

Ticker Talker

The Mended Hearts, Inc. SOC

South Orange County

Chapter 216 * Chartered 1989

Volume 26, Number 5

www.mendedhearts216.org

May 2016

Marissa's Story

Marissa was born 22 years ago with a half a heart. Her disease was discovered upon delivery due to low birth weight and low oxygen saturation.

She was a "Blue Baby". Blue babies "mix" oxygenated and deoxygenated blood due to their heart defect. Marissa's defect is Hypoplastic Right Ventricle with Pulmonary and Tricuspid Atresia and Dextrocardia. Once she was diagnosed at Mission Hospital she was immediately transferred to Children's Hospital of Orange County where the cardiologist gave her father 3 choices:

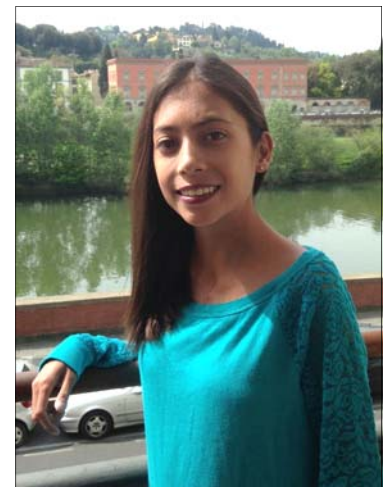
1. Do absolutely nothing and which would result in her death in 3 to 5 days.
2. List her for heart transplantation where she would have a 50% chance to live 10 years.
3. Have a series of staged surgeries over the next four years where she would keep her single ventricle heart and surgeons would redirect her blood flow around her defect. That solution had a 50% chance of her living 15 years.

The choice seemed obvious to her parents who took option 3, the choice that gave her the best chance to live the longest.

Her first surgery, at 3 months old, went well. At 18 months she had her second heart surgery. Unfortunately she experienced a serious complication to this surgery. She was rushed back to the hospital in bad shape, two chest tubes were inserted to drain fluid. She stayed in the hospital a month draining fluid and ultimately requiring a surgery to find the leaking lymphatic duct and tie it off to stop the leak. Whew! Her family felt lucky to get that fixed. It took quite a toll on Marissa. Her weight went down to 9 pounds

At age 4 Marissa underwent another surgery.

This surgery also did not go well. For two weeks after surgery her chest was open and she spent five weeks near death. After 2 months in the hospital she returned home quite ill and needing a feeding tube and constant monitoring. The doctors determined that her problem was related to her narrow pulmonary vein and suggested a novel solution. Her doctors devised a plan to put a large vessel



FOR THE HEART PATIENT AND THEIR FAMILIES

(Continued on page 4)

Chapter 216 Board of Directors and Contacts

Officers

<i>President</i>	Dennis Galloway	714-381-1906	
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National Headquarters

www.mendedhearts.org

Our Mission:

“Inspiring hope and improving the quality of life for heart patients and their families through ongoing peer-to-peer support.”

Note to recent heart surgery patients and others considering membership:

We hope all of you who have had a stent emplaced or undergone heart surgery or other heart procedures will seriously consider joining Mended Hearts. You will receive the next three issues of this newsletter to help you get acquainted with who we are and what we do. Of course you already know about our most important activity—visiting heart patients and their families before and immediately after surgery. We hope your Mended Hearts Visitor made a positive difference during your surgical experience. We invite you and your family to attend some of our upcoming monthly meetings (Third Wednesday each month, see page 1). We welcome you and your family as our guests and would enjoy having you join us as members (application, pg 11). We have shared a special experience, either as surgical patients or as caregivers and together we can smooth the path for each other and for those who follow down the same path in the future.

Visitors Report Apr. 2016

	<u>MO</u>	<u>YTD</u>
Hospital Visits	12	35
Phone Visits	2	9
Visitors	7	17
Visitors Trainees	0	0

Visitors: Chip DeSon, Ed Rocco, Greg Gensichen, Dennis Galloway, Ben Buchanan, Dave Butler, Fred Damiano

Visitors Coordinator for the months as follows:

May	Pat Phillips	949-472-9680
June	Jo Cristian	949-581-1824
July	Dee Nangle	949-582-2719

See you at the next meeting!

Barb Lane & Dee Nangle

Presidents Heartfelt Message



Just over a month ago one of our Mended Hearts board members and Secretary, Jeannine Leaper, shared a most incredible story of a family's love, courage, strength and faith, regarding their daughters' heart disease since birth.

After hearing the story I felt we needed to share this with all our members and asked that she seek permission to do so from the family. She returned with wonderful news that the family has granted us permission to share their daughters' story. Today I hope you found "Marissa's Story" truly inspirational.

As with many stories we find a story within a story as is the case with Marissa's.

Back on January 16, 2013 we had a guest speaker from Palm Springs share his expertise with our Mended Hearts members, his name, Dr. Steven R Gundry, cardiothoracic surgeon and director of the International Heart Lung Institute in Palm Springs, CA. That evening he shared with us his interest in moving from seeing patients in the operating room to seeing and helping patients change their health habits, thus preventing them from having to have procedures.

A few days following our meeting I always like to poll our members for feedback on their thoughts of that month's speaker. It was overwhelmingly positive to the point that many and I mean many went out and purchased his book, "Dr. Gundry's-Diet Evolution" and each shared later that they had great results losing weight and better lab results. As fate would have it, one of these books from a member found its way to Marissa's dad and you know from Marissa's Story what has happened since.

Many of you know that your Mended Hearts team and Cardiac Rehab group are always looking and searching each month to bring to you the best of medical professionals and information that help all of us live with and beat heart disease. I ask that you continue your membership and invite others to join us in learning more about heart disease and defeating it.

Cherish Each Day

Dennis

From the CardioPulmonary Rehab Center

Dear Mended Hearts

Keeping current in the field of Cardiac and Pulmonary Rehab can be a real challenge with on-going advances in medications, treatments and procedures.

Thanks to Mended Hearts, our staff will be able to keep up with all these advancements as you have GENEROUSLY SUPPORTED our entire staff with educational funds to attend state and national conferences and sit for certification exams. Our staff is definitely taking advantage of this wonderful opportunity as two of our staff members sat for the national Certified Cardiac Rehab Professional Exam last month, four attended the California Society of Cardiac Rehab state educational conference last month in Fresno, two more attended an extensive Cardiac Rehab Workshop in Wisconsin, two will attend a Diabetes Educators Conference in San Diego in the fall and several of our staff will attend the national AACVPR (American Association of Cardiac and Pulmonary Rehabilitation) conference this fall in New Orleans.

We certainly couldn't attend all these amazing events without the financial support of the Mended Hearts organization. Our goal is to disseminate the most current information and provide "Best Practices" in the care of all our patients, so please consider your contributions as a Wise Investment.

**THANK YOU SO MUCH
FOR ALL YOUR SUPPORT!!!!**

Here's to Your Healthy Heart!

Elaine 



<https://www.facebook.com/MendedHeartsChapter216>

"It's great to be alive-and to help others!"

Thank you to our Community Supporters



Marissa's Story *continued*

stent in her right pulmonary veins. Stents are normally for coronary arteries but in children with congenital heart disease, large diameter stents can be used for large pulmonary or arterial vessels. This procedure had only been done a few times in Spain, once at Johns Hopkins and it would be the first time UCLA had attempted this procedure. Luckily the pulmonary vein stent worked for Marissa and is still working for her 18 years later.

In the past 22 years, she's grown into a strong young woman with the help of seven thoracic surgeries. Each of those surgeries have helped her survive, but each has also come with its own set of complications. She enjoyed a 10 year period of relative good health, but eventually outgrew the surgeries and needed a heart transplant.

She developed a fatal gastrointestinal complication called Protein Losing Enteropathy. UCLA referred her to an expert cardiologist at Children's Hospital of Philadelphia who specialized in single ventricle patients who acquired PLE. The car-

diologist there suggested heart transplantation as now a risky, but best solution for resolving her PLE. She became a UNOS UCLA status 2 (the least urgent status) heart transplantation patient in January 2012. On January 23, 2012 they got the call that there was a heart for Marissa and get ready for transplant. Unfortunately, the heart did not survive harvesting. So Marissa was wheeled out of the OR and back to her room. She and her family were home the next day. It was a very bad day.

March 20, 2013 proved to be another very bad day when her family received the news that she was removed from the transplant list. She had developed inflammation, and appeared to have pancreatitis,

The news was devastating, but her father had recently read a portion of Dr. Gundry's book Diet Evolution. Dr. Gundry, a cardiothoracic surgeon and director of the International Heart Lung Institute in Palm Springs, had been a guest speaker at a recent chapter 216 meeting.

(Continued on page 6)

Chapter 216 Members Page - May 2016

Birthdays - May

Roger Bradshaw	05/07
Barbara Brickley	05/07
Nancy Christenson	05/07
Anthony Samanich	05/07
Bernd Leumer	05/10
William Silva	05/11
Richard F. John	05/12
Fred Bonn	05/13
Lee Goode	05/17
Keith Lindemann	05/23
Mona Mahieu	05/23
Roger O'Connor	05/23
Bill Pirie	05/23
Jean Cogan	05/30
Bill Huber	05/31

New Members

Always looking to grow our family, Mended Hearts welcomes you to join our cause.

You'll be able to make a difference in a patient's recovery and outlook on life, as well as interact with other members through local chapter meetings, volunteer opportunities and special events.

Your application is on page 11 of this newsletter, fill it out and join today!



Mendiversaries - May

Roger O'Connor	05/15/1984
Richard Kramer	05/01/2001
Ted Robinson	05/07/2006
Frank Bold	05/29/2008
Hal Schwartz	05/08/2013



The power of imagination makes us infinite.

John Muir

Chapter 216 Meetings 2016 Meeting Schedule

May	No Meeting
Jun. 3-4	Education & Training Conference
Jul.	No Meeting
Aug.	No Meeting

Mission Hospital Conference Center
26726 Crown Valley Parkway
Mission Viejo, CA



If we missed your mendiversary or birthday and would like it included in the Ticker Talker please email it to:

socalcarculture@yahoo.com

Marissa's Story continued

One of our members who'd attended that meeting had brought his book to the fire station where Marissa's father was working. Marissa's father immediately made contact with Dr. Gundry

Dr. Gundry seemed to know how to help Marissa the instant he met her. While explaining her medical history he grasped what was wrong and within seconds of finishing the history he enthusiastically said he had a great plan for Marissa. Dr. Gundry called this plan "the diet from hell". Aka the "Lectin Free" diet.

Marissa embraced the diet and improved to the point that she was once again on the transplant list. A heart became available several weeks ago and she had the transplant surgery Saturday March 26th! Her transplant surgery carried 10X the risk of a "normal" heart transplant. Approximately 10 hours later, with a few large bumps in the road, Marissa pulled through. Her chest had to remain open for a day or so and there were some difficult times for her, but she's made it out of the Cardio Thoracic surgery unit and into CICU.

When she came off the ventilator her father commented "Marissa just got off the ventilator and is crying tears of joy about her new heart....her lips are so pink! A long way to go but she had a good day!"

Her father talks of how resilient and strong Marissa is, but those who know the family see that her father and mother are just as resilient and exemplify the strength and commitment parents have for their children.

We all have our stories of heart disease, but few of us have traveled a path as difficult as Marissa's has been.

In addition to all the surgeries and procedures she has endured, she has lived with chronic CHF all of her life.

During those difficult years Marissa was able to have some fun attending summer camp at Camp Del Corazon, a non-profit corporation providing summer camp for children with heart disease or a history of heart

disease, held on Catalina Island. The camp has truly blessed their lives in this journey.



The Orange County Fire Authority Benevolent Association is setting up a trust fund in honor of this brave young woman and her family. All funds received will be donated to Camp Del Corazon.

Those wishing to make a contribution can send a check (note "Mike Long" on the memo line) to:

OCFA Benevolent Association
1 Fire Authority Rd
Bldg AE163
Irvine, CA 92602

If you are inclined to pray, please join us in praying for Marissa's speedy and full recovery.



SPECIAL ANNOUNCEMENT & BENEFITS

The Mended Hearts Inc.
National Conference in Mission Viejo CA.
JUNE 3RD & 4TH

DUE TO VERY HIGH INTEREST
All WHO REGISTER*
BEFORE MAY 20TH WILL RECEIVE A

50% DISCOUNT OFF THE REGISTRATION FEE

MENDED HEARTS CHAPTER 216
Your total investment is only \$25.00 for a one and a half day conference. On day 2, breakfast and lunch are included in your registration fee.

SO DON'T DELAY, REGISTER TODAY AT

www.mendedhearts.org

Use Promo Code: MH216

If you need help in registering for the conference you can call Janette Edwards at 214-390-3268 and she will assist you, please have your credit card and promo code ready for payment.

*NOT A MEMBER, become a member and save. Find Membership application on the last page of the newsletter or on our website www.mendedhearts216.org
You can also join at the conference.

This will be our last Mended Hearts Chapter 216 Monthly Member meeting until September.

So don't miss the opportunity to meet and talk with other members from Washington, Oregon and the State of California!
Mission Hospital Conference Center.

Cherish Each Day,
Dennis

"It's great to be alive-and to help others!"



Mended Hearts and Mended *Little* Hearts

Education and Training Conference

“On the Road” 2016

Friday: Hilton Irvine / Orange County Airport
Saturday: Mission Hospital Conference Center, CA

Tentative Program Agenda

Rev. 4/27/16

Friday, June 3, 2016: Hilton Irvine / Orange County Airport

- 1:00 – 2:00 p.m.** **Registration – Irvine Room Foyer**
Pick-up Name Badge, Conference Folder, Tote Bag
- 2:00 – 5:30 p.m.** **Celebrating Heart Survivors – Irvine Room**
Donnette Smith, Presidential Address, Mended Hearts
Patrick Farrant, Vice President
Ron Manriquez, Western Regional Director
Dennis Galloway, President, South Orange County Chapter 216
Nichole Sanchez, MLH Asst. Regional Director
- Fun Interactive Activity / Get Acquainted**
- MH & MLH of the Future Town Hall - Unwrapping the Strategic Plan**
Michele Packard-Milam, CAE, Executive Director
- Online Engagement & Connections**
Marcia Baker, M.S. in Ed., Director of Field Services
- 5:30 p.m.** **Social Time/Dinner on Your Own**

Saturday, June 4, 2016: Mission Hospital Conference Center

26726 Crown Valley Parkway, Mission Viejo, CA 92691

- 7:15 a.m.** **Continental Breakfast - Compliments of Mission Hospital**

Reserved tables/room for Valve Patients – Donnette Smith & Edwards

8:00 a.m.

Overview of Day's Activities – Marcia Baker

- ♥ **Motivating and Engaging Programs—How to get them in the door!**
Marcia Baker, facilitator
- ♥ **Raising a Ruckus—Marketing and Awareness**
Michele Packard-Milam, Executive Director
- ♥ **Building Hospital Relationships**
Hospital Panel
- ♥ **Interactive Activity: Be a Part of the Solution**

12 Noon

Lunch – Peer to Peer Networking
Regional Awards, Ron Manriquez, Western Regional Director

1:00 – 5:15 p.m.

Cardiovascular Medical Updates

- ♥ ***Heart Failure Symptoms and Treatments***
Peggy Kirkwood, RN, MSN, ACNPC, CHFN, AACC
Cardiovascular and Palliative Care Nurse Practitioner, Mission Hospital
- ♥ ***How to Prevent a Second Heart Attack***
Dr. Daniel L. Kulick MD, Cardiology, Mission Heritage Medical Group
- ♥ ***Valve Disease and TAVR***

BREAK

- ♥ ***Understanding Angina***
Nurse, Mission Hospital
- ♥ ***Specialty Pharmacies: How It Impacts Patients –***
Mike Capaldi, Sanofi
- ♥ ***The Truth About AFib***
Dr. Lynn Hung, MD, Cardiac Electrophysiology, Mission Heritage
Medical Group

5:30 p.m.

Closing Remarks – Donnette Smith

Mended Hearts

Chapter 216




Fundraiser Game

ANGELS.

Vs.



Tuesday, July 19th @ 7:05pm

-  **Special Lower View MVP-425 seating for \$29.00!**
-  **All Family, Friends and Neighbors are welcome to attend.**
-  **Tickets are limited. ACT NOW!**

**DEADLINE FOR
YOUR ORDER IS:**

July 12, 2016

We will accept: CASH and CHECKS
Make Checks Payable to:
MENDED HEARTS 216

Questions:

Alan Kiehn
949-582-1908

www.mendedhearts216.org

# OF TICKETS YOU WANT TO PURCHASE	PRICE PER TICKET Price listed is per person	TOTAL \$ AMOUNT OF ORDER	NAME:
			ADDRESS: (To mail tickets)
	\$29.00	\$	PHONE Number: ()
Sorry, unable to make the game. <u>Donation Only</u> \$			Email Address:

NO REFUNDS OR EXCHANGES!
PLEASE RETURN ORDER FORM WITH PAYMENT BY: 7-12-16
TO: ALAN KIEHN 25861 Cedarbluff Ter. Laguna Hills, CA 92653

The Mended Hearts, Inc. Chapter 216

Membership Application

Mended Hearts is a national nonprofit organization that has been offering the gift of hope to heart disease patients, their families and caregivers since 1951. Recognized for its role in facilitating a positive patient-care experience, Mended Hearts partners with over 460 hospitals and rehabilitation clinics and offers services to heart patients through hospital visiting programs, support group meetings and educational forums.

Our mission : "Inspiring hope and improving the quality of life for heart patients and their families through ongoing peer-to-peer support"

Please Print: _____ Date _____

Name _____ Spouse _____

Address: _____ City: _____ Zip: _____

Home phone _____ Cell phone _____ E-mail _____

If interested in receiving the newsletter electronically, please provide e-mail

Birthday (dd/mm) _____ Episode/Surgery date dd/mm/yy) _____

Physician/Surgeon _____

Type of procedure: STENT (PCI) _____ MI (Myocardial Infarction) _____ BYPASS _____

HEART VALVE _____ TRANSPLANT _____ ANEURYSM _____

ATRIAL SEPTICAL DEFECT _____ PACEMAKER/ICD _____

Hobbies & Interests: _____

I wish to volunteer to assist the Chapter in these areas:

Visiting Patients _____ Telephoning _____ Other (describe) _____

	Individual	Family
Dues: Initial, Annual, National & Chapter Dues	\$28	\$38
Life membership, National & Chapter	\$225	\$335

I wish to donate to defray Special Projects and Newsletter Expenses: \$ _____

Membership fees include both Chapter and National dues.

Return the completed application with check to: Mended Hearts, Inc Chapter 216, c/o Mission Hospital, Cardiopulmonary Rehab Center, 26732 Crown Valley Parkway, Suite 281, Mission Viejo, CA 92691

Annual billings will be from the National Office located in Dallas, Texas.

Billings will be on the anniversary of joining.

Ticker Talker
Mission Hospital Cardiac Rehab Center
26732 Crown Valley Parkway Suite 281
Mission Viejo, CA 92691
Return Service Requested
Dated Material



The purpose of this organization is to offer help, support and encouragement to heart patients and their families and to achieve this objective in the following manner:

1. To visit with physician approval, and to offer encouragement to disease patients and their families.
2. To distribute information of specific educational value to members of the Mended Hearts, Inc. and to heart disease patients and their families.
3. To establish and maintain a program of assistance to physicians, nurses, medical professionals, and healthcare organizations in education and research activities pertaining to heart disease.
4. To cooperate with other organizations in education and research activities pertaining to heart disease.
5. To assist established heart disease rehabilitation programs for members and their families.
6. To plan and conduct suitable programs of social and educational interest for members and for heart disease patients and their families.



St. Joseph Health 
Mission Hospital



St. Joseph Health 
St. Mary



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