates -

A way to keep in touch with each other. Send pictures & news of development or therapies that help to the newsletter editor.

Getting To Know You -

Family introductions and biographies of children. Send articles and pictures to the newsletter editor.

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Scientific Advisory Board →→→→→→→→→→

(Continued from page 1) Letter from Michele Abdulaziz

I wanted to once again thank the 2009 Conference Committee for all of their hard work and dedication in putting together the conference. Thanks to their hard work and determination, they succeeded in cutting costs well over 50% from the last conference!

For those of you who were not able to join us in Ohio for the conference, here is a brief summary of the daily events from the conference:

Wednesday: The conference started off with a Q & A from the clinicians/researchers/presenters who were at the conference: Dr. Heller, Dr. Gunay, Dr. Parisi, Dr. Glass, Dr. Doherty, Dana Knutzen, Dr. Boltshauser, Dr. Poretti and Rev. Ben Keckler. This was a great session. Participants were able to ask questions directly to the panel. There were opportunities throughout the week for participants to speak one on one with the clinicians during their individual clinic appointments. The day concluded with a nice dinner, followed by a key note address from Rev. Ben Keckler. Ben was so popular at the Dallas conference, we just had to ask him to return! There was also a brief explanation from Dr. Glass and Dr. Doherty about tissue samples that would be taken during the conference. The tissue samples received were more than we expected.

Thursday: Thursday started off with Dr. Parisi and Dr. Gunay presenting on the new findings of Cilium, and kidney functioning. After their presentations, individual appointments started and went on all day long. The mid-morning workshop was a presentation from Dr. Collop: "Unlocking Sleep Disorders." She provided a good overview of sleep disorders and distributed a questionnaire for research on sleep disorders. Approximately 20 people attended the Grandparent Social that Ruth Ritter (grandmother to Alex Altman) put together. The grandparents discussed the issues and accomplishments of their grandchildren, and how they help their children cope. Everyone had a great time!!! The afternoon started off with Adrian Young speaking about "Financial Planning". The Foundation held a general meeting in which the new board of directors were announced and voted in. There was an afternoon of family entertainment, including clowns performing skits and making animal shaped balloons and far out hats. Everyone joined in the fun. On Thursday evening, a very touching Remembrance Ceremony was held. Karen Tompkins shared some thoughts on the children who have passed away, a poem was read by Judi Reading, and she then handed out stars that she and her mom Luise Reading made. A slide presentation was shown and Cheryl Keckler and Luise led everyone in song. The names of all of our

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(Continued from page 3) Letter from Michele Abdulaziz

stars in heaven were read allowed. Following the ceremony, the Dads went out for a night on the town. This was the first year for a Dad's Night out, which was held at the local Cock n Bull Pub. About 25-30 men joined in on the fun and.....whatever happened in Cincinnati stayed in Cincinnati!!!!

Friday: Medical consultations/clinics continued all day. Karen Harvey began the morning workshops with a behavior presentation on "Issues in People with Intellectual Delays." Karen was well received at the last conference, and was invited back this year. Rev. Ben Keckler conducted a "Sibling Support Group For Siblings Of Individuals with a JSRD." This is an important session for siblings, and was well attended. The Bio Bank was open for blood samples, and we are thankful to all those who donated their blood for research. The Foundation sends out a big thank you to Danielle Dailey, a wonderful nurse from the local Cincinnati Children's Hospital, who performed all the blood draws for the Foundation's Bio Bank. The mid-morning session was a presentation from John McMahan entitled "Determining Functional Vision." John's presentation was fantastic and everyone appreciated all the information he shared with us. In the afternoon Dr. Grant Liu, a JSF&RCD Professional Advisor, conducted a presentation on "Eye Issues Common to JSRD." Everyone was very pleased with the information he presented and learned a lot about what to look for with their children's vision. Dr. Liu made time to meet with individual families after his presentation. This was truly appreciated by everyone who spoke with Dr. Liu. The mid afternoon presentation by Melinda Murphy, "An Introduction to the Feldenkrais Method", was well attended. Melinda demonstrated her techniques with children, using Bella Richard as her adorable patient, and also met with individual families the rest of the afternoon (and on Saturday). The rest of the day and into the night was free time for all. Families spent time together at the hotel pool, going to a Cincinnati Reds game, going out to dinner, playing games, or just mingling in the hotel lobby.

Saturday: Medical consultations continued throughout the day, finishing up by late afternoon. All clinicians made sure that everyone who wanted an appointment got one. There were two morning sessions on Saturday. The first workshop was a Teen/Adult session by Barbara Thomas, M.Ed., C.S.E. JSOC. She presented "Key Words for Teens: Happy, Healthy, and Safe." Many teens and adults with JS, and their parents, attended this wonderful and helpful session. The second session was presented by Marilyn Chadwick: "Key Words for Children: Facilitated Communication." Nate Trainor, an adult with JS, helped out with the demonstration. It was a very good presentation enjoyed by many. Following Ms. Chadwick's presentation, everyone was encouraged to try out the equipment that was demonstrated during the presentation. Some parents were amazed that their child communicate for the very first time. They asked a question and the child answered and they also asked the child his name, and he knew it. It was AMAZING!!! The afternoon was free time for all. Later in the afternoon, the Silent Auction opened. A huge thank you, once again, to Shannon Wilson and all the volunteers who helped put the silent auction together. Shortly thereafter, the closing gala dinner began. A DJ played music, kids sang karaoke and danced, bidding on items took place, families shared email addresses and phone numbers, pictures were taken, and hugs were freely given! The night ended with results of the silent auction, and heartfelt goodbyes were made to new friends and old. Everyone talked about looking forward to getting together again in 2011 in Orlando Florida. We hope to see you all again then!

I wanted to once again thank the 2009 Conference Committee for all their hard work and dedication. As I mentioned before, but it is worth repeating, the committee was able to cut costs by over 50% compared to the last conference. The silent auction brought in over \$3200, JSF & RCD merchandise sales were over \$1600, and conference sponsorships brought in over \$1700. There were many items donated in support of the conference, including all conference binders, lanyards, name tag holders and name tags, hand sanitizers, the embroidered polo shirts that the conference committee members wore, and many other items. I would also like to thank some other people for their contributions to the conference: thank you to the Venezia Family for allowing the Foundation to use their digital video camera to record the workshops, for editing all the digital video, and for putting it on DVD for the Foundation; thank you to the Seymour Family, The Tulumalo Family and the Fieldsted's for helping with the video taping of the workshops; thank you to all those that helped out at the JSF & RCD sales table—including Cheryl Keckler, Coby Tompkins and others (please forgive me if I missed your name and you helped out). This year the foundation had a childcare room available which was stocked full of toys—thank you to those that pitched in to make sure that the room was cleaned up every night. THANK YOU to everyone that helped make this conference such a success!!!

I mentioned above that my term as President (1 ½ years), Vice President (10 years) and Board Member (13 years) are over. It has been such a great and rewarding 13 plus years seeing the Foundation grow and educate families. I had the pleasure of meeting and working with really fabulous people. The best part was meeting all of you—our families! Many children have grown into wonderful adults and many are just starting the journey. I look forward to watching them grow and accomplish many things. The new Board has asked me to work alongside them as Past President. I am honored that they have asked, and I look forward to working with them. Remember, I am always here for you.

Your friend,

Michele Abdulaziz

Past President

Notes From Karen Tompkins and Nadine Philips

Conferences are so energizing! Meeting new families, catching up on news with old friends, seeing our children grow and play together: it is such a fabulous time of renewal. August is a bit difficult as the weight of reality (and school preparations) comes back to sit on the shoulders of parents. Try to remember the hugs and laughter from "our lobby" to help you through:) If you have never had the opportunity to attend a conference, we urge you to begin preparations now for the 2011 Conference to be held in Orlando FL. The tentative dates are July 13-16th with a focus on enhancing daily living for people with JSRDs.

The day after the closing of the conference dawned with an early morning meeting for the new Board of Directors. Fifteen people have volunteered to steer our Foundation into the next decade. You can read the minutes of that meeting in this newsletter. This is a very exciting time for us as leaders: the energy and experience from the Board Members is sure to capture the attention of monetary donors. We have all pledged to be a Board which is transparent in its efforts to serve the membership. Each of us feels the moral and fiscal responsibility of our position and we promise to do all we can to "grow the Foundation".

The work of the Foundation is based in communication and monetary need. In order for your Board of Directors to attain the goals the membership set out for us at the General Meeting held on July 16, 2009, we need more volunteers to be on the committees. If you have a few hours a month (or even a few hours ONE month) to assist in a specific project, please contact a Board Member listed in this newsletter. If you are not sure where you can help, contact Karen or Nadine and we will help you choose a project "just right" for your time and talents.

As always, this Foundation is about YOU and your family. In the next few months, the Board will be developing tools for you to utilize when talking to the press or for organizing a local fundraiser. Also, in the New Year, we will be updating information to share with your doctors and therapists. Look for these documents on the website.

Wishing you peace and strength!

Karen and Nadine

"The Key To The Future"

Joubert Syndrome Foundation Conference
Closing Remarks: July 18, 2009
The Rev. Ben Keckler

**"If I were to tell the world one thing,
I'd tell the world not to feel sorry for me and not to feel sorry for my sister.
I am happy becoming the person I want to become
And she is happy becoming the person she wants to become.
And you should be happy that each of us are doing that.
So, celebrate living with each of us – that's what we're supposed to do!"**

*Meglyn Ricker!
13 years old
Houston, Texas
as told to me at the Dallas Conference, 2006*

What a conference! The remarkable world of Joubert is stronger and better equipped to journey into our tomorrows. Thank you again for giving me space in your world. As I reflect on these last days of being together, I am reminded of a prism. A prism is a transparent body that is bounded in part by two nonparallel faces and is used to refract or disperse a beam of light.

Joubert kids of all ages are those transparent bodies, those prisms that disperse beams of light around us, teaching us that life requires us to have more and more keys for our future.

Joubert families are those transparent bodies, those prisms that disperse beams of light to their communities, teaching us that loving and growing with the gift received is the right and holy thing to do.

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Joubert Foundation participants are a vibrant ray of light that, when passed through a prism, disperse beams of light around us teaching one another and the watching community that, if there is a singular key to the future it is found in the words of Winston Churchill-- "Never Give Up."

Three closing statements, followed by a little something extra:

- While your thoughts are generally compartmentalized, make sure that your action plan touches body, mind and spirit. In other words, be holistic.
- When your action plan disintegrates right before your very eyes, allow your "Reaction Plan" to flow out of your compassionate core (even though the anger/frustration side seems to be winning).
- When dealing with the more global issues, never grow weary in advocating for justice, committing your energy to peaceful resolution and healing touches.

*May peaceful presence surround you,
Holy Love embrace you, and may you discover enough for each day.*

Mystery and the Magic Key Joubert Syndrome Conference, 2009

Closing Remarks, July 18, 2009
© Ben Keckler

On the west side of Interstate 75 near Cincinnati there is a Sheraton with 13 floors,
A conference was held there with the hope of unlocking Joubert doors.

Parents, siblings, doctors, professionals, and research folk, we gathered to learn
And grow individually and as a family looking for answers because we yearn

To be better people for the journey toward wholeness we face day after day.
Bear with me my Joubert friends I think the poet has a bit more to say.

We started with questions and responses thinking that might provide the key,
And we were reminded to "make peace with uncertainty" so we can be

Calm and focused, trusting there will be enough for each passage we face.
What a great key to hear right away, a rainbow of hope for running the race.

We continued with gatherings around tables to simply be with each other,
Learning about grace-filled living ways to demonstrate courage and never smother

The gifts within the children we love, some with a syndrome and others without.
The resources here were powerful, we can say that clearly, there is no doubt.

We had some free time as well to visit places like the Cock and Bull,
If you think I'm telling more, you are going to have to pull and pull.

Workshops and research projects were so important, giving us guidance for the trek,
Giving us plenty to process as we go home and sit out on our patio or deck.

Wrestling with how can we be the best that we can be,
For ourselves and our family helping friends and neighbors to see

There really are some keys for the future and only together can we fully grow,
And make the Joubert journey with enough keys to get us to the next place—Orlando.

Believing that a journey to the magic kingdom might bring yet another key of hope
For the challenging journey that we face daily as we try to cope.

Let's return to the beginning words, still keep searching to discover a magic key,
Remember: mystery will always surround you; breathe deeply and peaceful you will be.

Getting to Know You and Family Updates



Joshua Pelusi, Australia, 8 years old

Here is the article about Josh's Cross Country from earlier in the year. I was asked to write it for our support organization by our keyworker. I thought it might be interesting to some of the newbies, especially given the questions lately about having a full and happy life.

I probably should preface the story by noting that Josh (8 yo - JS) attends Year 2 in our local mainstream Catholic primary school with his WONDERFUL big brother Jakob (9 yo).

Josh's Big Race

Last week was Cross Country time for many children in many schools. I didn't give it much thought, really. Josh had been "training" with the rest of his classmates every morning this term. They'd do a couple of laps of the oval before they went into class. It was a nice way to warm up on a chilly morning. He just loved it, gradually increasing the number of laps he could do - even running six full laps on one particular day. Again I didn't think too much about it, except to note the smile and the enjoyment on his little face when he recounted his day. Being an active kid is not unusual for him, since his wonderful, young teacher takes the class out daily to exercise anyway - sometimes sit-ups or push-ups, and always stretches.

Then it was the BIG DAY. Off he went on the bus with all the other kids to the school Cross Country Carnival. Me, not giving it much thought again, stopped for a coffee on the way and turned up to watch the race. Before long, Josh and the rest of the Grade 2 and 3 boys were lined up awaiting the start of their race. Josh was standing with his friends warming up with the abovementioned stretches, even sit-ups and push-ups with me chuckling to myself, thinking "...and how is that going to help you with your running...?"

It would be true to say that I didn't give it much thought until the starting pistol was in the air. Then it hit me, and it hit me like a tonne of bricks. *Oh my goodness, Josh has a DISABILITY! He can't do this! I felt suddenly sick to my stomach and I began to get very, very nervous. He won't do it next year, I thought. I can't put him through this again. What's going to happen when he comes last? Will he even finish the race? Why didn't I THINK about this? It's too late now!* Of course he was going to come last. It's a no-brainer. Josh has Joubert Syndrome which is a physical disability that affects his balance and co-ordination. He struggles with even the smallest tasks. *What made me think that he would be able to run 1km in a race? A RACE? Was I mad?* I felt helpless, terrified, horrified, like I was the worst mother in the world. *Why didn't I protect him?*

Then before I knew it the pistol rang out and they were off! 26 little boys running their hearts out. And there was my darling Josh running too. He started quite well but it of course it only took a few seconds for him to fall well behind. By the 50m mark he would've been trailing the last of the pack by a good 20m. At that point my eyes started leaking - silent, quiet, hidden tears behind dark sunglasses because no-one needs to see me at my worst. I turned the video camera off as he disappeared from the oval to the "country" part of the course. Another mother from the school walked past behind me at that moment and said "He's all heart your boy. What a spirit." Well, that did it! The floodgates opened and I sobbed so hard even my legs were shaking. What had I done to my precious baby? I was helpless and so was he. What could I do? I couldn't make more of a scene by running off after him so I decided the best thing to do was to wait and see how this panned out. I knew that there were marshals all around the course. I knew that everyone in our lovely small school knew Josh and that he wouldn't come to any physical harm, so I waited. It might just be OK.

All of the other boys started coming back onto the oval for the final stretch to the finish line. I watched every other boy come back in one-by-one. *Where was he now?* A little while passed and I just kept willing him to come back through that gate. *You can do it, Josh... C'mon... Please finish... You can be proud...* The day's program seemed to pause as everyone waited for Josh so they could start the next race.

That's when I saw him. My brave, determined, precious Josh came jogging slowly through the gate. He was obviously tired, but he had a Grade 7 boy jogging alongside him, encouraging him. As they made their way around the track for the last hundred metres or so they were joined by another Grade 7er, and then another. *C'mon Josh! You can do it! You can DO IT!*

You know what? He DID IT! He ran all the way to that finish line and, with the whole of the school watching and cheering, ended with a dramatic shoulder roll. Not bad for a little boy who wasn't even meant to walk. When he got back to his feet, Josh joined the rest of the group, skylarking and high-fiving his friends. He was smiling and ani-

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Getting to Know You and Family Updates—cont.

(Continued from page 7) Josh Pelusi

mated. He was HAPPY! Where was the scared, sad, embarrassed little boy that I had expected? Here was a kid who was as proud as punch, mucking around with his mates. He walked off the oval smiling the biggest smile I have ever seen! He eventually saw me, ran up to me and said in his own unique little voice, "Mum, I came 26th!" I hugged him and hugged him. He knew there were only 26 boys in that race. He knew he came last. But he knew he did an amazing thing. He knew he had achieved greatness. Well, it looks like I got my wish that day. He finished that race and there was never a boy more proud of himself.

Upon reflection, I find it strangely curious that had I been a "better" mother Josh may not have raced at all that day. He may not have risked failure, sure. But he may not have had his incredible victory either. My idea of a "bad" mother and a "good" mother took on a whole new meaning that day. It's certainly challenged my picture of 'mother as protector'. I had let him go out into the world and he lived his life - his OWN life. He wanted to go. He went. He risked everything and he came home to open arms no matter what the outcome. Maybe that's what mothering is meant to be - helping our precious little babies go out into the world to experience the ups and the downs just like we did, with unconditional love waiting for them upon their return.

It's funny, you know. Not many people remember the name of the boy who won that race, but EVERYONE keeps talking about Josh and his bravery, his spirit, his achievement and his big, beaming smile.

*by Natalie Pelusi
July 2009*



Matilda "Tilly" Stapleton, Knoxville, TN, 9 months



I learned of Tilly's challenges while I was pregnant with her. During the routine 20 week ultrasound, my doctor found a "spot" on Tilly's brain and sent us to a group of neo-natal specialists who were trained in high risk pregnancies. After a battery of fetal MRIs and consultations with geneticists, neurosurgeons, etc., I was given the working diagnosis of Dandy Walker Syndrome.

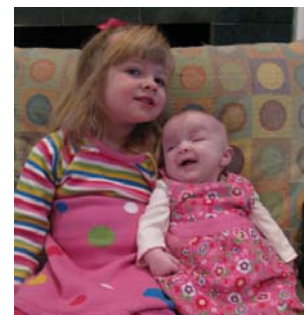
Tilly was born on September 12, 2008. She had a traumatic birth (her cord wrapped around her neck twice) and was immediately transferred to our local Children's Hospital NICU. After suffering severe reflux and consequently, feeding problems for several weeks, Tilly was fitted with a gastro tube and had fundoplication surgery. Though it was a tough decision to undergo surgery at such a young age, this allowed her to come home to her adoring family - big sister, Fiona, age 4, dog Lulu and cats, Molly & Biko.

Tilly has been blessed to receive services from day one. She had regular home visits from occupational, physical and speech therapists. Once she grew stronger, she was able to begin therapy on an outpatient basis. In a short amount of time Tilly was taking all of nourishment via mouth after mastering bottle feedings.

Once Tilly turned 6 months, her neurologist recommended an MRI. The MRI revealed the signature "molar tooth malformation" and at last, allowed for a more accurate diagnosis. Our pediatrician shared with me the link for the JSF & RCD website which has been a blessing to us all! I have been so excited with the information, the resources, and the outpouring of support from everyone in the JS community.

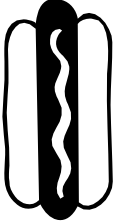
Tilly is now 9 months and has made huge strides in reaching her milestones. We could not have accomplished so much without the wonderful therapists at East Tennessee Children's Rehab Center. She is currently rolling over from back to side to tummy and is reaching, pulling, and holding toys. She is getting stronger and is improving in her head control. We can not wait to celebrate her future successes - sitting up, etc. with our JS family!

Tilly is a very loving, happy, and smiley baby girl. She is constantly giggling and entertaining her family. She loves being in the pool during aquatic therapy. She also enjoys spending time outdoors and with her pets.



by Kimberly Stapleton

Getting to Know You - In Pictures!

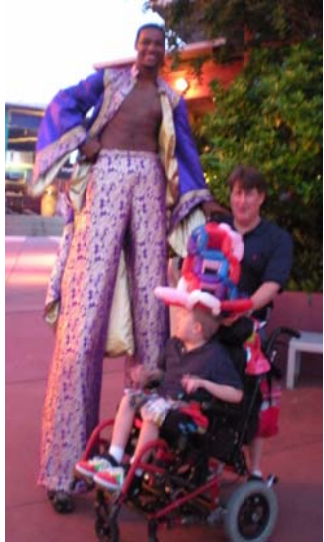


Dave Goldstein competed at the Nathan's Hot Dog Eating contest in Atlantic City. Lauren Gundling and her family were cheering Dave on!



Wayne and Will Hall with very Tall Man at Universal Studios in Florida. Note Will's cool hat!!!

→→→→



Ryan, Susan, Jessica, and Josh Goldstein smile for the camera during a Philadelphia Phillies baseball game.

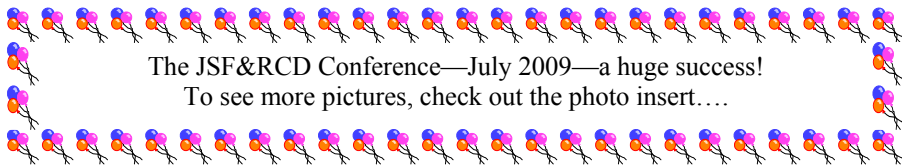
←←←←←←

Dave and Jessica Goldstein cheering on the Phillies!

→→→→→→

Looks like everyone is having a lot fun!





 The JSF&RCD Conference—July 2009—a huge success!

 To see more pictures, check out the photo insert....



The last night of the conference included a group shot of our children...

←←←←←←

Everyone had fun dancing the YMCA!

→→→→→→



Minutes July 19, 2009

**JSFRCD: Board of Directors
Cincinnati, Ohio**

PRESENT: Michele Abdulaziz—Past President

Amy Giesen; Elizabeth Joshi; Jon Morgan; Nadine Phillips; Alison Rickerl; Karen Tompkins; Amanda Tulumalo; Monica Venezia;

ABSENT: Kathleen Dartez; Kelly Seymour; Kimberly Stapleton; Balinda Richard; Carolyn Teschmacher; Samantha Wagget;

❖ Call to Order---- 8:38am

❖ Brief Introduction of each member

❖ Collection of emails, phone numbers, etc.

❖ Brief review of Board Member packages

Discussion: why we are voting the executive as a Board of Directors and not a direct vote by the membership—trying to move Foundation forward and this is one step closer to the goal of complete transparency

❖ BOD Agreement Letter

❖ Election of Executive

MOTION: To accept the slate of officers as listed.

Moved: Alison Rickerl

Second: Amanda Tulumalo

MOTION CARRIED

Treasurer—Jonathan Morgan

Secretary—Kelly Seymour

Vice President— Nadine Phillips

President—Karen Tompkins

❖ Results of General Meeting

I believe that our Foundation should focus on the following TWO goals for the next two years:

TOTAL RESPONDANTS: 31

28 Continue participation in the BioBank (1 recommended: have donor pay % of fee)

2 Expand our membership to include other Cilia Disorders

9 Reach more doctors to ensure prompt and accurate diagnosis

4 Fund research in practical areas of daily living (eg: therapies that make a difference)

5 Update technical support (data base; medical registry; website; etc)

3 Other: other ways of getting more funds

Obtain funding through grants, marketing, etc (professional hire?)

Regular conferences to increase conference attendees

❖ Joe Busam Foundation www.joebusam.org

Claire Cocharan (the daughter of Claire Busam) saw Jeff Wright with Adam. She gave him her business card and said “we can help”. Claire Busam was then called and invited to meet with our families. Claire Cocharan came to the hotel on Saturday afternoon and let us know about how their Foundation helps individuals needs assistance (for vans, communication devices, etc). The Board will address how best to utilize this new source.

❖ OTHER BUSINESS:

Children’s Rare Disease Network www.theprojectcharity.org

Canadian Organization of Rare Disorders--- JSFRCD is an Affiliate Member. Karen Tompkins was invited to speak at their conference May 1st. She will represent the Foundation on a conference call September 14th at 6. Accessing medical resources (eg: Children’s Inn, NIH) to support our Board Retreats, etc.

Discounted services for non-profit

Discussion of investment of funds on non-conference years

Monica and Alison to look into on-line meeting space (wiki; SKYPE; etc)

❖ Preparation for next meeting--- please review the documents in Board package

Participation in on-line discussions and research information as needed.

Next Conference Call: September 14, 2009 8pm EST (this date was from the minutes of the last Board meeting. It will be rescheduled.)



Raise Money for JSF—Here's How You Can Help!



REMINDER: ONLINE SHOPPING



Shop online. Support the JSF&RCD. Designate the Joubert Syndrome Foundation as the charity you'd like to help. Part of your purchase goes to our Foundation. After you have chosen JSF on the website, it should appear somewhere on the screen before you place your order. Check out: www.igive.com. Retailers may include Toys-R-Us, Amazon, Dell, Barnes & Noble, Harry & David, JC Penny, and 1800 Flowers. Send gifts to family and friends that live out of state directly from the online shopping sites. These sites are here year round. Don't forget birthdays, thank you's, or "thinking of you" gifts. **Happy shopping, and thanks for your support!**

MORE SHOPPING REMINDERS!! With a Club Card from Safeway, Genuardis, Tom Thumb, Randalls, Dominicks, Carrs Pavilions or Vons, , you can help our Foundation! Go to www.escrip.com, sign up, locate Joubert Syndrome Foundation and indicate JSF as your charity. Type in your club card number. That's it!! Every time you shop at these stores and swipe your club member card, part of your sale goes back to the JSF&RCD. Take a look at the participating merchant list on the website. With these merchants, you list either the credit card or ATM card that you use and part of the sale goes to JSF&RCD. Payless Shoes is one of the many merchants that participates in this program.


If you purchase shoes from Payless, why not have part of the sale go to a very good cause?! **Thanks!!**

Albertson's Community Partners: If you have an Albertson's/ Sav-on Preferred savings card you can have the Community Partners for the JSF & RCD attached to it. Take your Preferred savings card and the Community Partners card for the Foundation to any Albertson's or Sav-on and they can combine the two. You can also link the two via www.albertsons.com. Click on the Community Partners logo link. Once you log in, click on *sign me up*. The number of the JSF & RCD Community Partners is Joubert Syndrome Foundation ID# 49000123408. If you would like a Community Partners card please contact Michele at Michii@allaboutjoey.com or 805-527-1007. **Thanks to your participation, the JSF&RCD has received over \$3,000 since May 2002!**

United Way: If you are a **non-Federal employee**, you can select the Joubert Syndrome Foundation to be the recipient of your donations. Our ID # is 216294. If you are a **Federal Employee**, our CFC # is 2519. Also, many companies have employee/employer matching programs. Why not find out what your company does to support non-profit organizations? **Thanks!**

EBAY?
You can help out the JSF&RCD by shopping or selling on EBAY. When you list your items to be sold, you can indicate a portion of the sale to go to JSF&RCD. For more information on how to do this, go to <http://www.missionfish.org/ForSellers/forsellers.jsp>
Thank you!!

- • • • •
- **A simple bequest can change lives** •
-
- It's easy to make a bequest—a gift that
- lives after you. Simply remember the
- JSF&RCD with a statement in your will
- or trust.
-
- Your bequest in your will provides a
- legacy of your concern for children with
- JSF&RCD and their families. It will
- support the JSF&RCD as we strive to
- make a difference in the lives of fami-
- lies touched by JSF&RCD.
-
- The JSF&RCD is registered as a 501c3
- nonprofit corporation in many states.
-
- • • • •



The JSF&RCD is in our 18th year! Thanks to your participation and support, Joubert Syndrome is more quickly diagnosed in children and adults. Word is getting out there! Your efforts, and the hard work of our Foundation, continue to spread the word about Joubert Syndrome.

The JSF could not exist without each and every member, and your families and friends. We are asking for the continued support of all of your families and friends to help us with the JSF's Annual **Rainbow Letter** Fundraiser.

The "Rainbow Letter" presents a brief history of our Foundation, and our progress over the years. Please share the letter with your family, friends and others you meet who would like to support our Foundation.

The Rainbow letter can be printed from the Foundation's website at www.jsf&rcd.org under the "How you can help" section.

Thank you for your continued support!

Raise Money for JSF—More Ways for How You Can Help!

Here is something you can email to all your friends and family...and include the section at the bottom of Michele & Mike's note after the closing of all your emails. Every penny counts!

Dear.....

I'm a supporter of JSF & RCD and as you can imagine nonprofits are facing a fundraising crisis this year.

The good news is that more than 900 of the top Internet retailers and travel sites including Amazon, eBay, Target, Apple, Expedia and more have joined forces with GoodShop.com to donate part of every purchase to your favorite charity or school at no additional cost to you (more than 72,000 nonprofits are now on-board)!

It takes just a few seconds to go to www.goodshop.com, select your charity, and then click through to your favorite store and shop as usual.

Also, Yahoo has teamed up with GoodShop's sister site, GoodSearch.com, to donate about a penny to your cause every time you search the web. This is totally free as the money comes from advertisers.

To give you a sense of how the money can add up, the ASPCA has already earned more than \$23,000!

Please tell 10 friends about GoodShop and GoodSearch today. They've been featured in the NY Times, the Wall Street Journal, CNN, Oprah Magazine and more.

Charities need our help to spread the word now more than ever!

Thank you.

Michele & Mike Abdulaziz
Joey 11-22-93/7-5-03
Benjamin 2 years old

Raise money for the Joubert Syndrome Foundation & Related Cerebellar Disorders by using GoodSearch.com for all your internet searching needs! Simply go to www.goodsearch.com - and type in "Joubert Syndrome Foundation & Related Cerebellar Disorders" where you are asked "Who do you Goodsearch for?" Any questions please ask...

A note from Nadine.....

I hope that this finds everyone enjoying the last few days of summer vacation...it is hard to believe that another school year is about to begin! I wanted to take a moment to thank you all for coming to Cincinnati last month and say how great it was to see everyone!

As a member of the conference planning committee, I would like to thank those of you that completed and returned the conference evaluation form already. If you haven't completed one yet, I wanted to take the opportunity to remind you that your feedback is what helps us to improve your conference experience year after year!

The 2009 conference evaluation form is available on the JSF&RCD website (www.jsfrcd.org/ConferenceInfo.asp). Please print it out, complete it, and return to me via email, fax, or regular mail: **Nadine Phillips, 6993 Nocturne Rd N., Reynoldsburg, OH, 43068**

614-864-1362 (phone/fax)

nadinephillips@wowway.com

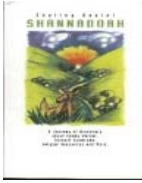
Also, if you would like to complete a copy of Dr. Nancy Collop's sleep questionnaire--even if you did not attend her presentation, you are encouraged to fill one out. Please contact me for that questionnaire. I would also ask that you return your questionnaire to the JSF. The JSF&RCD would like to keep copies of the information collected for our own records, and will forward the questionnaires on to Dr. Collop on your behalf. You can send your completed questionnaire to me at the address (or fax or email) noted above. If you prefer to not share your answers with the JSF&RCD, you can send your questionnaire directly to: Johns Hopkins Sleep Disorders Center, 601 N. Caroline Street Suite 1261, Baltimore, MD 21205

In regards to sending these documents to the JSF--no names/identifying information will be kept in relation to either of the questionnaires, unless you specifically put your name on either document!

Please do not hesitate to contact me if you have any questions or concerns! Looking forward to seeing everyone in

JOUBERT SYNDROME FOUNDATION and RELATED CEREBELLAR DISORDERS

PUBLICATIONS



Shannadoah by Shelley Boulet
\$15 USD (\$19 USD, outside US)

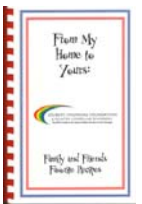
A journey of discovery about Dandy Walker, Joubert Syndrome, helpful resources and more. This book is written by a mother of 2 children that were diagnosed with Dandy Walker and then later diagnosed with Joubert Syndrome.



Purple Stew by Karen Tompkins

Originally \$22 - reduced price \$15 USD (Originally \$26— reduced price \$19 USD, outside US). Reduced price due to slightly damaged cover.

A great book for parents with a newly diagnosed child, Purple Stew shares the trials, tribulations, experiences, joys and sorrows from families who are raising children with Joubert Syndrome.



From My Home to Yours: Family and Friends Cookbook
\$12 USD (\$15 USD, outside of US)

This cookbook is filled with favorite recipes of Joubert Syndrome families from all around the world. Makes a great gift!

CONFERENCE VIDEOS



Conference videos include opening and closing ceremonies and all presenter and researcher information sessions. 2006 Conference DVD 8 DVD set \$35 USD (\$40 USD, outside of US)

Please inquire about conference videos from prior years (1993, 1994, 1996, 1998, 2000, 2002, 2004).

JSF&RCD MERCHANDISE



JSF&RCD Awareness Wristbands

\$2.50 each (\$3-4 S&H will be charged per order for this item *only* - regardless of quantity)

Multi-color swirled silicone bracelet is imprinted with "JSF&RCD" and the words "Faith, Hope, Love". Included on the inside of the wristband is the JSF&RCD web address. Looks great with *any* outfit!



JSF&RCD T-shirts

\$13 for youth sizes, \$18-21 for adult sizes

Limited sizes available.

100% white cotton t-shirts have the JSF&RCD logo silk screened across the chest. Available in youth and adult sizes.



JSF&RCD Car Magnet

\$10 each (\$4 S&H for 1-25 magnets)

Colorful magnets to display on your car to help spread the word about Joubert Syndrome.

**All prices include tax. Shipping/handling fees extra for wristbands and magnets.
Please use order form on the last page of this newsletter. Thank you!**

Next newsletter deadline

October 2009



BOARD of DIRECTORS of The Joubert Syndrome Foundation & Related Cerebellar Disorders

* Denotes Co-Founder

Karen Tompkins, **President** Nadine Phillips, **Vice President** Jonathan Morgan, **Treasurer** Kelly Seymour, **Secretary**
Kathleen Dartez Amy Giesen Elizabeth Joshi Balinda Richard Alison Rickerl Kimberly Stapleton Carolyn Teschemacher
Amanda Tulumalo Monica Venezia Samantha Waggett

Past Presidents: Cheryl Duquette* Michele Abdulaziz

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Latif Hamed, MD, FACS

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3230 SW 33rd Road, Suite 202, Ocala, FL 34474
352-237-0090 FAX: 352-237-0052
Call with questions regarding the eyes

Natalie Zozzaro, MS PT

Ladacin Network
1100 Airport Road, Lakewood, NJ 08701
O:732-905-7200
natalie.zozzaro@ladacin.org
Call with q re: Physical therapy

MaryAnn Trott, MA

1621 Richmond, NE, Albuquerque, NM 87106
W: 505-298-6752 ext 3427 H: 505-266-2632
prefers calls at home
wmtrott@comcast.net or trott@aps.edu
Call with q re: special education & sensory processing and how it affects learning & behavior

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Division of Neuro-ophthalmology Department of Neurology
University of Pennsylvania Medical Center
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Philadelphia, PA 19104-4283
215-349-8460 Fax 215-349-5579 Website: www.upno.org
Dr. Liu also sees patients at CHOP
(215-590-2791 www.chop.edu)

Alex Constantinescu, MD

Medical Director, Pediatric Nephrology
Joe DiMaggio Children's Hospital
1150 N 35th Ave, Ste 499, Hollywood, FL 33021
V: 954-265-9344; F: 954-986-5122
E-mail: docs4kidneys@yahoo.com
or aconstantinescu@mhs.net
Call with questions regarding kidney issues

Eugen Boltshauser, MD

Department of Neurology
Children's Hospital
Steinwiesstrasse 75, CH-8032 Zurich Switzerland
0041-44-266-7330 (7111) Fax 0041-44-266-7163
eugen.boltshauser@bluewin.ch
eugen.boltshauser@kispi.uzh.ch
Call with q if you are outside the USA.

Bernard Maria, MD, MBA

Jeffrey Edwin Gilliam Chair and Professor of
Pediatrics and Neurosciences
Exec Dir, Charles P. Darby Children's Research Inst.
Medical University of South Carolina
173 Ashley Avenue, Suite 409, PO Box 250514
Charleston, SC 29425
843-792-7715 mariabl@musc.edu
Call with questions regarding research & clinical manifestations

Sandra McNiff, M.S.Sp., CCC-SLP

Email sandramcniff@yahoo.com
Send email with questions about AAC intervention.
Reference AAC or Joubert.

Diane Lewis, MA, CCC/SLP

Children's Innovative Therapy Group, LLC
5109 Battery Lane, Bethesda, MD 20814
301-652-2220 FAX: 301-652-9555
dianelewisces@aol.com
Call with q re: speech - language pathology

Note: All Professional Advisors are available to parents, educators and the medical community to answer questions about JS, its management and ongoing research studies.