

The mothers—who sound like cardiologists to the untrained ear—discuss the children's progress and their setbacks, and about new medicines and treatments which could help their kids.

When the mothers are together, they share a special bond and code of understanding.

Parents of kids who are "heart healthy"—a term the mothers use to describe children without a CHD—just can't comprehend their daily lives.

"It's nice to be able to talk and not have to explain everything," said Brenda Campbell of Mansfield, whose daughter, Grace, now 29 months old, was born with a congenital heart defect.

"We can ask each other 'does she look blue to you?' That's our life now," Campbell said.

A bluish color could be an indicator that the child is not getting enough oxygen, and is a possible precursor to these parents' worst fear: that their child is going into congestive heart failure.

"That's certainly a daily worry," Lyn McPhail said.

Many of the mothers got their diagnoses while they were still pregnant, while others received the news—which they all called "devastating"—when their babies were just one or two days old.

Grace Campbell was born without a left ventricle in her heart. She had her first surgery when she was just six days old and her second surgery at 5½ months.

"They put in totally different plumbing to help her right ventricle do all the work," Brenda Campbell explained.

The Campbells have taken a proactive approach by organizing the Mansfield based "Grace's Run," which annually raises money for families with children with CHDs and for Children's Hospital.

Zachary Duong of Wilmington was born on the same day as Grace, and his mother, Sheila, met Brenda Campbell in the hospital. Zachary is now 2 years old. He was diagnosed with his CHD the day he was born and was rushed to Children's Hospital, where he spent the first three months of his life.

Megan Lea of Mansfield, now 18 months old, was born with a very rare set of CHDs. She has a condition known as Ebstein's anomaly, an abnormality in the tricuspid valve. She also has cardiomyopathy, a disease of the heart muscle that can cause it to lose its pumping strength. With cardiomyopathy, doctors have told the Leas that about one-third of the kids get better, one-third stay the same, and one-third get worse, so Megan's parents have no choice but to wait that one out.

There is a possibility that she will need a heart transplant at some point. She will also probably need valve surgery for the Ebstein's anomaly. Right now doctors are trying to manage her conditions with medications, and she is currently on four different heart drugs. Megan was on oxygen for the first 10 months of her life but is now breathing well on her own.

"The progress they're making is unbelievable, but it's scary because we don't know what their future is," Ellie Lea said. "Her cardiologist said that Megan looks a lot better than expected. We just take it one day at a time."

"The mother's group is good, because we understand each other," she continued. "Friends who aren't 'heart moms' ask, 'So, is she all fixed?'"

"I hate it when people ask that!" exclaimed Delys Poynton of Braintree, the mother of 19-month-old Amy, who was born with Hypoplastic Left Heart Syndrome (HLHP). Kids with HLHP undergo a total of three operations—known as the Norton procedure, after the doctor who discovered it—and then hope for the best. Like some of her

friends in Heart Buddies, Amy has undergone two of those three operations already.

"These little kids have already experienced things most people never have to experience in their whole lives," Delys Poynton said. "They get so used to seeing doctors, they get stranger fatigue" which affects the way they react to other people.

Ellie Lea recalled taking Megan to a hospital to visit a friend, and Megan "freaked out" as soon as she got into the hospital. Though just a baby, Megan understood exactly where she was, and she wasn't happy about it.

There's a name for the babies' reaction: "white coat syndrome." The children are so used to being poked and prodded by doctors that they develop an aversion to them.

Also, Delys Poynton said, many of the CHD kids develop eating problems.

"When you have tubes up your nose for so long, you don't want anything in your mouth," she said.

Liz Bogoyo of Chelmsford is the mother of 14-month-old twins: Allison, who is heart healthy, and Andrew, who was born with a CHD. Andrew was diagnosed when Liz was 17 weeks pregnant.

She recalled the trauma and exhaustion of having a brand new baby at home, Allison—"who we didn't even get a chance to know" because she and her husband were spending so much time at the hospital with Andrew.

Andrew has undergone two operations and will have to have one more. If that one goes well, he has an 85 percent chance of survival, his doctors have said.

Like the other families, the Bogyos said they take each day at a time and hope for the best.

Ruth Kennedy of North Reading found out when she was 19 weeks pregnant that her son, Ewan, now 2 years old, had a CHD. She received an initial diagnosis of just "heart defect" with no additional details and recalls "just sobbing" as she walked past the other women at Mass General who were waiting to get their ultrasounds. Ewan has had two operations with another one coming up.

"Long-term, they can't tell you what to expect. No one survived before. You just have to take it day by day and be happy with what you have," Ruth Kennedy said.

Because of the advances they've made in the last 20 years, there is no existing group of adults who would have had access to the medical care these babies are now receiving, the mothers said. Consequently, there is no real information available on what kind of future awaits these children. Their parents have been told by the children's doctors not to expect Olympic athletes, but to hope for a normal life. Still, no one knows for sure. The situation has given the mothers a different outlook on life.

"It's like a poem I heard about," Lyn McPhail said. The poem is all about planning for a trip to Italy, and anticipating being in Italy, but when you arrive at your destination, you're actually in Holland. You deal with being in Holland, she said, "but the dream you had of going to Italy is still very real."

"You just appreciate every little thing all the more. You're so grateful for the good things," said Ellie Lea. "It's a very humbling experience."

REV. HERBERT THOMPSON HONORED AS A GREAT LIVING CINCINNATIAN

## HON. JEAN SCHMIDT

OF OHIO

IN THE HOUSE OF REPRESENTATIVES

Tuesday, February 14, 2006

Mrs. SCHMIDT. Mr. Speaker, I rise today to honor the Right Reverend Herbert Thompson, Jr., a bishop, mentor, human rights advocate and community leader, who will be formally honored as a Great Living Cincinnati on February 16 by the Greater Cincinnati Chamber of Commerce.

The Chamber has bestowed this award on distinguished members of the community annually since 1967. Recipients of this prestigious award are chosen on the basis of professional achievement; community service; leadership; compassion; and vision. Past honorees have included Neil Armstrong, Dr. Albert Sabin and Charles Scripps.

Rev. Thompson was born and raised in New York, where his character was shaped by the hard-working and diverse community of Harlem during the 1940s and 1950s. After serving in the United States Air Force from 1952–1956, he enrolled at Lincoln University in Pennsylvania, where he graduated cum laude in 1962.

After a profound religious experience prompted him to serve, he enrolled at The General Theological Seminary, where he completed his seminary work and earned his master of divinity degree. He received his doctorate of ministry from The United Theological Seminary in Dayton, Ohio.

Ordained into the priesthood in 1965, Rev. Thompson served various churches and communities in New York until 1988, when he was elected Bishop Coadjutor of the Diocese of Southern Ohio. In 1992, he was consecrated as the eighth Bishop of Southern Ohio, and the first African-American elected to serve the Diocese of Southern Ohio in this role. He was only the fourth African-American diocese bishop in the history of the Episcopal Church.

Although he has lived in Cincinnati only since 1988, Rev. Thompson has had an enormous and lasting impact on our community. For example, in 1993, he organized a comprehensive "Summit on Racism" to ease racial tensions within the city. He also helped to push forward the concept for the National Underground Railroad Freedom Center.

Throughout his ministry, he has lived by these words: "To reconcile, to heal, to liberate, to serve." Rev. Thompson recently retired from the Diocese of Southern Ohio, but continues to be actively involved in the community.

Rev. Thompson has dedicated his time and energy to many organizations, including serving as chair of the Presiding Bishop's Fund for World Relief and co-founder of Global Episcopal Ministries. He has also served on the boards of St. Augustine College, Bexley Hall Seminary, General Theological Seminary, Kenyon College, Kanuga Conference Center, Cincinnati Symphony Orchestra, Cincinnati Ballet, Cincinnati Opera and the Freedom Center. Among his many awards and honors include the Arts Consortium of Cincinnati's Martin Luther King Jr. Dreamkeeper award.

Rev. Thompson has three children and one grandchild.

All of us in the Cincinnati area congratulate Rev. Thompson on being named a Great Living Cincinnati.

#### HONORING C. THOMAS KEEGEL

### HON. LINDA T. SÁNCHEZ

OF CALIFORNIA

IN THE HOUSE OF REPRESENTATIVES

*Tuesday, February 14, 2006*

Ms. LINDA T. SÁNCHEZ of California. Mr. Speaker, I rise today to recognize Mr. C. Thomas Keegel for his 45 years as a committed member of the International Brotherhood of Teamsters.

Mr. C. Thomas Keegel has been a Teamster since 1959, when he got his first trucking job and became a member of Teamsters Local 544 in Minneapolis, Minnesota. From steward to his current position of General Secretary-Treasurer, Keegel has served as an elected Teamster officer for three decades.

Keegel's skills as the union's chief financial officer were honed in the Minneapolis-St. Paul area. He built an area pension fund from \$3 million in assets to a \$220 million powerhouse for Teamster retirees. That pension fund now offers a top benefit of \$55,200 per year and excellent health coverage.

Since taking office on March 19, 1999, Keegel has instituted sweeping reforms in every area of the Union's finances. He has balanced the budget for the first time in more than a decade, hired skilled auditors and accountants, developed programs to extend these reforms to Teamsters Local Unions, Joint Councils, Divisions and Conferences and has undertaken the task of strengthening the Union's treasury and Strike Fund.

Keegel has taken a leading role in enforcing the Hoffa administration's commitment to running a clean union. As General Secretary-Treasurer, he instituted legal actions to recover money stolen from the Union treasury by the prior administration. He created safeguards to ensure that no such embezzlement ever occurs again. Keegel lent his energy, expertise, and enthusiasm to the continuation of the administration's comprehensive anti-corruption program.

As General Secretary-Treasurer, Keegel aims to lift up his Teamster sisters and brothers to even greater heights through his work as their fiscal watchdog and the guardian of their hard-earned dues money.

Mr. Speaker and distinguished colleagues, please join me in honoring Mr. C. Thomas Keegel for ensuring the International Brotherhood of Teamsters' continued financial stability and accountability.

#### IN HONOR AND RECOGNITION OF MARTIN E. VITTARDI

### HON. DENNIS J. KUCINICH

OF OHIO

IN THE HOUSE OF REPRESENTATIVES

*Tuesday, February 14, 2006*

Mr. KUCINICH. Mr. Speaker, I rise today in honor and recognition of Martin E. (Marty) Vittardi, devoted family man, public servant, community leader and dedicated volunteer. The leaders and members of the Parma Area Chamber of Commerce recently named him

as the recipient of the 2005 Individual Pride Award for his committed and compassionate volunteerism in raising funds and raising community awareness on behalf of the American Cancer Society.

Marty's journey of public service began nearly thirty years ago, while a student at John Carroll University, where he served as a Congressional Assistant to then United States Congressman Ronald Mottl. After graduating at the top of his class with a bachelor's degree in political science, he accepted the position of Deputy Clerk with the Cuyahoga County Court. He then served for eight years as a Legislative Representative for the Seafarers Union, where he garnered vital insight into the political processes that took him from our local community to Capitol Hill.

Marty has been entrusted with the faith and confidence of Parma residents and with members of the Cuyahoga County Democratic Party since the early eighties, as voters have consistently supported him in various City and County elected roles. In 1982, Marty was elected as the Cuyahoga County Democratic Executive Committeeman. That same year, he was elected to represent residents of Ward 3 in the City of Parma and was elected to the position of Ward 5 Democratic Leader.

In 1991, Marty was elected for a six-year term as the Clerk of Court for the City of Parma Municipal Court. He was re-elected to a second term in 2003. In addition to his professional endeavors, Marty has been a tireless volunteer and champion of numerous volunteer causes, and has been an active volunteer in many roles, including chairing school levy campaigns; raising funds for the Byers Field Foundation and Veterans Memorial; co-chairing fundraising drives for the American Cancer Society; and active leadership roles in several civic organizations, including the Parma Elks and the Parma Area Chamber of Commerce. Additionally, Marty is the founder and current chairman of the Community Leadership Group, comprised of elected officials, business owners and community activists whose mission is to foster positive change within all levels of the Parma community through the power of a unified commitment, shared vision and collective focus.

Marty's leadership, achievement, and most vital of all, his integrity and genuine concern for others, is a united legacy that co-exists with, and is strengthened by, the integrity, dedication, professional and personal excellence and shared vision of his partner in life—his wife, Lynn M. Vittardi.

With family as the cornerstone of their lives, Marty and Lynn have instilled a deep sense of giving back to the community and service to others within the hearts of their own children, now grown. Marty and Lynn's united focus on their parents, siblings, and above all, their children, Allison, Jessica and Mark, has never wavered and continues to be the center of their lives. Their children have followed a path of professional excellence and service to others, from the examples set by Marty and Lynn. Allison, her husband Nick and Jessica and her husband, Dominick, are education professionals. Their son Mark is in college, majoring in political science.

Mr. Speaker and colleagues, please join me in honor and recognition of Martin E. Vittardi, for his unwavering dedication, integrity and outstanding public service, especially his annual volunteer efforts with the American Can-

cer Society. Marty's energy, warmth and significant service continues to offer a light of hope and the promise for a better tomorrow within the City of Parma and throughout our entire community.

#### IN TRIBUTE TO ALAN AND ROMI SKOBIN

### HON. BRAD SHERMAN

OF CALIFORNIA

IN THE HOUSE OF REPRESENTATIVES

*Tuesday, February 14, 2006*

Mr. SHERMAN. Mr. Speaker, I rise today to pay tribute to Alan and Romi Skobin for their civic and philanthropic service to Los Angeles and the city of San Fernando and, particularly, their good work for the residents of my district in the San Fernando Valley.

On March 26, 2006, Alan and Romi Skobin are being honored by the executives of the Los Angeles Jewish Home for the Aging for their outstanding involvement with the organization. Their care for the elderly residents of the home demonstrates to all of us the importance of taking care of our parents and grandparents—this country's most important national treasures.

Mr. Speaker, Alan and Romi have a record of community and civic service that spans more than 30 years. Alan, a graduate of California State University, Northridge, has been a longstanding business leader in the San Fernando Valley. Currently he serves as vice president and general counsel of Galpin Motors, Inc. and is a member of the executive committee and board of directors.

He has also served as a commissioner with the Los Angeles Police Department since 2003. In this capacity, he has focused on the Community Based Policing program along with many other issues. His work for the city and the Los Angeles Police Department truly affects each Angelino personally.

Alan is a founding director and executive committee member of the Sheriffs Youth Foundation of Los Angeles County, which funds education and intervention programs for at-risk youth. Alan, a two-time cancer and brain tumor survivor, is also involved with Padres Contra El Cancer, a nonprofit organization that improves the quality of life for children with cancer.

Romi Skobin truly exemplifies the American dream. Her inspirational story began when she came to the United States as a refugee from Cuba in 1969. Romi also received her education locally, at Los Angeles Valley College, and began her career in public service when she joined the San Fernando Police Department in 1974. She currently serves as the records/system administrator, the highest ranking civilian position in the SFPD, and is the city of San Fernando's most senior employee.

Romi has also played an important role in Alan's success by raising their two successful children, Jeff and Jennifer, thereby allowing Alan to attend law school and participate in numerous civic activities.

Mr. Speaker, Alan and Romi Skobin are integral parts of the San Fernando Valley community and I wish to congratulate them wholeheartedly on being honored by the executives of the Los Angeles Jewish Home for the Aging.