

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 1

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2009 Membership Letter

Dear Friends and Family,

2009 promises to be an exciting, yet challenging, year for the Joubert Syndrome Foundation and Related Cerebellar Disorders. We are all looking forward to the upcoming JSF&RCD Conference, which will be held in July 2009. The conference committee has been very busy putting together a wonderful program! For more information about the events that are planned, please check out the Joubert website at www.jsfrcd.org. We hope to see you all there!

Donations that are received by the Foundation are used to cover many expenses, such as those associated with hosting a conference. As a result of the costs that are incurred, we have to look for other ways to reduce the expenses associated with running a Foundation.

The cost to print and mail *The Rainbow* newsletter 4 times each year is approximately \$2,750. This does not include the countless volunteer hours spent putting the newsletter together and getting it ready for mailing. In order to eliminate this expense, the JSF&RCD newsletter will continue to be produced 4 times a year; however, the newsletter will no longer be printed and mailed to paid members. **The newsletter, which is filled with stories about our children, questions and answers from parents, research updates, and articles of interest, will be available on the JSF&RCD website (www.jsfrcd.org).** We do realize that there may be families or friends who do not have access to a computer. In those rare instances, we will have a limited number of newsletters printed that will be mailed to families upon request.

The Foundation has a number of board members, who have served the Foundation for many, many years, whose terms will be expiring in July. We are looking for some dedicated volunteers interested in becoming more involved in the Foundation. If you are interested in becoming a board member, or learning more about the Foundation, please contact one of the board members.

Our Foundation is now in its 17th year! We will continue to focus on our goals of increasing participation in the Genetic Alliance BioBank and other research studies; increasing awareness of Joubert Syndrome and Related Cerebellar Disorders within our communities; enhancing our database; and improving our fundraising efforts. Our most important goal, however, continues to be providing support to you, our families! We hope you join us as we strive to achieve these goals in 2009!

We need your financial support. Our minimum membership contribution for 2009 remains at \$35.00 (\$40.00 for families outside the USA). Payment can be made by check or money order, credit card, or through Paypal at www.jsfrcd.org. If you pay online, please remember to provide updated information for the areas listed on the membership application. Your membership dues will help fund the JSF&RCD conference in July, as well as cover expenses for printing and mailing parent packets, maintaining our information-packed website, and supporting the Genetic Alliance BioBank, and other research efforts.

This membership letter was mailed to all families and donors in our database. Please take a few moments to update your family information. Please complete the membership application and return it with your membership payment to The Joubert Syndrome Foundation and Related Cerebellar Disorders, c/o Janet Gundling, 8 Ash Road, Jackson, NJ 08527. If you are unable to make a payment due to a financial hardship, and would like to be a member of the Foundation, please send us your updated information with a note that you'd like to remain a member. If you would like to be removed from the database, please indicate that as well.

Your paid membership, active participation in fundraisers, donations, and volunteer hours continue to be necessary for our Foundation's survival. Thank you in advance for your continued support of the Joubert Syndrome Foundation. Best wishes to all of you for a healthy and happy 2009! See you in July!

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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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2009 JSF&RCD Conference Information

REGISTRATION

Each conference attendee must register for the conference. Registration fees include: all workshops and materials, individual consultations with scientists, and 2 meals daily (except for Wednesday).

The registration fees for the 2009 conference will be:

\$300 – Adults \$225 – Grandparents/Caregivers/Individuals with JS, ages 11+ \$200 – Children, ages 4-11
\$0 -- Children, ages 3 and under *Individuals that will not be eating conference meals due to a medical condition and/or infants will not be charged a registration fee.

HOTEL

The JSF&RCD conference will be held July 15-18, 2009 in Cincinnati, OH, at the Sheraton Cincinnati North Hotel. You can find out more about the hotel's offerings at: www.sheraton.com/cincinnatiorth.

The confirmed room rate is **\$107/night** (price does not include any local/state taxes) for 1 king or 2 double beds, during the conference. This rate will be good for 3 days before/after the conference for those families that would like to extend their stay.

To receive these special room rates, families must make their own room reservations by June 23, 2009.

MORE INFORMATION

Additional information--including presenters, presentation topics, hotel information, and registration forms--is available on the JSF&RCD website under 2009 JSF&RCD conference.

We are looking forward to seeing everyone in Cincinnati this coming July!

The 2009 Conference Planning Committee

The Joubert Syndrome Foundation & Related Cerebellar Disorders needs your help!

The Joubert Syndrome has been around since 1992 and has made tremendous progress over the years. We are at a point in time where additional help is needed to keep the Foundation going. We are looking for volunteers to join the Board of Directors, to become officers, to help on various committees, and to help raise money to support the Foundation going forward.

Several Board positions will be opening up in July 2009. If you are interested, or would like to learn more about the responsibilities of board members, please contact us today. If you can spare a few hours a month, you are the right person for the job!

Board of Directors: The role of a member of the JSF&RCD Board of Directors is to ensure that the JSF&RCD is operated in a way that ensures progress towards the JSF&RCD's goals, both short- and long-term, and that the organization is operated in a responsible manner.

Responsibilities:

- ♦ Approve an annual operating budget, including any funding and expenditure plans
- ♦ Provide constructive criticism, advice, and comments on any and all aspects of the organization's operations
- ♦ Participate in Board meetings via toll-free phone calls every other month (approx. 2 hours in length)
- ♦ Chair/Co-chair a JSF&RCD committee
- ♦ Submit monthly committee reports to the Board via email (or designate a committee member to do so)
- ♦ Communicate with Board members and/or committee members via phone or email, as necessary
- ♦ Assist with JSF&RCD projects, as necessary
- ♦ Attend JSF&RCD Conferences and/or face-to-face board meetings
- ♦ Help raise awareness of the JSF&RCD in your area

Officers: Officer positions within the JSF&RCD include: President, Vice President, Secretary, and Treasurer. Officers do not have to be members of the Board of Directors.

Responsibilities:

- ♦ Duties of each position are inherent to the office
- ♦ Participate in Board meetings via toll-free phone calls every other month (approx. 2 hours in length)
- ♦ Submit monthly reports to the Board via email
- ♦ Communicate with Board members and/or committee members via phone or email, as necessary
- ♦ Assist with JSF&RCD projects, as necessary
- ♦ Attend JSF&RCD Conferences and/or face-to-face board meetings
- ♦ Help raise awareness of the JSF&RCD in your area

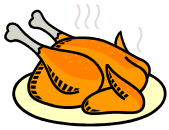
Term Limits: two (2) years, to coincide with JSF&RCD biennial conferences

Committee Members: Committee members act as advisors to the JSF&RCD Board of Directors on various aspects of Foundation business. There are no term limits for members. Current JSF&RCD committees and their primary responsibilities:

- ♦ **BioBank** -- administration of the JSF&RCD BioBank, including sample collections and distribution
- ♦ **Conference** – coordinate planning of the JSF&RCD family conferences, held every two years
- ♦ **Correspondence** – compose and mail cards to donors, JSF&RCD membership and/or professionals as appropriate ('thinking of you', sympathy, holiday, etc), assist with mass mailings to JSF&RCD membership
- ♦ **Finance** – oversee day-to-day financial aspects, approve annual budget, monitor committee expenditures, prepare charitable registrations, meet annually with accountant to prepare for tax return and audit
- ♦ **Fundraising** – organize and manage JSF&RCD fundraising activities, explore new ways to raise money
- ♦ **Grants** – apply to family foundations and major corporations for financial support/grants
- ♦ **Membership** -- maintain and monitor JSF&RCD membership, mail family packets, coordinate Regional/State Contacts
- ♦ **Scientific** -- attend medical conferences, maintain Professional Advisor and Scientific Advisor lists
- ♦ **Technology** – manage JSF&RCD database, website, publication of documents, conference DVD
- ♦ **Newsletter**— prepare the quarterly JSF&RCD newsletter

Responsibilities:

- ♦ Work and communicate with other committee members via phone or email, as necessary
- ♦ Participate in committee meetings via toll-free phone calls, as necessary
- ♦ Submit monthly committee reports to Board of Directors



How to Cook a Turkey

paraphrased from an article by Lori Miller Fox

Parents of children with special needs are all too aware of differences. Because of this, they get especially tired of being asked to keep up with other people's expectations. Finding the time or the patience to entertain for holidays, for example, is one luxury they can't always afford; however, many choose to spend their time in just this way – and they deserve to be applauded. So, to all the parents of special needs kids reading this, spend the holidays (heck, spend every day) in a way that is right for you and your family. If you want to entertain, do so – your way. Whether you go out, cook, or carry in, always bring laughter to the table.

Some turkey-cooking methods—

- *How an unfit school nurse cooks a turkey – Says it doesn't look right and sends it home.
- *How closed-minded case managers cook turkeys – Get everyone together in a big room, ask for everyone's opinion, and then cook it the way they planned to all along.
- *How an uncooperative Special Education Director cooks a turkey – Argues with you that you don't need a turkey.
- *How a lazy teacher cooks a turkey – Leaves it raw and hopes, when it's covered with enough gravy, no one will notice.
- *How a hostile teacher cooks a turkey – turns the heat up too high until it melts down, then, throws it out.
- *How a school bus driver cooks a turkey – Starts late, goes too fast, and then loses it in the oven.
- *How an unqualified school occupational therapist cooks a turkey – Doesn't cook the whole turkey, just cooks the wings.
- *How an incompetent school psychologist cooks a turkey – Says it does not lend itself to cooking, and then blames it on the bird.
- *How disinterested general education providers cook a turkey – Cook a ham, they do not know how to cook a turkey and it is not their job to *learn* how to cook a turkey.
- *How aloof Superintendents cook a turkey – Have it catered, because they don't want to get their hands dirty.
- *How an inadequate school speech therapist cooks a turkey – Doesn't care what it tastes like, as long as it's swallowed.
- *How aides cook a turkey – Make sure that the turkey does not irritate the teachers, staff, or other students while it's cooking.
- *How inept school Physical Therapists cook a turkey – They don't. They just can't get their minds off why it doesn't have good head control.
- *How an inferior transition coordinator cooks a turkey – Why bother? The side dishes are good enough.
- *How a reluctant tech team cooks a turkey – It never gets started. They're still evaluating which is the most effective way, gas or electric.
- *How a good teacher cooks a turkey – Cuts it up into bite-size pieces and cooks them separately to each child's individual taste.
- *How parents of special needs children cook a turkey – Cook a turkey? Yeah, like they have that kind of time! (And hats off to all of you who find the time to do just that.)

Happy Holidays to all (whatever you celebrate!), especially to the caring, knowledgeable providers who are complete opposites of those described above.



FYI...free websites...

Introducing www.DisabilityScoop.com, the premier source for developmental disability news. Whether you have a disability or you know or care for someone who does, DisabilityScoop.com is your one-stop source for reliable, unbiased news and information.

At DisabilityScoop.com, you will find:

- ♦ News stories that affect your everyday life, packed with useful information and tips. Full coverage of education, health, law, life and money issues directly facing the developmental disability community.
- ♦ A place to communicate and share with the millions just like you across the country who have or are impacted by developmental disabilities.
- ♦ Resources just for you, like how to find an attorney, school or therapist in your area.

www.transitiontocollege.net is an interesting website which addresses students with intellectual disabilities and college.



Getting to Know You and Family Updates



Raphael, 1 year old, Paris France

Raphael was born on 22/02/08 in Paris (France), which is where we live. He has been diagnosed with a syndrome related to the Joubert Syndrome, the Cogan - Type II, Oculomotor Apraxia (OMA) syndrome. He is astigmatic and long-sighted and therefore is wearing glasses. His kidneys, liver and retina have been checked and are fine. We did genetic testing in January and are waiting for the results.

As of today, Raphael can sit but he cannot move by himself or sit by himself. He has no problem in terms of motor functions related to his hands (he has his own way of holding a pen but can draw lines on a piece of paper, he can put cubes in a box etc.). He started saying a few words (four words exactly). He can clap his hands, wave goodbye, send kisses...

In terms of therapy, he started physical therapy (twice a week) in January, and end of March a third session per week will be added. Raphael is also seeing an orthoptist once a month to work on his oculomotor problems. In addition we started the Vojta method mid-January (we had two meetings) but I am not sure whether or not we will apply this method. We are also giving Raphael Omega-3 (EPA mainly). Raphael goes to daycare center while we're at work. He loves going there and being with other kids. He is a very sweet boy, happy all the time (or almost), very curious, who loves books and enjoys playing a lot.



Congratulations to the Goldstein's, New Jersey



We would like to announce the new addition to our family as of an hour ago. YES, we have a newborn girl named Jessica Rose Goldstein, born Dec 20th 19 1/2

inches, 7 lbs.

Sue was in Target about 1:00 when the adoption agency called and said that a woman has given birth and could not keep the baby. She did not want to even see it and asked for it to be placed in a good home. The social worker at the hospital called the adoption agency who immediate thought of us, being we have waited 3 years. They just brought her over. We have not told any family members yet as we are already going to a family dinner in a few minutes and will walk in late with our new holiday gift. This is the best gift we could have gotten for these holidays.

Dave & Sue

AND BIG BROTHERS JOSHUA & RYAN



Christopher Frazer, 16, Louisiana, enjoys shopping for a new game for his Wii!!!



FUTURE PREPPING YOUR CHILD

By Dan Coulter

Live in the moment. Prepare for the future. Two good pieces of advice. Success and happiness require a bit of both.

Balancing the present and future is hard enough for parents, but it can be even harder for our children who have Asperger Syndrome or similar conditions. Many are firmly anchored in the "live in the moment" camp. But ready or not, the future is coming.

I got to thinking about this when my wife, Julie, told me about her day at a high school college fair. She stood at table among a roomful of other representatives ready to explain the virtues of her alma mater to students. After each discussion, the students were supposed to get the representative's signature on a card. I suppose this was to ensure that students didn't just use the event as an excuse to cut class.

Some students in the room were interested and engaged the college reps with questions about the curriculums and campuses and their futures. Others spent their time hanging around talking with their friends and pretty much ignoring the representatives. Except to occasionally dart to a table, extend an arm and ask, "Would you sign my card?"

Interested in the future vs. living in the moment. In an increasingly tough, global job market, who's on track for a happy, successful life?

But preparing for the future doesn't mean you can't enjoy yourself now.

The magic formula is merging the two concepts to get our children so fired up about a subject that they use it to shape their futures. Many of our offspring have a head start. I can't even count the children on the autism spectrum I've met who are passionate about a special interest.

Sure, I hear you say, but how do I convert my son's obsession with Japanese Anime or my daughter's passion about weather into a career?

First, do some research about your son or daughter's interest. Contact people in a related business and find out what jobs exist in that field. Then, take your child to meet some of those people. You don't have to limit your aspirations to an existing job. Assess your child's skills and ask the people you're meeting with if an employer might craft a new job around those skills. Your weather-obsessed child may not be cut out to be an on-camera weather reporter, but might excel at building the computer models used in forecasting. If the skills your child has -- and wants to attain -- have value, you've got a shot. (If your child doesn't display a particular interest, perhaps your school could administer an aptitude test that could help you get the ball rolling.)

Your local community college also could be of help. Many have career programs and contacts with businesses you could use as resources. Or you could get in touch with your local chamber of commerce. Arranging a visit with a local artist or weather reporter could have a tremendous impact on even a young child. Set up these meetings with as many different people as possible. Discovering what your child doesn't want to do can be just as important as finding what he does. Remember, you're not working to absolutely determine your child's path. You're exposing him to possibilities and seeing what catches his imagination.

My son, Drew, has Asperger Syndrome. His special interests have changed over the years. When he was little, he was enthralled by Star Wars and Greek mythology. Later, he became fascinated with Japanese anime. But he's also interested in math and loves working with spreadsheets. At this point, he's hedging his bets, getting training in accounting so he can support himself while he finishes writing a book.

After getting a B.A. in creative writing, Drew went back to college for an accounting degree after we introduced him to an accountant and let him see what a job in that field would be like. And after he took a basic online accounting course to make doubly sure.

(Continued on page 8)

(Continued from page 7) Future Prepping Your Child

Business people often appreciate others who take the initiative. You may be surprised at the number of people who would be willing to talk with a student about their jobs. Especially if the student is excited about the visit. Some of these visits could even result in a part-time job or internship where your child can learn important job-related social skills.

Unemployment is especially high among people with Asperger Syndrome, not because they don't have the skills to do a job, but because they have difficulty interacting with supervisors and co-workers. Outstanding job skills and a base level of social skills can be a winning combination for someone with Asperger Syndrome.

A part-time job in high school can help your child learn crucial workplace lessons that could make the difference in keeping a full time job later on. If it's too much to deal with a job after school hours, consider a summer job. But try as hard as you can to find something related to your child's interests.

Consider how your child reacts when asked to do something that doesn't appeal to him. Compare that to how animated he can be when urging you to let him do something he loves. I just know that when my son is not interested in something, working on it can be like a long hike in ill-fitting boots. When he is interested, he's winged Mercury.

Here's hoping you can link your child's passion to a career that makes preparing for the future one of the most fun things he can do with his moments.

He might just land a job ahead of the typically developing kids who spend their living-in-the-moment time hanging out instead of talking to representatives at a college fair.

Now wouldn't that be something?

Dan Coulter is the producer of the videos, "Asperger Syndrome: Transition to College and Work" and "Asperger Syndrome: Transition to Work." You can read more articles on his website at: www.coultervideo.com.

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Categories of Disability under IDEA Law

There are 14 specific primary terms included in IDEA under the lead definition of "child with a disability." These federal terms and definitions guide how States define disability and who is eligible for a free appropriate public education under special education law. The definitions of these specific terms from the IDEA regulations are shown beneath each term listed below. Note, in order to fully meet the definition (and eligibility for special education and related services) as a "child with a disability," a child's educational performance *must be adversely affected* due to the disability.

(Check out NICHCY's website for more information).

1. Autism... ...means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects educational performance. Characteristics often associated with autism are engaging in repetitive activities and stereotyped movements, resistance to changes in daily routines or the environment, and unusual responses to sensory experiences. The term autism does not apply if the child's educational performance is adversely affected primarily because the child has emotional disturbance, as defined in #5 below.

A child who shows the characteristics of autism after age 3 could be diagnosed as having autism if the criteria above are satisfied.

2. Deaf-Blindness... ...means concomitant [simultaneous] hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness.

3. Deafness.....means a hearing impairment so severe that a child is impaired in processing linguistic information through hearing, with or without amplification, that adversely affects a child's educational performance.

4. Developmental Delay.....for children from birth to age three (under IDEA Part C) and children from ages three through nine (under IDEA Part B), the term developmental delay, as defined by each State, means a delay

(Continued on page 9)

(Continued from page 8) *Categories of Disabilities*

in one or more of the following areas: physical development; cognitive development; communication; social or emotional development; or adaptive [behavioral] development.

5. Emotional Disturbance.....means a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree that adversely affects a child's educational performance:

- (a) An inability to learn that cannot be explained by intellectual, sensory, or health factors.
- (b) An inability to build or maintain satisfactory interpersonal relationships with peers and teachers.
- (c) Inappropriate types of behavior or feelings under normal circumstances.
- (d) A general pervasive mood of unhappiness or depression.
- (e) A tendency to develop physical symptoms or fears associated with personal or school problems.

The term includes schizophrenia. The term does not apply to children who are socially maladjusted, unless it is determined that they have an emotional disturbance.

6. Hearing Impairment.....means an impairment in hearing, whether permanent or fluctuating, that adversely affects a child's educational performance but is not included under the definition of "deafness."

7. Mental Retardation.....means significantly subaverage general intellectual functioning, existing concurrently [at the same time] with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance.

(Note: *Mental Retardation* is the term found in the law since passage of the original legislation in 1975. In 2008, the American Association on Intellectual and Developmental Disabilities (AAIDD) (formerly the American Association on Mental Retardation, AAMR) and members of the community recommended use of the term *Intellectual Disability*. For changes in language to be made in the regulations, Congress must first change it in the legislation. Until such action occurs, we provide the existing language from IDEA.)

8. Multiple Disabilities.....means concomitant [simultaneous] impairments (such as mental retardation-blindness, mental retardation-orthopedic impairment, etc.), the combination of which causes such severe educational needs that they cannot be accommodated in a special education program solely for one of the impairments. The term does not include deaf-blindness.

9. Orthopedic Impairment.....means a severe orthopedic impairment that adversely affects a child's educational performance. The term includes impairments caused by a congenital anomaly (e.g. clubfoot, absence of some member, etc.), impairments caused by disease (e.g. poliomyelitis, bone tuberculosis, etc.), and impairments from other causes (e.g., cerebral palsy, amputations, and fractures or burns that cause contractures).

10. Other Health Impairment.....means having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that—

- (a) is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, sickle cell anemia, and Tourette syndrome; and
- (b) adversely affects a child's educational performance.

11. Specific Learning Disability.....means a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, that may manifest itself in an imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations. The term includes such conditions as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. The term does not include learning problems that are primarily the result of visual, hearing, or motor disabilities; of mental retardation; of emotional disturbance; or of environmental, cultural, or economic disadvantage.

12. Speech or Language Impairment.....means a communication disorder such as stuttering, impaired articulation, a language impairment, or a voice impairment that adversely affects a child's educational performance.

13. Traumatic Brain Injury.....means an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance. The term applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech. The term does not include brain injuries that are congenital or degenerative, or brain injuries induced by birth trauma.

14. Visual Impairment Including Blindness.....means an impairment in vision that, even with correction, adversely affects a child's educational performance. The term includes both partial sight and blindness.

Contact NICHCY, P.O. Box 1492 Washington, DC 20013 Tel: (800) 695-0285 Fax: (202) 884-8441
nichcy@aed.org



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



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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 Michei@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!!

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The JSF&RCD is in our 17th 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.

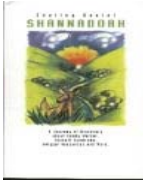
The "Rainbow Letter" presents a brief history of our Foundation, and our progress over the years. Please share the letter with your family, friends and others you meet who would like to support our Foundation.

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!

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).

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Next newsletter deadline



2009

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843-792-7715 mariabl@musc.edu
Call with questions regarding research & clinical manifestations

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

Email mcniffsandra@hotmail.com
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Reference AAC or Joubert.

Diane Lewis, MA, CCC/SLP

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

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