

# The RAINBOW

The Joubert Syndrome & Related Disorders Foundation 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 & Related Disorders Foundation plays an important role in educating physicians and their support team and in increasing public awareness.  
[www.jsrdf.org](http://www.jsrdf.org)

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Winter 2010

January, February, March

## Notes from the Executive Committee

Snow is falling outside some of your windows as this note is being written. It is so wonderful to be within a few hours drive of families that really understand the challenges we face as people affected by Joubert Syndrome and related disorders. We encourage everyone to plan a regional gathering in the next six months to celebrate your connections. It is 18 months until our next conference and many of you may need an extra JSRD Boost to make it through!

As you read previously, the Global Genes Project will be a series of “homegrown” events on February 28, 2010 to mark Rare Diseases Day. We hope that each of you will find a way to spread the word about our organization. (For more information regarding the Global Genes Project, contact Elizabeth Joshi at [ejoshi@jsrdf.org](mailto:ejoshi@jsrdf.org)). Consider this a dress rehearsal for our 10by10 Campaign! By October 10, 2010, it is hoped that each member will either host an event where 10 people invite 10 people to attend, each donating \$10 to participate, OR you could simply ask 10 friends to ask THEIR 10 friends to donate \$10. All monies from this Campaign will offset costs for the 2011 Conference.

If you are planning a gathering, please be sure to let others know: use Facebook, Yahoo!Groups, and/or Twitter to advertise. We have a JSRDFoundation group on each of these social networking tools. Also, if you are going to be doing a **fundraiser** that benefits the Foundation, there are **guidelines** to follow. Please read this month’s Board Meeting minutes regarding the use of the **Foundation logo**. Other policies and procedures are being developed this year to protect our members from fraudulent practices. As we grow larger and stronger, we also become more vulnerable. The Board of Directors is preparing for our future!

Aside from a Board Policy Handbook, the JSRDF Board Members will be meeting in New York, NY with the Cuidiu Consulting Group this summer to develop a Strategic Plan. The Foundation was awarded up to \$25,000 in consultation time with this well-known firm due to a successful grant application this past November. We look forward to sharing all these documents with you next fall.

As always, there are so many tasks and not enough time. We really need YOU or your sister or your neighbour... We have specific tasks that could be 10 hours total or 10 hours a month. Whatever time and talents you have, we can help you be active in our Foundation. Contact any of the Executive Committee... we look forward to hearing from you!

Until next time,  
*Karen, Nadine and Michele*

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**The RAINBOW**  
The Joubert Syndrome &  
Related Disorders Foundation

[www.jsrdf.org](http://www.jsrdf.org)  
Newsletter

## 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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SEND Newsletter Articles to:  
**Looking for a new Editor...If interested,  
please contact Karen Tompkins**

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*(Continued on page 3)*

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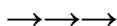
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Updated on 1-25-10

**Please note: If you don't see your state listed, and would like to serve as a State Contact, please let us know. Thank you!**

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**Meet the Medical Members**

Over the years, there have been many members of the medical community who have made a difference in the lives of people with Joubert Syndrome and related disorders. Over the next few issues, we will profile several of the key players.

**Dana Knutzen, MS, CGC** Dana Knutzen is a certified genetic counselor working with the University of Washington Joubert Research Center in Seattle. Dana received her master's degree in genetic counseling from the University of Michigan in 2002 and became a board certified counselor in 2005. In 2003, she joined the UW team studying the genetic causes of Joubert syndrome and related disorders. Dana is the point of contact for the research study and welcomes contact from families attending the meeting who have questions about participation ([knutzd@u.washington.edu](mailto:knutzd@u.washington.edu)). When she is not working on research, she works part-time as a clinical genetic counselor providing prenatal and pediatric counseling services for the military at the local army post in Washington State. Dana lives just south of Seattle with her husband and son.

*editor's note: The work that Dana carries out behind the scenes, is a major contributing factor to the success of the medical portion of our last few conferences. Thanks, Dana*



**Board of Directors Conference Call**  
Meeting Minutes January 25, 2010

Present: Michele Abdulaziz, Jon Morgan, Kathleen Dartez, Karen Tompkins, Amy Geisen, Samantha Waggett, Elizabeth Joshi, Nadine Phillips, Kelly Seymour, Carolyn Teschmacher, Amanda Tulumalo

Regrets: Alison Rickerl  
Absent: Balinda Richard

Called to order 8:05 EST

Adoption of Minutes from November 2, 2009 meeting: Samantha made motion, Kelly seconded the motion

**ACTIONS:**

1.) **LOGO**

**MOTION:** To continue to support the work of the Logo Committee until a new logo is developed with the intent to adopt said logo upon completion. Kathleen made motion, Samantha seconded motion. A tentative deadline for the new logo completion to be set for March 29, 2010. **APPROVED:** 7-3 in favor

2.) **PIE GRAPH:** Showing how monies are utilized in the Foundation

Pie graphs that have already been proposed will be adopted by unanimous vote; pending a color and/or pattern change in order to have better delineation on sections of the pie graph.

3.) **USE OF JS LOGO AT EVENTS/FUNDRAISERS**

Unanimous agreement that we adopt the following policy: Any event that names the JSRDFoundation as a recipient of the funds raised is required to have the official JSRDF logo displayed prominently on any marketing materials. The logo should be the same size or larger than any other logo included on said materials.

**FOLLOW UP**

1.) **BUDGET:** have their budgets completed and submitted by February 17, 2010

**INFORMATION**

Kathleen has agreed to Chair the Grant Committee. Responsibilities will be: searching for grants that meet our needs, or creating projects to meet the criteria of a grant.

Matthew Smith (Laura Buchanan's brother) is presently working with Alison to write an R13 grant in order to have the scientist's expenses covered by NIH at the next conference.

Elizabeth Joshi updated us on the Global Genes Project and what we can do to participate. Global Genes project is end of February.

Karen Tompkins updated us on membership: Amy & Samantha are ready to make the calls to membership on the database. Michele will facilitate that. Carolyn and Michele will discuss the update to a better database, Results Plus instead of Access.

Policy Committee: please send the items that you feel need to be written into the Board Policy Manual within the next two weeks. You only have to give the title and an overview, you do not have to write the specific policy.

Carolyn Teschemacher discussed Advocacy on Capitol Hill. Global genes project working on it Advocacy for Rare Diseases/Syndromes, Carolyn discussed doing advocacy work in congress for us, and suggested we schedule meetings and bring our kids. Advocacy can play a HUGE role in funding for our foundation.

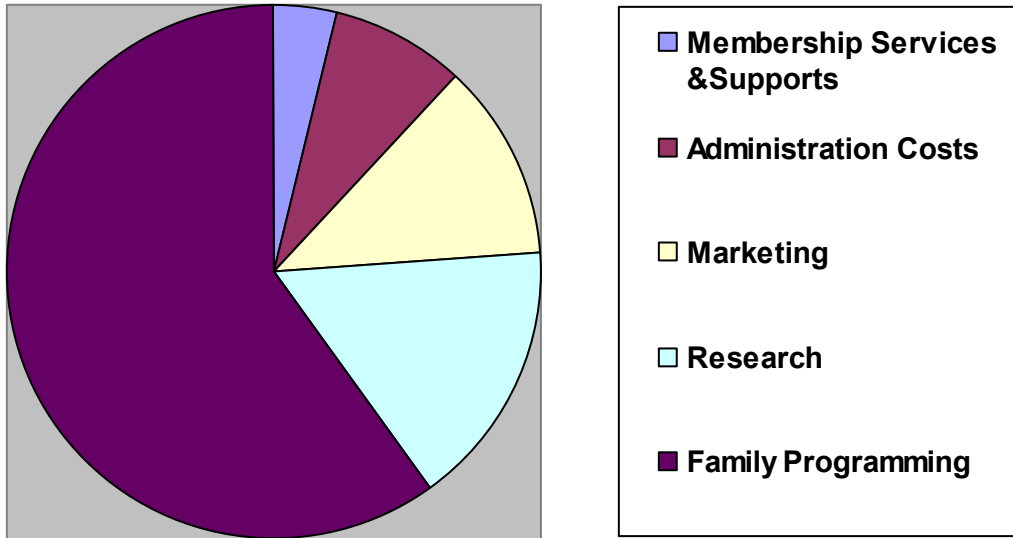
Meeting adjourned at 9:36 EST.

Minutes prepared by Kelly Seymour, Secretary

Karen Tompkins  
President 07/09 to present  
Canadian Contact: 01/99 to present

## FINANCIAL BREAKDOWN: JSRD Foundation

\*Totals based on financial information from 2006-2009



**MEMBERSHIP SERVICES & SUPPORTS** (newsletter; new family packets; information sheets; memorial stars; cards; etc) -- 4%

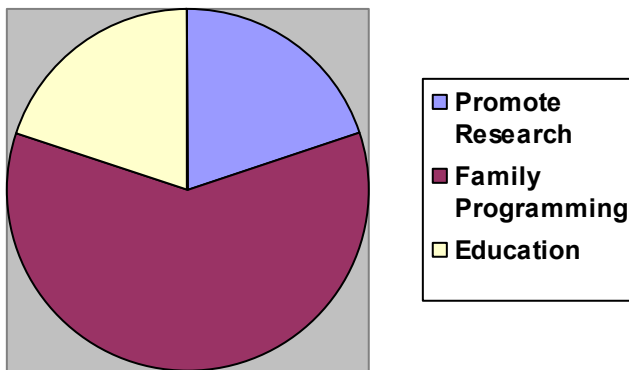
**ADMINISTRATION COSTS** (audits, state registrations, accountant, teleconferencing, etc) -- 8%

**MARKETING** (JSRDF merchandise, website, etc) -- 12%

**RESEARCH** (attendance at scientific conferences; participation in Genetic Alliance BioBank) -- 16%

**FAMILY PROGRAMMING** (JSRDF CONFERENCE expenses; etc.) --60%

### Your Donation Dollars at Work for the JSRD



### Promote Research 25%

The JSRDF, and its Scientific Committee, is responsible for monitoring the gains made in the scientific community that benefit the families affected by JSRDs. The JSRDF also attends conferences for professionals that need to know more about JSRDs (eg: pediatric neurologists; genetic counselors; radiologists; etc). In addition, the JSRDF is always looking for members of the scientific community who are willing to conduct research studies in areas that will benefit the daily living of our members affected by JSRDs.

### Family Programming 60%

At present, the main program offered to families is the biennial conference. The JSRDF has hosted nine conferences since 1993. The fee for individuals to attend the conferences covers the cost of food (1-2 meals and 1 break per day) and the attendance and participation of professionals and scientists who give workshops; visit with families individually; as well as offer specialized sessions for groups of families with similar questions/concerns. Through donations, the cost for families will be either reduced or eliminated.

### Education 15%

The JSRDF, and its Growth and Development Department (Donations; Grants and Marketing), is responsible for increasing awareness of JSRDs in the general public. This requires the support of the Technical Committee in order to utilize the website and social networking tools at our disposal. Brochures and media packages are also being produced in order to put a face to the Foundation --- our kids!



# Getting to Know You and Family Updates

**Christopher: Ten months old, Mississauga, Ontario, Canada**

I'm so glad to find this group as my baby was diagnosed a week ago. He is the most wonderful, happy and beautiful baby!!! I LOVE him!!!! Perfect in my eyes! He is always laughing and playing, and he absolutely adores it when we sing to him.

Christopher was born on January 16th, 2009. He is now ten months old as of November 16th, the day he was diagnosed with Joubert Syndrome by Genetics. He has already had a balloon dilation procedure on his heart, and after ended up in CCU on a breathing machine and feeding tube at one week old. At that time they had to do an ultrasound/scan on his brain, and they did discover his cerebellum was abnormal and small...they never did any more tests, even though I told every doctor about it! He could have been diagnosed since then.

He had hernia surgery at two months old. He had his open heart surgery at six months old for aortic stenosis, and will need it again at four or five years old, and so on. This is the only thing the doctors do not think is tied to Joubert Syndrome.

We are at the hospital sometimes several times for the week. He has had casts on both of his feet until five months old, probably due to the hypotonia—weak ankles. His hypotonia is more severe in the upper body, and he can finally hold his head up, but cannot sit or stand still. We don't know what vision he has left in his left eye, due to ptosis and ocular-motor apraxia of the third nerve. We finally had the MRI done on November 12<sup>th</sup>. That showed the molar tooth configuration. When he was first born, he had sleep apnea for a few months. Now he has rapid breathing all of the time. All of these symptoms are now understood as Joubert Syndrome.

It has been a very difficult struggle with the hospitals and doctors to get the help he needs. But I must keep pushing forward. I know that this article could be much, much longer, and if I can be more detailed to get advice or help from someone... please let me know.

Thanks.  
Venetia Deonan



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## Congratulations!!!

**Natasha Chloe Seaman  
arrived on  
December 23rd at 6:31 pm  
weight 7 lb 10 oz  
19 3/4 long**

**Her big brother is very protective  
and is usually by her side to help.**

**The Seaman Family**





## Black & Gold to the SuperBowl-----Chris Frazer's Dream Comes True!!!!!!

Greetings and a BIG WHO DAT to you all from New Orleans. As some of you already know, our son Chris (soon to be 18) is a HUGE New Orleans Saints Football fan. He bleeds "black & gold" and we go to all the home games as a family. We were so excited when after 43 years of playing, our team had advanced to the Playoffs and the Superbowl!

I've always told everyone and especially Chris that the Superbowl was an experience for the "rich & famous". Well, the Saints held a lottery for Season ticket holders and on the Monday before the Superbowl, we got a call that our name had been picked from the lottery for a chance to purchase 2 tickets to the Miami SuperBowl.

Without a doubt, Mike said we were going! Within a day, we had found a place to stay and left on Thursday to drive that 17 hour drive all the way to Miami.

What a LUCKY guy Chris was!!! His Dream in life had come true...his team was going to the Superbowl and so was he!! He couldn't believe it. Since we only had 2 tickets, I had to stay back at the condo with GramPatti and we had our own little SuperBowl Party.

Mike and Chris had an AWESOME time and I just wanted to share some highlights of their experience with you all.

When we got to our condo, the curtains had "fleur di lis" on them (a sign). This is the symbol for the New Orleans Saints. On my way to the elevator, I met two guys (one wearing a colts hat) and I gave them a Who DAT hello. One of them was a 1981 Superbowl champ. He had played for the Raiders and won the Superbowl in the Superdome against the EAGLES. His name was Ira Matthews. He said his wife was from New Orleans and he was pulling for the Saints. He showed me his ring and I invited him to come back to our room to meet Chris. He let Chris try on his ring (it is SO HEAVY!) and let us all put it on and he took pictures with us. (another sign---Superbowl ring) How cool and coincidental was this!

Mike said the game was like a home field advantage game. It seemed like over 60K Saints fans were there. The crowd was loud and I could hear them on TV. They will never forget this night---none of us will. WE are all still pinching ourselves in disbelief.

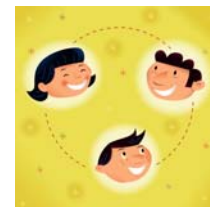
GramPatti, (Mike's Mom) and I chose to watch in the condo so we could see and hear everything. After the game was over, we looked over the balcony and could see the fireworks going off in the stadium. I needed some WHO DATS to celebrate with so I ran downstairs to find a family dancing in the streets with umbrellas and music playing loudly. They gave me an umbrella and we all danced. Then other families from Louisiana came out and they were dancing too. It was all women (the men were at the game!) WE had our own little Bourbon Street and parade right in the parking lot. The management was watching and were a little worried. I told him not to worry--it was just Mardi Gras coming to Miami and Mardi Gras may never end. You know us New Orleans people like to have a good time....

It was total destiny that this trip came to be...Total Destiny for the Saints to finally go to the SuperBowl and win and totally destiny that our names were picked to get tickets to the SuperBowl. What more could Chris possibly dream for now!!!!

Stephanie Frazer



# Getting to Know You



Bryce DiPietrantonio, Gorham, ME, 3 years old

Hello! My name is Michelle DiPietrantonio. I live in Gorham, Maine. I am a stay at home Mom with 2 wonderful children. My oldest son is a healthy 7 year old child. My youngest child was 3 years old on January 15th. His name is Bryce.

Bryce has had health issues ever since he was born. He has had asthma, acid reflux, and a thyroid problem that I never knew a child could possibly have. He has been in and out of the hospital since he was born.

He was diagnosed with an infant health movement disorder when he was only a week old. He has had many therapists and has seen many different doctors and has been put through many different tests including EEG, Sweat Test, Blood Work, CAT Scans, and MRI's—to name a few. The latest test was taken on 10/23/09 in the form of an MRI and then, after almost 3 years of looking for answers, I got an answer to what was happening with my Bryce.



*Bryce decorating the tree—December 2009*

On November 3, 2009 I sat down with his neurologist and I got my answers. I was told Bryce was suffering with Joubert Syndrome. I have had a hard time dealing with the diagnosis but I have had a lot of family support. As a mother, it is hard to hear but I've become a stronger person because of it. Having a diagnosis has put everything he has been suffering with into perspective. The diagnosis explains the tremors, feeding and sensory issues, eye problems, low muscle tone, developmental delay in speech, gross motor and fine motor skills.

My family has been very supportive and has been trying to help me but they don't know what I have been going through mentally. My hope is to find someone who has been in the same shoes to help me through this. There are good days for me but then there are days when I get depressed and wonder why or even blame myself, even though this is not my fault and I try to tell myself that. I want to give my child the best life that I can possibly give him and to help him cope with what God has dealt us. I'm looking to find other families that I could talk with that are going through the same thing. I don't know where I should start. I don't have access to a computer but I want to reach out and try to find someone who has been through this. Talking to a family who has been through this or is presently going through this is therapy for me.

Thank you!

*Michelle*

## 2011 Conference Information

The 10<sup>th</sup> Biennial JSRDF Family and Educational Conference  
July 13 – 16, 2011  
At the Doubletree --International Drive, Orlando FL

### Ideas to Help You Get to the JSRDF Conference--

We know that coming to the conference can be a hardship for families, especially in these tough economic times. Here are some ways JS families have raised funds to help cover their travel and conference expenses in the past.

#### **AIR TRAVEL:**

There are several nonprofit charitable flight organizations that offer free air travel for individuals that meet certain qualifications. For more information, you can contact the following organizations:

Angel Flight – 1-800-296-3797 or [www.angelflight.org](http://www.angelflight.org)

Miracle Flight -- 1-800-359-1711 or [www.miracleflights.org](http://www.miracleflights.org)

#### **GENERAL FUNDRAISING:**

Other successful ways to raise funds have included:

- \*Pampered Chef parties
- \*Pizza Hut night
- \*wine and cheese parties
- \*pasta night with Karaoke
- \*dinner theatre--- pizza \$1 slice
- \*silent auction
- \*approach unions and organizations that you are part of for support
- \* letter writing campaign to local civic groups (Masons, Sertoma, Kiwanis, Knights of Columbus, Lions Club, etc.) in your community asking for support
- \*dinner/special event fundraisers where people pay a fee to attend (grocery stores may give donations
- \*ask local high school groups (Key Club, NHS, student council, etc.) about holding a fundraiser to benefit your family/the JSF&RCD
- \*letter writing campaigns
- \*chocolate bar sales
- \*homemade pies to order
- \*popcorn sales
- \*night of music by local performers
- \*yard/garage sale : ask family and friends to donate items that they no longer need
- \*raffle fundraiser: ask local businesses to donate items, and then sell raffle tickets
- \*golf tournament: approach local businesses to sponsor holes, family/friends donate items for a silent auction at the dinner
- \*organizations such as your local ARC or Developmental Disabilities Organization --some may have

If you have other successful methods you have used to raise money, we would love to hear about it!

### INFORMATION

*Michele Abdulaziz has lists, by state, of Parent to Parent Programs and Parent Information and Training Centers. The lists are quite long. If you are interested in obtaining information about these resources, please contact Michele. Also, these sites may be a starting point for families to get funding for a "medical/educational conference". Please contact Michele at [mabdulaziz@jsrdf.org](mailto:mabdulaziz@jsrdf.org).*

## Note from the Newsletter Editor:

*Number of years creating the newsletter - 12, Number of newsletters - 48, Number of pages - 649, benefit to families and friends of the Foundation..... PRICELESS!*

I have truly enjoyed constructing *The Rainbow* for the past 12 years. I hope you all have enjoyed reading it! I have come to the realization that I now need to focus on other priorities. I look forward to reading future issues, and seeing the many wonderful things this Foundation continues to do for all of us!

If you are interested in taking over publication of *The Rainbow*, please reach out to Karen Tompkins. Thank you! Janet Gundling

## Get Together—Chicago—2010



### Where :

Mayan Adventure Indoor Waterpark @ The Holiday Inn -  
Chicago/Elmhurst  
624 North York Rd, Elmhurst IL 60126  
630-279-1100, 1-866-358-6255  
[www.mayanindoorwaterpark.com](http://www.mayanindoorwaterpark.com)  
[www.hielmhurst.com](http://www.hielmhurst.com)

### When:

Thursday-Sunday June 17-20, 2010

Room Prices are as follow for a standard 2 queen beds room

\$89.00 Just for hotel stay; \$139.00 for hotel and 4 water park passes

\$154.00 for hotel, 4 water park passes and 4 breakfast vouchers to be used in their restaurant.

For any family over 4, there will be an additional \$10.00 a night per person for the water park.

If you have any problems booking under Joubert Syndrome our block code is "JSF".

Wheelchair access rooms available upon request ( I think I reserved 5).

Hotel pluses are : free airport shuttle from O'Hare

refrigerator and microwave in each room

free 5 mile radius shuttle

arcade

waterpark is totally wheelchair accessible except the 2 big slides

family dinning and snack area on site

I need some feed back on a couple of things: Possible day trip on Saturday for the entire group.

\*Legoland Discovery Center \*Lincoln Park Zoo \*Brookfield Zoo \*Shedd Aquarium

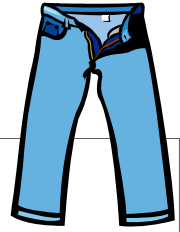
\*We can have use of a conference room for free if we order food.... Need to know of any interest for a Saturday night pizza for dinner?? Don't have a cost per person, probably would need to get some totals first.

If you have any questions please don't hesitate to contact me. I hope I didn't forget anything, if so just let me know. This is open to any JS family including friends and family members. It is just a chance to get together with friends and talk about our children!!! Also when you book your reservation can you please send me an e-mail with your family name so I know who is coming.

Amy Giesen 920-687-0428 [amy.giesen@thedacare.org](mailto:amy.giesen@thedacare.org)

Mom to Alyshia and Brittany both JS

## UPDATE



Hi Everyone!

I wanted to take this opportunity to encourage everyone to check out the website for the Global Genes Project: [www.globalgenesproject.org](http://www.globalgenesproject.org)

The Global Genes Project also has Facebook and Twitter pages--please consider taking a look at them. I have been working on the initiative since late summer and I hope all of you will consider getting involved in some way.

On this initiative, we have partnered with the Children's Rare Disease Network (CRDN) and other children's rare disease/disorder organizations to raise awareness about our common need and goal of more media, corporate and research involvement. Through the initiative, the participating groups are also provided with an opportunity to raise much needed funds for their causes.

In recognition of World Rare Disease Day at the end of February, members of JSRDF and other "rare" organizations will be hosting jeans parties and having jeans days at work, school, etc. through which donations (in our case) will go to JSRDF--Would any of you consider hosting a jeans party, even if it's just a few friends over? We are playing on the "jeans" and "genes" theme with these efforts. Perhaps a school, church or employer might consider hosting a jeans day whereby participants donate a nominal amount for JSRDF to wear jeans (maybe \$1 or \$5)?

My former law firm in Chicago is doing this in February for JSRDF. Please let me know if you think this is something you would consider participating in.

The CRDN is not taking any funds from these efforts; rather, the CRDN is asking that our members and members of other "rare" organizations provide any photos, video, blogs, etc. of any jeans-themed events, so that the CRDN can use them to further promote the cause and demonstrate some unity in the children's rare disease/disorder community.

We are also selling \$1 Makes a Difference paper cutouts (fashioned to look like jeans with legs overlapping, like an awareness ribbon). The CRDN is customizing the cutouts to reflect the particular group using them to raise funds. For example, those that JSRDF members use will indicate that the proceeds from the sale of the cutouts will go to JSRDF. I have approached some local businesses (restaurants, stores, a salon, etc.) to sell these in February for \$1.

If you are interested in approaching any businesses in your area, please let me know and I can get you the design. The ad agency working on these (pro bono) is also planning to create a poster that can be customized with our logo for the Global Genes Project. The CRDN has done a wonderful job in getting the advertising, public relations, documents, social networking, etc. set up for this initiative and really deserves a lot of thanks. I appreciate you considering participation in this initiative!

Elizabeth Joshi

## What's in a Name?

From the [www.disabilityisnatural.com](http://www.disabilityisnatural.com) E-Newsletter by Kathie Snow

See the third-grade boy having fun, playing with his classmates at recess? Sometimes his pals give his wheelchair a push, other times he wheels himself. Their teacher, Mr. McHale, arrives to escort his students back to class, and he calls out to the boy, “Hey, Hollywood, let’s round ‘em up and move ‘em out!” Hollywood grins, and his eyes light up behind his sunglasses.

The boy was very light sensitive, and the large, dark glasses shielded his eyes from the bright sun. He loved movies (and was quite a ham), and his teacher thought he looked cool—like a Hollywood star—in his oversized dark shades, so he nicknamed the boy Hollywood, and he named him well.

Some might have referred to the boy—my son, Benjamin—as the wheelchair boy, crippled kid, sped student, CP kid, or some other offensive descriptor. But to his teachers and classmates, he was Hollywood—he wore the name proudly—and what a difference the name made!

What about you? Are you the PTA Prez, Yankee Bob, Hot Mamma, or maybe something more generic, like the sports nut, the scrap-booker, or the church lady? Maybe you have different descriptors: one with family, another at work, and a different one when you play.

Maybe you named yourself or someone else named you, but whatever the descriptor, it’s most likely something relevant and meaningful that says something positive about you. (If others gave you a negative label, hopefully they don’t use it in front of you, and shame on them for using it at all.)

Can we do the same for people with disabilities? Let’s use nicknames that tell us something positive, interesting, or unique about the person, instead of a medical diagnosis (CP kid, retarded, autistic, Down’s, etc.) or a pejorative characteristic (hair-puller, head-banger, foul-mouthed, aggressive, manipulative, etc.). What difference could this make in a person’s life?

Imagine the outcome when Mr. McHale met with the fourth-grade teacher to discuss the next school year for my son, and he talked about *Hollywood*—instead of the CP kid or something else. Mr. McHale presented Benjamin as a delightful, funny, and talented boy, so that’s how the fourth-grade teacher was introduced to him. His nickname and the positive characteristics shared were more important and more valuable, and they revealed more about him, than the diagnosis.

As we change, nicknames change. Later, Hollywood was replaced by HeroMan because of my son’s love of super-heroes. Other affirmative descriptors followed (including College Man and Handsome).

It’s critical to ensure that any nickname used is positive, and is also embraced by the person so named. During my own childhood, being called Motor Mouth was not pleasant.

Is there a Hollywood in your life, or maybe a Superstar, Pizza Guy, Book Lover, Baseball Boy, or Pink Lady? What if we saw Mary’s love of wearing pink as a unique passion, instead of an inappropriate obsession? Don’t people *without* disabilities have unique passions that are valued and/or respected?

Imagine sharing information about a child or adult with a disability that *begins* with a positive, interesting, respectful nickname at a team meeting, or when introducing the person to someone new. Imagine using that term on a regular basis with the person (“Hey, Hollywood!”).

The words used about us can have a powerful impact. People can evolve and grow in positive ways when positive terms are used, and they can rebel and react in negative ways when negative terms are used. What outcomes do we want?

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Contact [kathie@disabilityisnatural.com](mailto:kathie@disabilityisnatural.com) for reprint permission.

Visit [www.disabilityisnatural.com](http://www.disabilityisnatural.com) for new ways of thinking!



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



**REMINDER: ONLINE SHOPPING**



Shop online. Support the JSRDF. Designate the Joubert Syndrome & Related Disorders Foundation as the charity you'd like to help. Part of your purchase goes to our Foundation. After you have chosen JSRDF on the website, it should appear somewhere on the screen before you place your order. Check out: [www.igive.com](http://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](http://www.escrip.com), sign up, locate Joubert Syndrome & Related Disorders Foundation and indicate JSRDF 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 JSRDF. 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 JSRDF. 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!!**

**UPDATE:**

**Albertson's Community Partners Program has been discontinued (effective January 31, 2010)**



The foundation will receive its last check sometime in February.

This fundraiser/campaign brought in \$3391.25 since May 2002.

**Thank you to all who participated over the years!**

**United Way:** If you are a **non-Federal employee**, you can select the Joubert Syndrome & Related Disorders 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 JSRDF 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 JSRDF. 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 •
- JSRDF with a statement in your will or •
- trust. •
- 
- Your bequest in your will provides a •
- legacy of your concern for children with •
- JSRDF and their families. It will sup- •
- port the JSRDF as we strive to make a •
- difference in the lives of families •
- touched by JSRDF. •
- 
- The JSRDF is registered as a 501c3 •
- nonprofit corporation in many states. •
- 
- • • • •



The JSRDF is in our 19<sup>th</sup> 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 JSRDF 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 JSRDF's Annual **Rainbow Letter** Fund-raiser. 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.jsrfd.org](http://www.jsrfd.org) under the "How you can help" section.

**Thank you for your continued support!**

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or aconstantinescu@mhs.net  
*Call with questions regarding kidney issues*

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

**Next newsletter deadline:                  April 2010**

**SAVE THE DATE: July 13 -16, 2011 for the JSRDF Conference in Orlando Florida. Please check the JSRDF website, under conferences, for more information as it becomes available!**