

# Heart to Heart

Volume 6, Number 1 • Spring • Summer 2009

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## 2009 CCF GRANT RECIPIENT SELECTED for PROMISING STEM CELL THERAPY

The Children's Cardiomyopathy Foundation (CCF) is pleased to support the promising research of Charles Murry, M.D., Ph.D., director of the Center for Cardiovascular Biology and professor of pathology and bioengineering at the University of Washington. As CCF's 2009 research grant recipient, Dr. Murry will focus his research on deriving cardiovascular cells (cardiomyocytes) from pediatric cardiomyopathy patients to shed light on the disease mechanism and possibly establish new cardiac repair therapies.

The grant aims to grow heart muscle and vascular cells from stem cells made from readily available human skin cells.

As the skin cells will come from the patients themselves and not from embryonic stem cells, the newly generated cells will be genetically identical. This novel approach will circumvent the ethical controversy and possible immune rejection associated with using embryonic stem cells for therapy.



Charles Murry, M.D., Ph.D.

"Pediatric cardiomyopathy, by virtue of being genetically based, is an ideal disease to study using patient-derived induced pluripotent stem cells," Dr. Murry

*continued, page 3*



Talya and Tiana Tillman

On December 8, 2008, *People* magazine featured **Chicago Bears** cornerback **Charles Tillman**, but the coverage wasn't about his sensational tackles and interceptions on the field, it was about his young daughter's fierce fight against cardiomyopathy.

## The LITTLE HEART THAT COULD: The TIANA TILLMAN Story

On May 17, Charles Tillman was looking forward to flying back to Chicago with his family for the start of the Chicago Bears organized team activity (OTA) workouts. **Tiana**, his three-month-old daughter, came down with what was thought to be a cold. Three days later, Tiana was airlifted to Children's Memorial Hospital in Chicago. Her heart was failing.

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Children's  
Cardiomyopathy  
Foundation

**A Cause for Today... A Cure for Tomorrow**

The *Heart to Heart* newsletter is published biannually by the Children's Cardiomyopathy Foundation (CCF), a national organization dedicated to saving lives and improving the quality of life for children with cardiomyopathy. CCF's mission is to accelerate the search for a cure by supporting research, educating physicians and patients, and increasing awareness and advocacy related to the needs of affected children and their families. CCF is a publicly supported tax-exempt organization as described under section 501(c)(3) of the Internal Revenue Service.

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## From Lisa Yue, CCF Founder & President

Since CCF was founded seven years ago, it has grown into a global community of families all touched by cardiomyopathy. Over the years I have been struck by the incredible people within our community all motivated by the same mission to finding a cure. These CCF families, from across the globe who give their time and talents, come from all different backgrounds because cardiomyopathy knows no boundaries.

This issue shares the stories of families making a difference: families who organize fundraisers, create DVDs to raise awareness, and form support groups. We also have a special interview with Charles and Jackie Tillman. Charles is a cornerback for the Chicago Bears, and he, his wife and two daughters were living a dream before their lives changed forever.

These stories are our story, our collective cardiomyopathy story, which shares the heartache and hope felt after a cardiomyopathy diagnosis. As I hear from and speak to more parents, I am finding we need more ways to communicate and come together as a community. With this in mind, it is my vision to enhance our website in the coming months to make it a truly interactive community where families can upload photos and stories, exchange information and tips, and have quick access to support.

Now seven years strong, CCF continues to grow and help families around the world. It's been rewarding to be a part of this global CCF community, and I'm grateful for the inspiration and dedication of those who have supported CCF in their own unique way over the years.



## CCF Spring Appeal:



We are  
One Family,  
One Community.

An immeasurable source of strength, the CCF community provides comfort, support and guidance to families living with this disease. We are one community, working hand-in-hand searching for a cure.

**Watch for our spring appeal mailing.** We need your support to continue our work on behalf of all families affected by pediatric cardiomyopathy.

A donation and company matching gift also can be made using the enclosed envelope or online at [www.childrenscardiomyopathy.org](http://www.childrenscardiomyopathy.org).

## CCF-FUNDED INVESTIGATOR Published in *Human Molecular Genetics*

CCF-awarded investigator, **Ju Chen, Ph.D.**, of the University of California at San Diego published his latest research findings in the November 21, 2008 edition of **Human Molecular Genetics**. This is the third publication that has resulted from his study, which was funded by CCF in 2005.

The findings in the article, “**Cardiac-Specific Ablation of Cypher Leads to a Severe Form of Dilated Cardiomyopathy with Premature Death**,” conclude that the Cypher protein plays a pivotal role in maintaining cardiac structure and cardiac function in mouse research models. In his study Dr. Chen shows that the removal of the Cypher protein from the heart results in dilated cardiomyopathy with premature death and suggests that specific biochemical signaling pathways working in conjunction with mutations in the Cypher

protein causes heart failure.

Dr. Chen was awarded seed funding by CCF for his research, “**Involvement of Cypher Specific Isoforms in Dilated Cardiomyopathy**.” Findings from this preliminary study helped Dr. Chen secure a five-year grant from the **National Heart, Lung and Blood Institute** in 2006. In the following year, Dr. Chen published his research results in two scientific journals, *Progress in Pediatric Cardiology* and *Trends in Cardiovascular Medicine*.

## CCF Grant Recipient Selected for Stem Cell Therapy

*continued from page 1*

explains. “We should be able to make cardiac muscle tissue that is genetically identical to the patient and then use this to better understand the basis for cardiac dysfunction and how to establish novel treatments.”

**Dr. Murry will focus his research on deriving cardiovascular cells (cardiomyocytes) from pediatric cardiomyopathy patients to shed light on the disease mechanism and possibly establish new cardiac repair therapies.**

Dr. Murry will use skin cells from genetically healthy pediatric patients to test this approach. He will inject four genes into fully-developed skin cells and then “re-set their clocks” to the embryonic stage, creating

induced pluripotent stem (iPS) cells. The iPS cells will be directed to differentiate into cardiac and vascular cells using protocols previously established in the Murry lab. The differentiated cells will then be combined to create three-dimensional cardiac tissue with an organized blood network system resembling human heart tissue.

Dr. Murry hopes to use skin cells of pediatric cardiomyopathy patients from Seattle Children’s Hospital. By forming 3-D cardiac tissue from the iPS cells of these patients, he can gain a better understanding of cardiomyopathy physiology, screen new drugs for its treatment, and potentially use the cells for heart repair.

With the extensive research he has completed on adult cardiac patients, Dr. Murry believes that lessons learned from the adult heart will translate readily to his proposed research application and will pave the way for future pediatric therapies.

## New HCM GENETIC TESTING Available

PGxHealth, a full-service CLIA laboratory, has been offering genetic testing for hypertrophic cardiomyopathy (HCM) since July 2008. It joins **Correlagen**, **GeneDx** and the **Harvard-Partners Laboratory** as providers of genetic testing services for cardiomyopathy. PGxHealth’s HCM panel screens for nine sarcomeric genes; MYH7, MYBPC3, TNNT2, TNNC1, MYL2, MYL3, ACTC, TNNI3, TPM1 plus three lysosomal storage disorder genes; GLA (Fabry Disease), LAMP2 (Danon Disease), and PRKAG2 (Wolf-Parkinson-White-Syndrome).

PGxHealth offers a comprehensive reimbursement process with major health insurers including **Medicare** and **Medicaid**. For more information, please visit PGxHealth’s website ([www.pgxhealth.com](http://www.pgxhealth.com)).

### CLINICIANS & SCIENTISTS

#### Request for Research Applications on Pediatric Cardiomyopathy

(Dilated, Hypertrophic, Restrictive, Left Ventricular Non-Compaction or Arrhythmogenic Right Ventricular Cardiomyopathy)

#### Description of Opportunity:

The Children’s Cardiomyopathy Foundation (CCF) is inviting investigator-initiated research applications for innovative basic, clinical, population, or translational studies relevant to the cause, diagnosis or treatment of cardiomyopathy in children under the age of 18 years. Funding is available in the range of US\$25,000 to US\$50,000 for one year of total direct costs.

#### Eligibility Requirements:

The principal investigator must hold an M.D., Ph.D. or equivalent degree and reside in the United States or Canada. The investigator must have a faculty appointment at an accredited U.S. or Canadian institution and have the proven ability to pursue independent research as evidenced by original research in peer-reviewed journals.

#### Application Deadline:

Grant guidelines and application form are available online at [www.childrenscardiomyopathy.org/site/grants.php](http://www.childrenscardiomyopathy.org/site/grants.php). The deadline for grant submissions is September 4, 2009 with final award decisions made by January 2010.

For more information, contact  
Lisa Yue, CCF President at  
866-808-2873, ext 901 or  
[lyue@childrenscardiomyopathy.org](mailto:lyue@childrenscardiomyopathy.org)

# CCF Family Members CREATE DVDS on PEDIATRIC CARDIOMYOPATHY

Three motivated CCF family members, **Tucker Davis**, **Misty McGatha** and **Heather Tucker**, have tapped into their creative energies to create inspiring DVDs to share with others the stories of their loved ones living with pediatric cardiomyopathy. The slideshows not only communicate facts, but also put a face to the disease in a memorable and comprehensible way, featuring pictures of families and children who live with the disease and informative text about pediatric cardiomyopathy and CCF's work.

Tucker Davis, son of CCF parents **David and Carol Davis**, was inspired by his youngest brother **Nathan's** struggle with cardiomyopathy. "As I've grown, I have become more aware of the seriousness of Nathan's heart disease," says Tucker. "I wanted to do something to help people understand that even though he's no longer in the hospital and looks like he is fine, there are still serious issues that he has to deal with every day." Tucker, a high school junior from Clinton, Okla., has presented his DVD to his school and local civic clubs.

Misty McGatha's life changed forever the day her daughter, **Sandee**, was diagnosed with dilated cardiomyopathy at 13 months. "We were told she would not leave the hospital without a new heart," says Misty of Van Buren Ark. "That was six-and-a-half years ago and today she is off all medications and is very active in softball & gymnastics...with her own heart!" To mark her daughter's fifth year of living with cardiomyopathy, Misty created a slideshow featuring many of the families she has come to know through CCF's listserv.

Joshua and Heather Tucker developed their slideshow to present at a fundraiser luncheon at Joshua's employer, **World Wide Group** in Spokane, Wash. The

video shares the story of how CCF was established as well as the story of their daughter, **Evangeline**, who was diagnosed with dilated cardiomyopathy at 3 months old. "The video really touched people," says Heather. "There wasn't a dry eye in the house."

The families believe their hard work will shed light on the trials and triumphs of CCF families living with the disease. Copies of Tucker Davis' DVD are available upon request through CCF. The Tucker's video is posted on [www.youtube.com](http://www.youtube.com) (search Children's Cardiomyopathy Foundation) and Misty McGatha's DVD is viewable from CCF's website ([www.childrenscardiomyopathy.org/site/slideshow.php](http://www.childrenscardiomyopathy.org/site/slideshow.php)).



## Medtronic Global Heroes Selects CCF as Beneficiary

The **Medtronic Foundation** donated \$4,000 to the Children's Cardiomyopathy Foundation on behalf of **Medtronic Global Heroes Tracie Happel, Shannon Polkinghorn, Katherine Thomas and Mark Carbonetta**. The Medtronic Global Heroes program chooses 25 runners from around the world whose lives have been improved by the help of medical technology and pays for them to travel to and participate in the **Medtronic Twin Cities Marathon** in Minneapolis, Minn. As part of the program, Medtronic donates \$1,000 to the nonprofit patient organization each runner selects. CCF was chosen by all four Medtronic runners, making it the most popular beneficiary organization of the races.

Tracie Happel and Shannon Polkinghorn have pacemakers, Katherine Thomas has an Intrathecal Baclofen therapy pump, and Mark Carbonetta has an implanted cardioverter defibrillator (ICD). With the assistance of their medical devices and motivated by their fighting spirits, these four runners "continue to live our running and racing dreams despite a heart condition," said Tracie Happel.

# A ROYAL FLUSH

## for CCF's First Annual

# POKER FUNDRAISER



Lisa Yue, CCF president and Jason Alpin, tournament winner

participants who made the event such a success.”

Everyone enjoyed an evening of cocktails, delectable food and poker playing. The night's grand prize winner was **Jason Alpin** of Imperial Capital, who won a \$10,000 entry to the **2009 World Series of Poker Main Event** in Las Vegas. Second prize, an all-inclusive trip for two to Las Vegas, went to **Marc Schwartz** of **Taconic Capital Advisors**. **Maggie Dowd** of **UBS** won the third prize of an Atlantic City get-away at **Harrah's**

Resort. Fourth prize, golf and lunch at **Hudson National Golf Club**, went to **Mark Frank** from InTrade Group. Fifth prize, tickets to a **NY Giants** game, went to **Ben Brogadir**. Sixth through tenth prize winners of \$75 gift certificates to **Modell's Sporting Goods** were **Zach Roth, Andrew Susser, Chris Savinelli, Dennis Witte** and **Beau Harbour**. First through fourth prize winners also received membership packages to the online poker site **SpadeClub.com**.

CCF hosted its first charity poker event, **All-In For A Cure No-Limit Texas Hold 'Em Tournament**, February 11, at **Strata** in New York City. With more than 160 attendees and 17 sponsors—including **Imperial Capital, InTrade Group, Brigade Capital Management, Katten Muchin Rosenman, Richards Kibbe & Orbe, Kramer Levin Naftalis & Frankel, RBS Greenwich Capital** and **TD Securities**—the event was a great success, raising more than \$124,000.

“I was excited to see so many poker players show up to help raise money for the thousands of children affected by this terrible disease,” said **Carney Hawks**, CCF board member. “In these challenging economic times, we are truly thankful for the support of our sponsors and individual



CCF Board members, Eddie Yu, Ian Sandler, Carney Hawks & attendee Al Piper



Attendees playing poker at Strata

7th Annual  
**Golf Classic**  
2009



Children's  
Cardiomyopathy  
Foundation

## SAVE THE DATE!

Montclair Golf Club  
West Orange, New Jersey

### Monday, July 20, 2009

Invites will be mailed in May. To reserve your playing spot or inquire about sponsorship opportunities, please contact **Sheila Gibbons** at 866-808-CURE (ext. 902).

Visit our event web page for more information.

#### 2009 Event Sponsors:

Anonymous Firm; Brigade Capital Management; Eric Cole; Harrah's Resort Atlantic City; Carney Hawks; Imperial Capital; InTrade Group; Katten Muchin Rosenman; Kramer, Levin, Naftalis & Frankel; Norm Louie; Modell's Sporting Goods; RBS Greenwich Capital; Richards Kibbe & Orbe; Edgar Sabounghi; Ian Sandler; the Sandler Family; SpadeClub.com; TD Securities; and the Yu Family.

## CCF FAMILY FUNDRAISERS

### World Wide Group Holiday Party Raises Funds for CCF

CCF parent, **Heather Tucker** and **World Wide Group**, Spokane, Wash., chose to support CCF at their holiday charity luncheon. The event, held on December 17, 2008, raised more than \$6,500 for CCF. The event honored Heather's daughter, **Evangeline**,



who was diagnosed with dilated cardiomyopathy and is now two years old. Heather and her husband, **Joshua**, created a video (see Families Create DVDs article) to show at the event which was attended by over 50 World Wide employees.

"I found CCF online while doing a search in November of 2007," says Heather. "I have been profoundly grateful for all the help CCF has provided my family." Heather knew World Wide Group sponsored a different charity each Christmas and persistently followed up for two years until the company selected CCF this past Christmas.

## More Family Fundraisers...

- In September 2008, **Mary Andrea** and **Shari Burns**, teachers from **Eastbury Elementary School** in Glastonbury, Conn., organized a walkathon in memory of **Colette Lane**, granddaughter of Principal **Dr. Sheryl Harriman**. Colette was 19 months old when she died of cardiomyopathy. On the day of the walkathon, students and staff wore pink shirts as a tribute to Colette's favorite color. Their efforts helped raise more than \$1,700.
- **Janessa Cavallo** and the **Iona College Delta Beta sorority** in New Rochelle, N.Y., hosted "**Punk-d**," a charity concert with college bands on November 22. The concert raised funds for CCF in memory of her father who passed away suddenly from cardiomyopathy.
- The **Fraser family** held a bowling fundraiser, **Cole's Bowl for a Cure**, in honor of their son's first birthday. More than 100 people attended the February 22 event in Ontario, Canada, which included a live band, face painting for the kids and a silent auction of many donated items from the community. The event raised more than \$3,000.
- **Melissa Witt** and **Sharon Belles** held their **Second Annual Sweetheart Social** fundraiser February 28, at the **Quilted Cottage** in Saginaw, Mich. The event, a silent auction of beautifully hand-made quilts, was planned in honor of Melissa's daughter, **Samantha**, who has dilated cardiomyopathy.

## Update on CCF's Parent Support Groups

CCF support groups offer a chance for parents of affected children to share information in an informal setting and connect with others who are facing similar experiences. Meeting four to six times a year, CCF has five support groups currently meeting at hospitals around the country. Scheduled groups are listed below. New groups are being formed in other states. Contact Kella Boyer, 866-808-CURE, ext. 905, to learn more about our existing groups or to see if a group is forming near you.

### ✓ GEORGIA

**Children's Healthcare of Atlanta at Egleston, Atlanta, Ga.**

**Conference Center, Classroom 5**

April 25, 2 - 4 p.m.

Guest speaker Dr. Mahle will speak on new medical technology and stem cell research as it relates to pediatric cardiomyopathy.

### ✓ MASSACHUSETTS

**Boston Children's Hospital, Boston, Mass.**

**Pavilion I Meeting Room**

April 28, 6 - 8 p.m.

June 23, 6 - 8 p.m.

August 25, 6 - 8 p.m.

October 27, 6 - 8 p.m.

December 8, 6 - 8 p.m.

### ✓ MICHIGAN

**C.S. Mott Children's Hospital, Ann Arbor, Mich.**

Meeting date & time to be determined

### ✓ NEW YORK

**Golisano Children's Hospital, Rochester, N.Y.**

**Strong Children's Heart Center, Room ACF-D**

March 14, 11 a.m. - Noon

June 13, 11 a.m. - Noon

September 12, 11 a.m. - Noon

December 12, 11 a.m. - Noon

### ✓ NORTH CAROLINA

**Duke University Medical Center, Durham, N.C.**

**McGovern-Davidson Health Center, Room 4902**

March 26, 6:30 - 8 p.m.

April 23, 6:30 - 8 p.m.

May 28, 6:30 - 8 p.m.

June, Baseball game outing. Details TBD.

September 24, 6:30 - 8 p.m.

October 22, 6:30 - 8 p.m.

## WOULD YOU LIKE TO HELP WITH A SUPPORT GROUP?

CCF is searching for parent volunteers for new groups in Miami, New York City, Houston, Cincinnati, Philadelphia and Omaha.

Again, contact Kella Boyer at ext. 905 to learn more.

# Our Circle of Hearts:

## HONORING 2008 TOP DONORS

The following corporations, foundations and individuals have made significant contributions to CCF, and we gratefully acknowledge their generosity and commitment to helping us find cures for tomorrow. Due to space limitations we are unable to acknowledge all of our 2008 supporters but extend our heartfelt thanks to those not listed.

If an error has been made, please accept our sincere apologies and notify us so that we may correct our records.

### \$10,000 and Over

Jeff Altman Foundation  
Bank of America Foundation  
CIBC World Markets  
Emil Costa  
Kramer Levin Naftalis & Frankel  
Norm Louie  
Medtronic Foundation  
Morgan Stanley  
Richards Spears & Orbe  
Edgar Sabounghi

### \$9,999 – \$5,000

Anchorage Capital Group  
Angelo, Gordon & Co.  
Evan & Beth Bernardi  
Blank Rome  
Bond Street Capital  
Andrew Brenner  
Brigade Capital Management  
Camulos Capital  
Benji Cheung  
Citigroup Global Markets  
Cleary Gottlieb Steen & Hamilton  
Lucas Detor  
Deutsche Bank Securities  
Robert & Karen Dishner  
Fried, Frank, Harris, Shriver & Jacobson  
Robert & Heather Gallivan  
Bill & Cynthia Goebelbecker  
Goldman, Sachs & Co.  
Shelley Greenhaus  
Hunton & Williams  
ICAP High Yield  
Jefferies & Company  
JP Morgan Securities  
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Lee Millstein  
Newedge USA  
Taconic Capital Advisors  
Tullett Prebon High Yield  
Wachtell, Lipton, Rosen & Katz  
Eddie & Lisa Yu

### \$4,999 – \$1,000

Abrams Capital  
Akin Gump Strauss Hauer & Feld  
Dan & Stacie Allen  
Robert Ambriano  
Rich Barrera & Purnima Puri  
Steven Bleier

Richard Brennen  
Broadpoint Capital  
Matt Carter  
Chatham Asset Management  
Sheree Chiou  
CIBC World Markets, Real Estate  
Finance  
Eric Cole  
Kevin & Ursula Corgan  
Elks Cranford Lodge  
Credit Suisse  
James Croom  
Victor & Patti DiSanto  
Tom & Shawna Doster  
Tom & Margaret Driscoll  
Jon Eckert  
Epic Asset Management  
Jared Epstein  
Roger Gilbert  
Robert & Dana Hamwee  
Malone & Jennifer Hart  
Mike Heaney  
Andrew & Rachel Hee  
Mike & Laura Henderlong  
Mike & Jennifer Hommefyer  
Lincoln Isetta  
David & Sarah Johnson  
Joseph Kasper  
Monica Keany  
Kids Helping Kids  
Mike Kirsh  
Jonathan Kolatch  
Daniel & Lauren Krueger  
Robert & Jackie Larsen  
Margaret Lee  
Lehman Brothers  
James Malley  
Joe Mannello  
Alain & Claudina Marcus  
Eugene & Renae Martin  
Clint & Kourtney Matter  
McDermott Will & Emery  
Miller Buckfire & Co.  
Kate O'Connor  
John O'Meara  
Dan & Lauren Ornstein  
Gene & Carmen Pagnozzi  
Michael & Leslie Petrick  
Posman Books  
Riva Ridge Capital Management  
Donald & Mary Lou Rossi  
Rothschild  
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Jacob & Melissa Sabin  
Whitaker Securities  
Scott & Sarah Snell  
Southpaw Asset Management

Stonehill Capital Management  
Neal & Constance Sullivan  
Theuerkorn Foundation  
Van der Linden Family Fdn.  
Vanessa's Big Heart Foundation  
Todd Vannucci  
Venor Capital Management  
Wagner Family Foundation  
Mark & Erica Warner

### \$999 – \$500

Gary Albahae  
Ken & Doreen Amano  
Archer Capital Management  
Andrew & Heidi Arthur  
Thomas & Shawn Boyce  
John & Barbara Callahan  
Bob Carroll  
Caspian Capital Advisors  
Robert Chui  
Tim Coleman  
James & Stephanie Cullinane  
Maureen D'Alleva  
Vincent D'Arpino  
Kathleen Dering  
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Karen Eltrich  
Edward Farscht & Lynn Jaeger  
Peter Fernandez  
Stephen Flynn  
Robert Frahm  
Robert & Jill Franz  
Doug & Shawna Froland  
Ken & Melissa Glassman  
Richard & Anne Grissinger  
James & Sheryl Harriman  
Carney & Melissa Hawks  
Tim & Tami Horan  
Daphne Hsu  
JMG Capital Management  
Bryan & Suzanne Karen  
Jed & Mary Kelly  
George Khouri  
David Klein  
Clint & Heather Kollar  
Stuart & Nicole Kovensky  
John & Jean Lepore  
Joseph Lyons  
Michael & Cynthia McEachern  
Thomas Mullarkey  
Lawrence & Jillian Neubauer  
Marty & Marina O'Malley  
Ann Railey  
Restoration Capital Management  
John Robinson  
Marc & Laurie Rollo

### \$499 – \$250

Armins & Cynthia Ruis  
Jason Safriet  
Adam & Heather Savarese  
Tom & Kathryn Saxton  
Chaney Sheffield, Jr.  
Jeffrey & Patricia Shilling  
Terri Lynn Stump  
Michael & Kristin Thomas  
Spencer Wells  
John & Jessica Withrow  
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Sunil Aggarwal  
Anton Anikst  
Carolyn Beckedorff  
Seth Bernstein  
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Ted & Aileen Burdick  
Peter Carroll  
Curtis & Lauralee Chamberlain  
Chesapeake Partners  
Sergia Coffey  
Marilyn & Merle Daniel  
Patricia DeLuca  
Carla Denly  
Robert Depiro  
Leslie Finerman  
James Fitzpatrick  
Stephen & Patricia Gerber  
Shelley Gifford  
William & Jean Goebelbecker  
Michael & Whitney Gomez  
Robert & Lori Hamilton  
Brent & Melinda Hanson  
Jed Hart  
Roger & Judi Hill  
Roger Joseph  
Joo In Kang  
Rick & Kristin Lasch  
Alan Maislen  
Edith Mazza  
Jeff & Noelle Miller  
Emilie Ng  
Justin O'Hara  
Michael & Ellen O'Hare  
Jeff Panzo  
Jennifer Parker  
Igor Pavlov  
Laurent Renard  
Ryan & Mandy Russell  
Greg & Cindy Ryan  
Brian Steinberg  
Ira & Shelley Taub  
Jim & Corinna Taubner  
US Sailing Team  
Bob & Annette Voreyer  
Stephen Walker & Diane DeLuca  
Darryl Webster  
Jack & Katheryn Wright  
Janet Yang-Devinney  
Dixon Yee  
Bill & Jean Yue  
Dick & Maggie Yue

## October Declared NATIONAL SUDDEN CARDIAC ARREST Awareness Month

In September 2008, the U.S. Congress passed a resolution declaring October as “National Sudden Cardiac Arrest Awareness” month. This legislation is designed to address the lack of national understanding about sudden cardiac arrest (SCA). Every year, during the month of October, organizations focusing on heart-related matters will implement activities to raise awareness about the risk of SCA. The goal is to improve the public’s ability to identify warning signs, encourage individuals to seek timely medical attention, and promote the need for further research into this silent killer.

## NEW NIH WEB RESOURCE: Useful Information on Clinical Trials

Recognizing that children are not just “little adults,” the National Institutes of Health (NIH) has launched a new website dedicated to providing parents and healthcare providers with information on children’s medical research. The site, **Children and Clinical Studies** ([www.nhlbi.nih.gov/childrenandclinicalstudies/index.php](http://www.nhlbi.nih.gov/childrenandclinicalstudies/index.php)), covers topics such as how studies are conducted, participant safety and privacy, and definitions of common terms encountered in clinical trials. Using both text and short videos of children, parents and providers, the NIH explains the importance of conducting research in children, the rewards and challenges of participating, and things to consider before deciding to enroll your child in a clinical trial.

## First Trial of GENE THERAPY for ADVANCED HEART FAILURE SHOWS PROMISE

At the 2008 American Heart Association Scientific Sessions, Celladon Corporation presented the positive findings of a genetically targeted enzyme replacement therapy, Mydicar, that they are developing to treat advanced heart failure. Under the guidance of Celladon co-founder Roger Hajjar, M.D., director of the Cardiovascular Research Center at Mount Sinai School of Medicine, New York, the newly developed therapy was shown to be safe and to have improved the heart function in seven out of nine adults in Phase I clinical trials. Dr. Hajjar will continue with Phase 2 of the study, which is expected to enroll 46 patients from 13 hospitals.

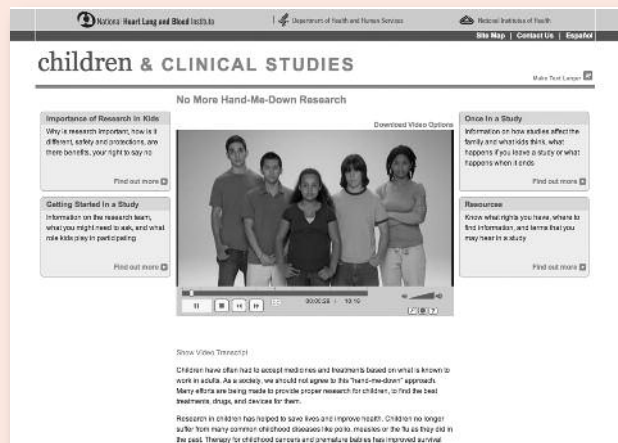
The Mydicar treatment involves a one-time infusion of a benign virus that transports the gene that produces enzyme SERCA2a for the heart. This enzyme plays an important role in ensuring that the heart contracts and relaxes properly. In late stages of heart failure, it was found that the enzyme levels drop. Mydicar repairs this molecular defect by restoring the depleted enzyme SERCA2a in the cardiac muscle, thereby reversing the

cardiac disease and improving cardiac function.

“This is different than what has been called enzyme replacement therapy in other diseases where people have manufactured and administered the enzyme into the bloodstream rather than introduce the gene that codes for the enzyme,” states CCF Medical Advisor Dr. Steve Colan, who reviewed the study findings. “The gene approach has a much higher likelihood of success because the enzyme gets produced in the cell and continues to be produced long term instead of requiring repeated infusions.”

He expects the type of cardiomyopathy patients that are most likely to respond favorably to Mydicar are those with acute onset dilated cardiomyopathy. “The hypertrophic and restrictive cardiomyopathies would be unlikely to respond because their myocyte contractility is generally normal,” Dr. Colan noted.

Current trials are being conducted on adults first for two reasons: to further assess safety and effectiveness before it is introduced to the pediatric community and to resolve the concern that gene delivery could affect the reproductive cells of younger patients.





# Q with Melissa Groman, LCSW



## Maintaining a Marriage or Relationship Through Difficult Times

**Melissa Groman** is a licensed clinical social worker in private practice in New Jersey. As a marriage therapist, she has been helping couples create satisfying, loving relationships for more than 20 years. Her work has focused on the gentle understanding of human relationships and helping people move forward through difficult times.

**Maintaining a marriage or committed relationship can be difficult, especially when caring for a child with a chronic illness such as cardiomyopathy. What are the most common things that can cause stress and tension in a marriage under these circumstances?**

We all come into a marriage with our own unique set of hopes, expectations and needs. We also bring along our individual barometer for tolerating discussions, intense feelings and upheaval. It is typical for one spouse to easily express their emotions and the other to have great difficulty knowing how they feel and how to talk about it. Emotional conversations can be overwhelming to some, while the absence of emotional dialogue can feel abandoning to others. One partner may have the idea that it's best to minimize attention to the illness and to keep things "normal." This

may lead to feelings of frustration or dismissal of what the other partner may be experiencing. For the spouse who feels anxious or angry, this can be upsetting and may create a feeling of distance in the marriage. Anxiety, anger and frustration are normal—though often painful feelings—for both spouses. The key is to learn how to deal with them in a way that is good for the relationship and fosters closeness.

Facing an overload of responsibilities, partners often wish their spouse could mind read and know how to communicate with them. Sometimes spouses believe that if their partner really loves and understands them, they would know what to say or do without having to be asked. Accepting that good communication takes practice and is not a natural by-product of love can go a long way towards making a better marriage.

**What are the top things you advise couples/partners to do to maintain a healthy and happy relationship?**

I suggest that couples commit to making time weekly, and in non-crisis times, to have "crucial conversations." Crucial conversations can be divided into two main categories: business and emotional. Emotional crucial conversations can include discussions about feelings—such as fear, anger and frustration—and thoughts about the future. Business crucial conversations can include household tasks, finances, parenting issues and family priorities. Couples who can agree to consult with each other have a better chance at riding out the stormy times intact.

Paying attention to the effect your own words and actions have on your spouse can go a long way in helping communication

*continued, page 11*

## Keeping Your Marriage Healthy and Strong

- Take time out for yourself and give your partner permission to do the same.
- Be willing to ask for help specifically and pleasantly.
- Avoid using emails and texting. Try to speak directly whenever possible.
- Understand your spouse's ability to tolerate the unknown, grief and medical information. Don't push for more discussion, assistance or space if your spouse is at their limit.
- Remember to just listen to your spouse sometimes. Let your spouse talk freely without commenting or correcting.
- Show consideration to your spouse and continue to say "please" and "thank you."
- Stay affectionate with your spouse and maintain a healthy intimate life.
- Acknowledge what your spouse does right and what you find most helpful.
- Build a network of supporters who can listen and help when you need more than your spouse can give.
- Be careful of outside influences on the marriage, such as in-laws or friends, who may be too opinionated or interfering. Put your marriage/spouse first.
- Check your expectations to see if they are realistic given the current situation.
- Seek professional help when things get rough.
- Communicate how you feel to your partner in an honest and direct way. Say what you mean in a nice way.
- Use "I" statements as much as possible (e.g. "I feel frightened when you yell." Or "Is there a way I can say how I feel that will be okay with you?")

## The Tiana Tillman Story

*Continued from page 1*

Tiana spent the next several weeks in the hospital. Charles and his wife, Jackie, were then told by doctors that Tiana had dilated cardiomyopathy and that she may need a heart transplant to survive. They were devastated, "I left the room; I felt like I was going to die," said Jackie. "Charles stayed behind and they told him that Tiana might not make it through the night."

Physicians ran myriad tests on Tiana and every member of the family to try to find a cause, but like the majority of pediatric cardiomyopathy cases, the cause was never identified. Cardiomyopathy in children can be either acquired (through a viral infection or cancer chemotherapy) or inherited through one parent or both parents. In Tiana's situation, they thought the disease might be related to a mitochondrial disorder but test results were inconclusive.

The Tillmans felt as though they were suddenly thrust into a frightening, new world where the outcome was unknown. "After every procedure, every test, it felt like the hour glass was turned over and we were racing against time," said Jackie. With each day, the Tillmans hoped that Tiana's heart would recover or stabilize, but instead her condition continued to deteriorate.

The most heart-wrenching day came when Charles and Jackie were told that the only option for Tiana was a heart transplant. The Tillmans had many reservations about the transplant and her quality of life afterwards, but after long, difficult discussions with Tiana's doctors, they made the decision to go forward with a heart transplant. "We knew that that's what we needed to do," Jackie said. "to give her a chance at life."

"I think probably the toughest thing that I had to battle with, and I still battle with it now, is that I knew in order for my daughter to live, another kid had to die," Charles said.

Trying to make sense of all that had happened to their family, both Jackie and Charles searched for answers and support. It was the Children's

Cardiomyopathy Foundation (CCF) and the Chicago Bears that threw them lifelines and gave them the encouragement to move forward.

CCF provided the informational and emotional support that Jackie needed. While in the hospital, she searched online for answers and found CCF's website. "It was the only thing that came up," Jackie said. "I registered right there in the hospital." Jackie found guidance and answers in CCF. "It gave me knowledge and reassurance that I wasn't alone."

For Charles, his team provided an anchor of support. "My teammates gave me strength by believing in me," said Charles. "They stuck by me the whole time, were very supportive in every way. Not just my teammates but the whole Bears organization."

On August 31, after 97 days facing seemingly insurmountable odds, Tiana left the hospital with a new heart. It was a difficult and long journey for the family, filled with shock, pain and hope. Life is

very different now for the Tillmans. There are many visits with the cardiologist and endless doses of medication. But in the end it is something that has made them all stronger.

"This helped my mental toughness. You always have to bring your 'A' game!" Charles said.

"It teaches you about letting go; that you don't have control over everything," said Jackie. "My family was brought closer and it's made me stronger in love, faith and family."

CCF was a lifeline for Jackie and now she wants to give back. She hopes to start a CCF support group in Chicago and get more involved with CCF in other ways. Jackie looks back at the experience with a strengthened faith, "I felt like God's timing was perfect because looking back on it, everything happened so perfectly," she said. "I would have loved if it never had happened, but every detail, every moment, was like a master plan. Tiana lived through things the doctors didn't know if she would or not. I think what I wanted to happen and when I wanted them to happen wasn't realistic, but His timing was perfect."

Talya and  
Tiana Tillman



## A PARENT'S PERSPECTIVE

By Jackie Tillman

My daughter Tiana Tillman was born a normal healthy baby girl on Feb. 11, 2008, and thrived for three months. Tiana began showing signs of a cold on Saturday May 17. On Tuesday, Tiana was taken to Children's Memorial Hospital in Chicago by helicopter because her heart was failing. I can't even begin to explain our shock, pain and disbelief. Once we arrived at Children's my husband and I were told by the doctors that Tiana had dilated cardiomyopathy. Tiana lived in the ICU for three months. Our hope for her the first two weeks in the hospital was that her heart would improve on its own.

We began researching every option available for Tiana, including every genetic disorder, heart information, cardiomyopathy and heart transplants. Tiana did not get better and there was still no explanation for why she developed cardiomyopathy.

We placed Tiana on the heart transplant waiting list two weeks after she was hospitalized. Placing her on the waiting list was very hard for us, to say the least, because we didn't want to believe our three-month-old baby needed a new heart to live. Everyday we hoped her heart would begin to heal itself but that never happened. While waiting for a heart Tiana's health slowly deteriorated: she

## Maintaining a Marriage or Relationship Through Difficult Times

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go more smoothly during stressful times. Each partner's ability to tolerate ambiguity, fear, grief and frustration can vary greatly. It is often helpful to step back and study how you express yourself and the effect it has on your partner. Do you raise your voice, criticize, demand or sound harsh? Do you withdraw? What causes your spouse to retreat or to come closer? Be aware of your goals and motives. Also, look at how approachable you are. Do you make it difficult for your spouse to say what they need or feel? Do you yell, point out faults or past errors, leave or shut down? Aim for understanding and respect at all times.

Couples who take time out to be alone together usually fair better than couples who do not. Couples can take turns picking pleasurable activities that appeal to one or the other or both. Couples who make a decision to keep working together can build resiliency, a fortress of strength and shared understanding in the relationship.

**When a child is ill there are many medical decisions that must be made. Sometimes parents disagree on one or more of these decisions. How can parents work together more effectively to make these difficult decisions together?**

battled infections, was intubated for two months, was paralyzed for three weeks, was on ECMO for 13 days, and then the Berlin Heart for two days before receiving a heart in July.

We are eight months out from transplant and Tiana continues to do well with her new heart. Tiana is a tough baby with an attitude; that's why I believe she made it... She loves to sing and clap. She has this amazing spirit about her.

This experience has put us into a world we didn't know existed. We have learned so much and met many families with similar experiences. Our goal now is to work for a cure, to help families in need, and to keep informing others about cardiomyopathy and organ donation.

You may have different ideas about your child's care—such as pain management, time, activity restrictions, your child's wishes—but each of you ultimately wants what is best for your child. Realize there is not always one right answer.

Some parents believe that they are responsible for their child's illness. This kind of self-blame can lead to undue pressure to control or fix things. Understanding that parents cannot control the diagnosis but can work together to take the best possible care of everyone helps lift this burden. When discussing options, keep conversations primarily focused on the facts and information. Be willing to be direct about your preferences, but take the time to validate your spouse's concerns. Using phrases like, "I understand your wish is to..., but I am concerned about that because..." can help dialogue go more smoothly.

Also, having crucial conversations ahead of time can help reduce stress and fear-based thinking when it comes time to making emergency decisions. When talking things through, create good circumstances: don't have discussions on an empty stomach or when either of you are very tired. Respect your spouse's schedule and time preferences for discussions. Some spouses can talk for hours, while others can only tolerate a short factual discussion. These styles are not indicators of love, care or connectedness, as much as they are of one's own experience, ability or safety zone. Couples can learn to adapt to each other's communication needs and meet somewhere in the middle.

**If a family or couple would like to attend counseling, how can they find a therapist in their area that is knowledgeable about common issues associated with caring for a seriously ill child? What credentials should the parents look for?**

While it is best to get a recommendation from a friend, doctor or social worker, therapists can be found on-line or through your insurance company. Make sure that the therapist has experience working with couples, has

a state license and proper training. The therapist should help to facilitate productive dialogue, offer support and foster resiliency. If you have concerns about the therapy, you should voice them to your therapist who should welcome them and seek to address them.

**Often, parents will put their life on hold just to care for their critically ill child and risk "burn-out." What do you suggest for parents dealing with this situation and how can parents still take time out for themselves, individually and as a couple, without feeling guilty?**

Guilt implies that one is not living up to an obligation. Parents forget that taking good care of themselves and their marriage is part of the obligation of taking care of their child. Burn-out occurs when parents ignore their own needs and focus solely on the needs of their child. If a parent is to maintain a stable presence in their child's life, they have to remember to nourish themselves on a regular basis. Simple things that allow for a brief escape or to help let off steam are psychologically necessary. Moreover, when parents allow themselves to pursue an interest outside the bubble of the illness, they usually find that everyone—self, spouse, child—benefits.

**Accepting that good communication takes practice and is not a natural by-product of love can go a long way towards making a better marriage.**

No one is able to maintain a perfect balance of caring for themselves, their marriage and their child, especially while working and running the house. Making the effort to be aware and do even a few small things on the checklist for marital health can go a long way in keeping the relationship healthy and strong.

**Melissa Groman** can be reached at 973-667-8777 or through her website [www.pathtohealing.com](http://www.pathtohealing.com)

# HearttoHeart

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## Update on CCF'S MEMBER LISTSERV

Open to parents of children with pediatric cardiomyopathy and professionals in the field, the CCF listserv, known also as the **CCF Forum**, is one of the most popular resources offered by the Children's Cardiomyopathy Foundation. The listserv allows members to share information and provide support to each other via group e-mails. Occasionally, expert guests are scheduled to answer questions posted by listserv members. Listed below are scheduled guests for the next few months.

### Heart Camps

Susannah Craig, Director of  
Camp Bon Coeur  
March 23-30

### Left Ventricular Non Compaction Cardiomyopathy

Dr. John Jefferies, Texas Children's Hospital  
April 20-27

### Clinical Trials

Allison Cirino, CGC, Elizabeth Sparks, N.P.,  
Brigham and Women's Hospital  
May 4-11

### Pediatric Heart Transplants

Dr. Beth Kaufman, Children's Hospital  
of Philadelphia  
October 5-12

For those of you who have missed previous guest sessions, transcripts of past Q&A sessions are available. The compilation, *Answers from the Experts: CCF Cyberguests*, covers topics such as: special education and other school related issues, medications and common side effects, nutritional and feeding issues, exercise restrictions, echo and lab reports, genetics, spectrum of grief, and pace-makers and defibrillators.

Parents and healthcare professionals who would like to subscribe to CCF's listserv or wish to receive a copy of *Answers from the Experts: CCF Cyberguests* can contact Kella Boyer at 866-808-CURE, ext. 905 or [kboyer@childrenscardiomyopathy.org](mailto:kboyer@childrenscardiomyopathy.org).

## HOW CAN I HELP CCF?

You can make a difference by planning a community event to raise awareness of pediatric cardiomyopathy. Events not only raise critical funds for CCF programs, but they also help people understand that pediatric cardiomyopathy is an important and serious health issue that warrants their attention. CCF staff can provide information on how to create simple, fun-filled fundraisers based on your goals and schedule. We can advise on event planning, publicity and development of event materials to ensure that your event is a success.

Please call Sheila Gibbons at 866-808-CURE, ext. 902, for help with your fundraiser.