



JOUBERT SYNDROME &
RELATED DISORDERS FOUNDATION

The faith to believe, the hope to dream, the love to see it through

The RAINBOW

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.jsfrcd.org

Volume 18, Issue 4

Fall 2009

October, November, December

Notes from the Executive Committee

As the leaves are changing in the northern states and countries, the Foundation is also going through a variety of colourful changes!

The first change is the creation of an Executive Committee comprised of the President (Karen Tompkins), Vice-President (Nadine Phillips) and the Past-President (Michele Abdulaziz). This Committee approach will ensure greater transparency within our organization. The Executive Committee, along with the Board as a whole, is working toward updating many of the important documents that govern the Foundation, including by-laws, Mission and Vision Statements, and Strategic Plans. The Board has also adopted goals to focus our decision making on other issues such as projects and fundraisers. It is our hope that by taking this important step to create goals and subsequent action plans, the Foundation will grow stronger in order to serve the membership more effectively.

One goal that will pertain to each of you is the Board's commitment to contact each present and past member by phone to discuss your expectations of the Board of Directors as well as how the Foundation can serve the members. We will also take the opportunity to update our contact information at that time. If you know of anyone who has moved in the last year that may not have updated their information with us, please have them email membership@jsrdf.org or call Amanda Tulumalo at 609-538-1917.

The Board has initiated three new ways to raise the awareness of JSRDs. Please read more about the 10by10 Campaign (page 4); Global Jeans Day (page 9); and the new book *Different is Just Different* (page 10). All three are in line with the goals of the Board and a fun way to talk to new people about our kids AND make a difference!

Until next time☺

Karen, Nadine and Michele

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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.

JSF&RCD President

Karen Tompkins
519-776-5787

brainjuiceca@teksavvy.com

SEND DONATIONS TO:

Jonathan P. Morgan, Esq.
Morgan Rose, LLC
414 Hungerford Drive, Suite 252
Rockville, MD 20850
(301) 838-2010 - Main
(301) 738-7193 - Fax

SEND Newsletter Articles to:

Janet & Joe Gundling
8 Ash Road Jackson, NJ 08527
Tel: 732-886-6379

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Regions and Coordinators

PACIFIC Region (AK, CA, HI, OR, WA)

MICHELE ABDULAZIZ, Simi Valley, CA • 805-527-1007 • michii@allaboutjoey.com
CAROLLEE KRAUT, Camas, WA • 360-254-7945

WESTERN Region (AZ, CO, ID, MT, NV, NM, OK, TX, UT, WY)

SCARLETT SMITH, Broken Arrow, OK • 918-355-5308
ALISON RICKERL, Houston, TX • 281-286-9820 • smith_alison@hotmail.com

MID-WESTERN Region (IL, IN, IA, KS, MI, MN, MO, NE, ND, SD, WI)

SANDY BEVERLEY, Ingleside, IL • 847-587-5631 • mjbmail@core.com
JULIE SEBEST, Troy, MI • 248-641-7762 • jrsebest@yahoo.com
MICHELLE MCMILLIN, South Elgin, IL • 847-841-7230 • jpmslave@yahoo.com

SOUTH EASTERN Region (AL, AR, FL, GA, LA, MS)

STEPHANIE FRAZER, Mandeville, LA • 985-727-9196 • stephfraz1@bellsouth.net
ERA HALL, Savannah, GA • 912-233-9204 • erahall@comcast.net

MID-EASTERN Region (DE, KY, MD, NC, OH, SC, TN, VA, WV)

LIZ MORGAN, Rockville, MD • 301-424-9202 • lizmorgan66@yahoo.com
NADINE PHILLIPS, Reynoldsburg, OH • 614-864-1362 • nadinephillips@wowway.com
WENDY & MARK DEMARZIO, Midlothian, VA • 804-639-2913 • wendydem@comcast.net
mdezarzio16@comcast.net

NORTH EASTERN Region (CT, ME, MA, NH, NJ, NY, PA, RI, VT)

SUSAN GOLDSTEIN, Voorhees, NJ • 856-753-7652 • Eaglefan68@aol.com
JANET GUNDLING, Jackson, NJ • 732-886-6379 • jjgund@aol.com

AUSTRALIA

TRACEY STOTT, Redlynch, QLD • 61-7-40392387 • rtstott@bigpond.com
SUZANNE BLIOTT, Newcastle NSW • 02-49715433 or 04-22192846 • suzanne@aapt.net.au

BRAZIL

GILBERTO & LUCIANE DORIGATTI, Vacaria Rs Brazil • 054-231-3945 • gilbergatti@mko.com.br

CANADA

KAREN TOMPKINS, Kingsville, Ontario 519-776-5787 brainjuiceca@teksavvy.com

GERMANY: Gabriele Bruggehofe • In den Weiden 6 D-67722 Winnweiler 0049 6302 924377

ICELAND: THORHALLUR MAACK, Iceland • +354 897 0011 • thmaack@hive.is

INDIA: Debbie Townes, Juhu, Mumbai • debfridge@hotmail.com

ISREAL: AVIVA SHAUL, Hofit (972) 9-866 6561 • shaul-av@zahav.net.il

ITALY: BRUNO ORIO, Italy • +39.031880188 • b_orio57@hotmail.com

NEW ZEALAND

MICHELE REID, New Zealand • 0064 03 612 9950 • michelle.richard@paradise.net.nz

UNITED KINGDOM: FAITH DOUTHWAITE, W. Yorkshire • 01977 709173 • Faidid@aol.com

Below is a list of State Contacts within the USA. If you are interested in being a state contact, please contact Michele Abdulaziz at michii@allaboutjoey.com

STATE CONTACTS

AL - Sue McGlynn Birmingham, AL 205-678-2278 - mcglynnns@charter.net
AR - Nicole Ford Jacksonville, AR, 501 833-9217 - rford41@comcast.net
AZ - Cindy & Robert Schmitt, Anthem, AZ 623-444-7775 - rcschmitt@cox.net
CA - Michele Abdulaziz, Simi Valley, CA 805-527-1007 - Michii@allaboutjoey.com
CO - Samantha Waggett, Castle Rock, CO 720-519-0366 - waggett@comcast.net
GA - Era Hall, Savannah, GA, 912-233-9204 - Erahall@comcast.net
IL - Sandy Beverley, Ingleside, IL, 847-587-5631 - mjbmail@core.com
Michelle McMillin, Elgin, IL, 847-888-3736 - jpmslave@yahoo.com
IN - Roni McMains, Greencastle, IN 765-653-2880 - rmmcmains@depauw.edu

(Continued on page 3)

(Continued from page 2) State Contacts

KS - Jennifer Juenemann, Oberlin, KS, 785-475-2600 -
gjjuenemann@kans.com
LA - Stephanie Frazer, Mandeville, LA, 985-727-9196 -
stephfraz1@bellsouth.net
MA - Denise Jones, Tewsbury, MA 978-851-7675 -
Denise.Jones@med.va.gov
MD - Liz Morgan, Rockville, MD, 301-424-9202 - lizmorgan66@yahoo.com
MI - Julie Sebest, Troy, MI, 248-641-7762 - jrsebest@yahoo.com
Teresa Seaman, Tipton, MI 517-592-5710 - tseaman96@frontiernet.net
MN - Jackie Olson, Edina, MN 952-920-0664 - gandjolson@aol.com
NJ - Susan Goldstein, Voorhees, NJ, 856-753-7652 - Eaglefan68@aol.com
Janet Gundling, Jackson, NJ, 732-886-6379 - jjgund@aol.com
OH - Nadine Phillips, Reynoldsburg, OH (614) 864-1362 -
nadinephillips@wowway.com
OK - Scarlet Smith, Broken Arrow, OK, 918-355-5308
Philisha Lowe, Midwest City, OK, 405-610-3617 -
rug5ratz@wmconnect.com
PA - Luise Reading, Lititz, PA, 717-626-4953 - RDGCLJ@aol.com
SD - Jamie Brandt, Sioux Falls, SD 605-941-0969 - jamiem005@aol.com
TX - Alison Rickerl, Houston, TX, 281-286-9820 -
smith_alison@hotmail.com
VA - Wendy and Mark DeMarzio, Chester, VA 804-530-9345 -
wendydem@comcast.net mdemarzio16@comcast.net
WA - Carollee Kraut, Camas, WA, 360-254-7945
WI - Amy Giesen, Kimberly, WI, 920-687-0428 - amy.giesen@thedacare.org

Chair - Dan Doherty, MD
♦ John Carey, MD
Dept of Pediatrics
University of Utah Health Sc Ctr
50 N Medical Dr.
Salt Lake City, UT 84132
E-mail: John.Carey@hsc.utah.edu
♦ Howard P Levy, MD PhD
Johns Hopkins Univ Dept Medicine
10753 Falls Rd, Ste 325
Baltimore MD 21093
Tel: (410) 583-2774
Fax: (410) 583-2883
E-mail: hlevy3@jhmi.edu
♦ David B Flannery, MD
Medical Col Georgia
Dept Pediatrics, Sect Genetics
1120 15th St, BG 1071
Augusta GA 30912-3720
Tel: (706) 721-2809
Fax: (706) 721-5697
E-mail: dflanner@mail.mcg.edu
♦ Eric Rosenthal, MS, PhD
Myriad Genetic Laboratories, Inc
320 Wakara Way
Salt Lake City, UT 84108
Phone (Work) 801-584-3054
Phone (Cell) 858-248-0987
E-mail: erosenth@myriad.com

Scientific Advisory Board →→→→→→→→→→

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.

Dr. Dan Doherty, MD, PhD

CHAIR: Scientific Advisory Board

Dr. Dan Doherty grew up in upstate New York and earned his MD/PhD at the University of California, San Francisco (UCSF) followed by Pediatric Residency and Developmental-Behavioral Pediatrics Fellowship at the University of Washington in Seattle. He is now an assistant professor at the University of Washington, caring for children with all types of disabilities, particularly children with brain malformations and spina bifida. He also provides prenatal counseling for women carrying fetuses with central nervous system imaging abnormalities. His research interests include identifying the genetic causes of hindbrain malformations such as Joubert syndrome and studying these disorders in model systems such as zebrafish, mice and cultured cells. Ultimately, the goals are to provide better information and treatments for patients with brain malformations as well as learn more about normal and abnormal brain development. When he's not at work, Dan spends time with his wife and two children exploring the natural wonders of the Pacific Northwest.



10 by 10 Campaign

DO YOU REMEMBER the shampoo commercial that urged you to “tell two friends and they’ll tell two friends and so on and so on....” ??? Today, I am urging you to TELL **TEN** FRIENDS! Between now and October 10, 2010 (10-10-10) I am hoping you will ask

10 friends to ask 10 of THEIR friends to donate \$10 to the JSRDF.

Each member that “makes the asks” could bring in \$1000 in donations. These monies will go directly to offsetting the cost of programs offered to the membership (i.e. 2011 conference) as well as promoting research and education goals.

When you let us know that you are ready to ASK TEN FRIENDS, you will be sent the following documents:

- ✓Bookmarks to print off and hand out to donors
- ✓Tracking sheets to print off for your friends
- ✓Master tracking sheet to print out for you
- ✓Return address to send back the tracking sheets and checks

The purpose of this campaign is two-fold. First of all, we all have an “inner circle” of family and friends who have supported us over the years. Instead of asking them to donate monies again, we ask them to approach THEIR inner circle for donations. Even if their friends and families are not able to donate, we have educated one hundred people who may not have otherwise heard about our Foundation.

Please go to www.365to10by10.com and click on SIGN UP, OR email 10by10Campaign@jsrdf.org and request the Campaign materials, OR phone Karen Tompkins in Canada at 519-776-5787 to have the materials mailed to you. The website is also set up to take donations via PayPal.

Instead of simply asking for money, you could choose to host an event that costs \$10 per person. Then, you would ask 10 friends to INVITE 10 friends to the event (pot luck; concert; etc). Visit www.365to10by10.com and click on IDEAS. Be sure to let us know when and where your event is and we will provide you with a Media Kit that you can edit for your event. **Launched on October 11, 2009, we have 365 days to complete our 10by10 Campaign. GOOD LUCK☺**

Please Support the Joubert Syndrome Foundation by using iGive!!

By Elizabeth Joshi

Hi Everyone! I know there has been mention of iGive before on the foundation website, but as a new member of the board's Growth and Development Committee, I wanted to reiterate how wonderful this tool can be for raising funds for the foundation. I joined iGive recently and made just a few purchases online and it amounted to more than \$20 for the foundation.

I took what's below from iGive.com to explain how it works. Please note that the foundation will receive a \$5 donation for a purchase made within 45 days of joining. With the holidays approaching, it would be wonderful if JS families could keep iGive in mind (and maybe spread the word to family and friends via e-mail, Facebook, etc.) before ordering something online.

Once you are on the iGive website, you can connect to a number of retailers--for apparel, flowers, gift items, etc. It's great, easy and those extra \$5 donations could really add up for the foundation. Thanks so much for considering this!!

From the iGive website:

If you do happen to make a purchase through iGive within 45 days of joining, they'll donate an EXTRA \$5 to your favorite cause! With 757 stores in the iGive Mall and the new iSearchiGive.com search engine, it's easy to find the things you need AND raise money for a good cause.

HOW IT WORKS:

1. Join iGive.com to support Joubert Syndrome Foundation and Related Cerebellar Disorder. It's free, safe, and easy to join. <http://www.iGive.com/welcome/warmwelcome>. Don't feel like registering? Take iSearchiGive.com out for a spin and raise a penny (or more!) per search. Just visit <http://www.iSearchiGive.com> and type "Joubert Syndrome Foundation and Related Cerebellar Disorders" in the "Select Your Cause" area.
2. Shop through iGive.com's online mall ~ OR ~ Raise a penny search at iSearchiGive.com The iGive Mall features over 700 trusted online retailers like Amazon.com, Staples, Nordstrom, JCPenney, eBay, Expedia.com, Barnes & Noble, QVC, & PETsMART to name just a few! You'll NEVER pay more when you reach these stores through iGive.com. And if you take advantage of the coupons and free shipping deals posted at iGive.com, you might even save a few bucks! And with iSearchiGive.com, each qualified search earns a penny (or more!) for your cause.
3. Watch the \$\$ roll in for Joubert Syndrome Foundation and Related Cerebellar Disorders! Up to 26% of EACH purchase through [iGive](http://iGive.com) benefits your cause, along with a penny (or more!) per qualified search at iSearchiGive.com. Make that first purchase within 45 days and get a bonus \$5 donation, too!

Getting to Know You and Family Updates



Reggie Bush (Chris), Drew Brees (Mike)
and Trooper

TRUE FANS..... through and through
Hope all is well with everyone!

Stephanie Frazer
Louisiana

Tompkins, Kingsville, Ontario, Canada

The Tompkins NIH Experience☺

Kevin and I used to believe that if Erin didn't have eye/kidney issues by now, she never would have them. At the last conference, my family learned that this may not be an accurate assumption. Researchers at the National Institute of Health are looking at kidney and liver disease in ciliopathies such as autosomal recessive polycystic kidney disease, nephronophthisis, and Joubert syndrome. We were still having blood work and ultrasounds done every few years but we were not doing them annually. Erin was not showing any of the symptoms that are associated with kidney distress (frequent thirst and urination).

We had just discovered the genetic basis for Erin's Joubert Syndrome (C22D2A) and we were eager to learn. I had met with Dr. Meral Gunay (principal investigator of the NIH study on ciliopathies and JSRDs) and Dr. Theo Heller (investigates liver disease) while in Cincinnati. They were very concerned that people with a JSRD and were asymptomatic may become complacent about the annual blood work and ultrasounds and miss the early warning signs of kidney complications. Kevin and I agreed to enroll Erin in their study.

Erin is now 16 years old. We do not "force" her to have medical procedures done; she needs to agree to them. We discussed with her the types of tests (blood work; urine collections; ERG; MRI; EEG; ultrasounds; pulmonary function and echocardiogram). She agreed, with the promise of Cheesies and cookies, to participate in the study.

On October 19, 2009, we all boarded a plane to Washington, D.C. to spend five days at the Children's Inn. The flights, taxi/shuttle and room were all paid for. There was a stipend each day for food and the Children's Inn often supplied breakfast and supper. The Inn was a WONDERFUL place to be☺ Clean, colourful, spacious and friendly: the staff was helpful and there was always someone to talk to or a place to curl up and be quiet.

The first two days of testing were very long and difficult for Erin. Since she is not a little child, she could not curl up on my lap and nap when she wanted to or fall asleep in a stroller. She did manage to get through both days without a meltdown and she did a great job of "keeping it together". Thursday and Friday were easier days: not quite as long and the tests were not as difficult for Erin to tolerate.

Our results were a blessing! Not only does Erin not have any current symptoms, the organs themselves have no signs of genetic malformations. The way I understand it, Erin has a very low risk of ever developing problems with her retinas, kidneys or liver

For us, the participation in this study was a success story. We went hoping to discover if there were early warning signs and left knowing that we can breathe a lot easier. We are still not letting our guard down, however. We know that there are still so many things about our kids that surprise the doctors. We will continue to monitor her blood work and kidneys every few years to make sure that things are still on track for her.

If Erin's organs had shown any malformations, we would have known to monitor her yearly. Indeed, the NIH study pays for multiple visits over several years in order for them to learn more about our kids and the onset of these complications. We are so thankful that we took the time to participate. There are so many unknowns about our children's futures. It was good to be able to get a glimpse into one aspect.

Board of Directors Conference Call November 2, 2009—Minutes

Present: Michele Abdulaziz; Kathleen Daertez; Amy Geissen; Elizabeth Joshi; Jon Morgan; Nadine Phillips; Karen Tompkins; Amanda Tulumalo; Samantha Waggett

Regrets: Kelly Seymour; Kimberly Stapleton

Absent: Balinda Richard; Alison Rickerl; Carolyn Teshmacher; Monica Venezia

Called to order 8:08pm EST

***Adoption of Minutes:** Adopt Minutes from Aug 31, 2009 (Moved: Nadine; Samantha 2nd)

***Mission/vision statement: MOTION:** To adopt the draft Mission and Vision Statement from Sept 2009 (Moved: Jon; Amanda 2nd) **MOTION CARRIED**

Our mission is to serve individuals worldwide who are diagnosed with Joubert Syndrome and related disorders, their families and support networks by creating opportunities to connect with other families, researchers and/or medical professionals via a variety of mediums.

Our vision is to provide information and supports (including, but not limited to, newsletters; conferences; medical and therapeutic updates; attaining assisted devices; etc) to all stakeholders in the lives of people affected by Joubert Syndrome and related disorders.

***GOALS MOTION:** Move to adopt the goals as revised Oct 26, 2009 (Moved: Nadine; Elizabeth 2nd) **Motion Carried**

During our term in office (July 2009-July 2011)

1. Two research projects will be undertaken. Each project will reflect a “daily living” goal for the individuals/families with Joubert Syndrome and related disorders. (I.e.: assistive communication devices; common observable traits of JSRDs throughout their lifespan [tongue thrusting; apnea improving; etc]; alternative therapies etc)
2. A corporate donor will be found to underwrite the cost of creating, copying and distributing our professional marketing materials (press package).
3. Past donors will be contacted personally to thank them and illicit annual donations.
4. Participation in two awareness/fundraising campaigns at a national or international level. (10x10, Global Jeans Party)
5. Each member will be contacted and asked what the Foundation can do to better serve their needs. New goals will be drafted, in a timely manner, based on their responses.
6. Begin to lobby government and lawmakers to increase funding/support for the people the Foundation serves.
7. Expand our panel of Professional Advisors to include:
 - a) Insurance Issues, attaining medical care, attaining necessary local support resources, educational issues and resources
 - b) Expert Parent Advocates that can effect change between the relationship of the healthcare providers and associated professionals and parents/caregivers, as well as the educational community and the alternative therapy community.
 - c) Financial Issues specific to people with special needs and their parents/caregivers as well as available resources for fundraising, grants and scholarships for individuals

Pie Graphs of Financial Expenditures and Donation Dollars : Discussion surrounding categories and labels.

Decision: Karen will make changes based on the discussion. Will resend in order to have an email vote by end of November.

Logo --- report from Kimberly and Amanda. BRIEF Discussion and Vote: Will the Board grant an extension to finalize the new logo or will the Board move to changing the name within the existing logo. Decision: An extension will be granted for one month to find a new logo.

Amanda will chair an ad hoc committee to achieve this goal. All interested Board Members will respond to her emails in the next week.

Finance: need accounting software updated. Discussion surrounding future audit; reimbursement policy;

Budgets----Developed by Committee Chairs to reflect the projects in their Action Plans.

Other Business:

Merchandise: need to liquidate the branded items we currently have

Next Meetings: *Email Committee Reports (including action plans and any minutes from meetings) to Kelly on or before November 2 AND December 7, 2009 AND January 2, 2010. (First Monday of every Month)

*Conference Call on Monday January 25, 2010

Future Business:

Action plans-- This is the next step to the Goals that we adopt. A goal is just a statement unless you sit down and commit to paper WHO will do WHAT task by what TIME in order to achieve the goal. Your action plan can cover a one or two year period. Please call or email Karen if you want help in putting this together:)

Your Committee's Action Plan should detail HOW your committee will work toward achieving one or more of the Foundation's goals. This also provides focus for each chair and their members. Sometimes we get stuck in the brainstorming.

We need to make decisions and act on them. New ideas are always welcome; however, it is necessary at this point to decide and move forward. Perhaps, keep a log of all the great ideas and refer to it every few months to discern if it is time for a new project. GOALS are achieved by specific PROJECTS☺

Adjourn 9:26pm EST [Moved Jon; 2nd Nadine]

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

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

Mom to Alyshia and Brittany both JS

Leber Congenital Amaurosis

Three young adults with Leber congenital amaurosia (LCA), a severe, degenerative disease of the retina, reported improvement in vision after undergoing a specialized gene transfer procedure. This disease results from a mutation of a gene known as RPE65 and causes severe impairment of vision, beginning in infancy or early childhood. In October and December 2007, and later January 2008, the patients received a sub-retinal injection to replace the nonfunctioning gene as part of a phase I clinical trial funded by the National Eye Institute (NEI). The clinical study, led by investigators at the University of Pennsylvania, Philadelphia, and the University of Florida, Gainesville, tested the safety of the gene transfer procedure in humans.

“This ground-breaking gene therapy trial builds on 15 years of research sponsored by the National Eye Institute,” said Paul A. Sieving, MD, PhD, director of the NEI. “The study has partially restored vision in three young adults, and it demonstrates that gene therapy can be effective in treating human vision disease. Many human diseases are inherited in families and result from mutations in a single gene. These genetic conditions are particularly suited to potential treatment by gene therapy. This trial is an important demonstration of “proof of principle” and shows that we are on the right track. We can now invest in further work to refine, and ultimately expand, genetic treatment approaches.”

Given the positive results, the study will now be expanded to include more patients and will involve delivering healthy RPE65 genes to a wider area of the retina to confirm the effectiveness of the therapy and to refine gene transfer techniques. The NEI is part of the National Institutes of Health (NIH). For further information, go to <http://www.nci.nih.gov/lca/>.

Research Information.....

From: AnneMadeo [anne.madeo@nih.gov]

Sent: October 14, 2009 12:06 PM

To: Genetic Alliance Member Email List

Subject: [memberforum] NIH research into experiences of parents with a child who is undiagnosed

The National Human Genome Research Institute at the National Institutes of Health (NIH) is sponsoring a study that seeks to learn more about how parents of children with an undiagnosed medical condition think and feel about their child's condition. We hope that this knowledge will improve the health care and counseling for these parents. Men and women who are 18 years or older and have at least one child with a medical condition that has remained undiagnosed for more than 2 years are needed to take part in this study. Participation involves one survey that takes about 45 minutes to finish. The survey can be taken online or a paper copy can be mailed to you.

For additional information about this study, you may review the Notice to Participants <<http://www.surveymonkey.com/StudyNoticeUncertainty>> disclosure.

If you have questions, please contact: Anne C. Madeo, MS, Principal Investigator Genetic Counselor National Human Research Institute National Institutes of Health Bldg. 31, Room B1B36 31 Center Drive, MSC 2073 Bethesda, MD 20892-2073 Phone: 301-443-2635 Email: anne.madeo@nih.gov

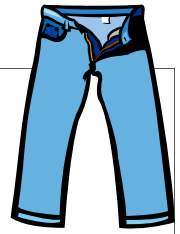
Send Us Your Updated Email Info!!!!



Would you like to receive the latest information from the JSRD? Keep up to date by sending us your latest email address. We would like to keep you informed of the latest information on research, fundraising, conferences, and general news by sending you “JSRDF E-Blasts”. So, if you would like to make sure you are in the loop, send your email address to Amanda Tulumalo at atulumalo@jsrdf.org.



Growth and Development Projects....



I wanted to update you on some of the progress as to the **Global Jeans Party** campaign led by the Children's Rare Disease Network (formerly known as Project Charity--Nicole Boice, the founder and CEO is a close friend of Kelly Seymour). The CRDN has been working hard to encourage various organizations pertaining to children's rare disease (often genetic in nature like JS) to join forces for the Global Jeans Party, to be held the weekend of Feb. 26-28 (as Feb. 28 is World Rare Disease Day). I would love it if each of you would consider hosting any type of jeans-themed party (with jeans being a play on the word "genes") at which you accept some type of donations on behalf of JSRDF. The party can be big or small, can be simple or fancy, and can be for kids or adults. In other words, it can be anything you want and could be held at a home or business. The scale of the party is completely up to you. The goal is to get as much participation from JS families as possible, so please encourage others you know touched by JS (other foundation members or even some of your own friends/family) to consider hosting some sort of jeans party. For example, I told my old law firm about this and they are going to have a "jeans day" in the law firm and have some prizes/raffles and collect money for JSRDF. In addition, one of Shaan's caregivers is organizing one at her church. Even though we are partnering with other organizations for children's rare disease on the Global Jeans Party campaign, our organization will keep the proceeds from the parties we host.

Nicole Boice is working with an advertising agency and various large corporations considering partnership on this project. She asks that if you host a jeans party, that you please provide her with any photographs, media stories, blogs, Facebook posts, etc. so that she can gather all such materials from the parties held by JS families and others touched by children's rare disease. She will then take these materials in an effort to garner more media and corporate attention for the plight that all those affected by children's rare disease share--the need for research and better funding to improve our children's lives. The philosophy of the CRDN is that when you take all of the many rare children's diseases and put them together, rare is actually quite common.

I have been working with Nicole and fellow committee members on various aspects of the planning of the Global Jeans Party campaign. One item that we are presently working on is to contact businesses (local and national) to encourage them to sell paper cut-outs of jeans at check-out for \$1.00. I have approached a local Starbucks and have made a list of other potential companies that we intend to approach. The proceeds will be shared by the organizations like JSRDF involved in the Global Jeans Party. If any of you have any ideas regarding this or the Global Jeans Party campaign in general, or if you have any questions, please feel free to contact me.

I will keep you posted as things unfold further! Thanks!

Elizabeth Joshi



This is Shoo Bear!

**Join her as she talks
about all the different
things she likes!**

**Shoo Bear knows that
every one is different.**

**Buy your copy today
and support the
JSRDFoundation.**

DIFFERENT IS JUST DIFFERENT

by Karen Tompkins

illustrated by Karen Morand

Published through Walkerville Publishing

Shoo Bear is the 'brainchild' of Karen Tompkins. Karen is a teacher with a background in Special Education as well as Arts Across the Curriculum. She has devoted her career to ensuring that students of all ages believe that "different is just different... it is not a judgement."

Her older daughter, Erin, has Joubert Syndrome [www.jsrfd.org] and has struggled with "Why did God make me different? I don't want to be different!"

The book is in response to wanting to help all people celebrate their differences.

Karen Tompkins' daughter started her education in a mainstream classroom with some supports for academics and her physical needs. In grade 4, Erin started to notice that her best work was not the same as her classmates work. One day, Erin came home very upset. When questioned, she said through her tears: "Why did God make me different? I don't want to be different!". The usual discussion of everyone is different just didn't sit well with Karen; after all, Erin felt that her difference was VERY different. This book is a reflection of Erin's pain and Karen's learning that different is just different.... really.

The Joubert Syndrome & Related Disorders Foundation has purchased multiple copies of this book as a fundraising tool. For every book purchased, 60% of the money goes directly to the Foundation. Consider the many people in your life that could benefit from this book! Karen Tompkins also has a website that features many free downloads that support her book. www.ktompkins.com/different.

You could purchase a book for your:

- child's teacher and present it with a copy of a lesson plan from the website
- niece or nephew with copies of the coloring pages +/- or word puzzles
- a friend who is expecting with a copy of the Guided Reading Script for Parents

ALSO: Consider visiting the Foundation's website www.jsrfd.org and downloading the flyer and order form available there. Bring those to your workplace; church or club and sell multiple copies to other people... no need to buy them all yourself:)

There are several ways to order:

\$10/book purchase price. \$2 S&H for 1-2 books; \$5 S&H for 3-10 books \$10 S&H for 11-20 books.

International Shipping fees are the same as US Shipping.

If you are ordering more than 20 books, please contact Amy Giesen (agiesen@jsrfd.org) for specific charges.

All orders are to be paid in US funds to the JSRDFoundation.



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 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!!

- • • • •
- **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. •
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- The JSF&RCD is registered as a 501c3 •
- nonprofit corporation in many states. •
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- • • • •



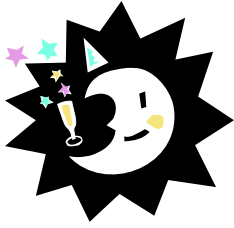
The JSF&RCD is in our 18th year! Thanks to your participation and support, Joubert Syndrome is more quickly diagnosed in children and adults. Word is getting out there! Your efforts, and the hard work of our Foundation, continue to spread the word about Joubert Syndrome.

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.jsfrcd.org under the "How you can help" section.

Thank you for your continued support!



Next newsletter deadline

January 2010



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Florida Eye Specialist Institute
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

Grant T. Liu, MD

Professor of Neurology & Ophthalmology
Division of Neuro-ophthalmology Department of Neurology
University of Pennsylvania Medical Center
3 West Gates Bldg., 3400 Spruce Street
Philadelphia, PA 19104-4283
215-349-8460 Fax 215-349-5579 Website: www.upno.org
Dr. Liu also sees patients at CHOP
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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 Bmaria@mcg.edu
Call with questions regarding research & clinical manifestations

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

Email mcniffsandra@hotmail.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
dianelewiscs@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.