



**2021-2022**IMPACT REPORT

WWW.HYPEREMESIS.ORG

22Years of HELP and HOPESHG

www.hyperemesis.org

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Kimber MacGibbon, BSN, RN Executive Director, Co-Founder

# A Message from our EXECUTIVE DIRECTOR

The last two years have been amazing as we have emerged from the Covid pandemic stronger. We took that time to focus on launching our 1MOMis2Many campaign and our Ambassador Council.

We published new genetic studies that continue to support our initial finding that the gene, *GDF15*, is the greatest genetic risk factor for HG. Our studies on the HELP Score and cannabis use were published, as well as a summary article on HG. Several of these studies have been presented at conferences in the US, India, Israel, and the UK.

On the heels of our launching our Advocacy Newsletter to Hill staffers in Washington, DC, we had the incredible opportunity to meet with Secretary Beccera's office at the HHS, and leadership at the

Texas Department of HHS. The new Texas HG mandate opens doors for HER to collaborate on policy and program development with Texas HHS.

Looking ahead to 2023, HER is poised to launch a bold initiative to educate healthcare providers about HG. Several organizations have already expressed interest in this game-changing program. We can't wait to share it with you in the coming months.

Finally, mark your calendars! In 2024, we will host the biennial ICHG conference in Ventura, California, during the first week of November. Watch your inbox and social for exciting details.

Thank you for your ongoing support of HER Foundation! We could not do this very important work without you.

- Kimber

# **OUR MISSION**

The Hyperemesis Education and Research Foundation's mission is to provide Hyperemesis Gravidarum (HG) support, advocacy, education, and research to improve treatment and outcomes.





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#### RAISING AWARENESS AND ADVOCATING FOR CHANGE

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Why we support HER



# With your support, we are MAKING AN IMPACT 21-22

The HER Foundation is the global voice of HG Progress. We're a 501(c)3 nonprofit that provides support, groundbreaking research, advocacy, and education on hyperemesis gravidarum. Since 2000, we have been the leading source of information on HG and have helped over 2.2 million people across the globe.

6000+

PERSONAL SUPPORT

hours to families in > 55 countries



325+

EDUCATIONAL PACKETS

distributed to medical providers

400,000
WEBSITE
VISITORS

from 175
countries

24

RESEARCH
PUBLICATIONS &
PRESENTATIONS

in over 169 countries



# HER STORY

"The HER Foundation was a ray of hope during the physical and psychological misery of my first HG pregnancy. Their resources helped educate me and my loved ones about what I was going through and how to advocate for better healthcare solutions. It has made a world of difference in my second HG pregnancy that I've been able to get access to these medical interventions early on and minimize the effects of this debilitating condition."

-RACHEL (USA)





Beyond the physical and financial impact of HG, the psychosocial impact is incalculable as many family relationships dissolve, future family plans are limited, or pregnancies are terminated. Women often lose their employment because of HG and are frequently undertreated. They are often left feeling stigmatized by a disease erroneously presumed to be psychological. At the end of pregnancy, HG survivors are left coping with PTSD and navigating the health challenges of their HG children.

but in her GENES

Funding for HG research is rare. Your generous donations provide critical support for much of the HG research occurring today.

\*\*\*\*\*\* 50% of children exposed to HG in utero will have a neurodevelopmental diagnosis.

2021-2022

# RESEARCH HIGHLIGHTS

The HER Foundation Research Committee is focused on answering some of the most important questions patients, providers, and families have about HG. Our breakthrough psychosocial, genetic, and child outcome studies have changed the way HG is viewed. When HER genetic research discovered the gene *GDF15* is likely the main player in HG, we also learned HG is biologically related to the severe and sometimes fatal wasting syndrome, cachexia. We also published peer-reviewed scientific studies on the risk of recurrence, outcomes of babies exposed to ondansetron, and other genetic risk factors associated with HG.

Whole-exome sequencing uncovers new variants in GDF15 associated with hyperemesis gravidarum (BJOG, 2022). In this study, the nausea and vomiting hormone gene GDF15 was the only gene associated with HG, further implicating GDF15 as the most likely cause of the disease. A rare mutation in GDF15 was identified that increases risk of HG over 10-fold.

Patterns of Use and Self-reported Effectiveness of Cannabis for Hyperemesis Gravidarum (Geburtshilfe Frauenheilkd, 2022). More respondents reported NVP symptom relief and weight gain with ondansetron than other antiemetics, but many were still unable to gain weight within two weeks of their first dose. Cannabis products may be perceived as a more effective alternative, but more research is required to understand its mechanism and safety. This study also identified racial disparities in HG treatment.

Hyperemesis Level Prediction (HELP Score) identifies patients with indicators of severe disease: a validation study (Geburtshilfe Frauenheilkd, 2021). The HELP score performs better than the PUQE score in identifying severe disease and we recommend its implementation in clinical settings.

Neurodevelopmental delays and in utero exposure to hyperemesis gravidarum (Chapter in Diagnosis, Management and Modelling of Neurodevelopmental Disorders - The Neuroscience of Development). It is VERY important to know that in the case of HG the old wives' tale that the baby is getting everything it needs from mom may not be true—get vitamins, get help, and let doctors know that the current evidence suggests overwhelmingly that HG is associated with increased risk of adverse outcomes.

Pregnant, Miserable, and Starving in 21st Century America (AJOG Global Reports, 2022). HG causes enormous misery and numerous adverse outcomes for mother and child. These patients need early identification, increased provider awareness, advocacy resources, routine vitamins, and supportive care.



Genetic predictors of ondansetron effectiveness and recurrence risk for hyperemesis gravidarum (ACOG, USA)

Association of GDF15-GFRAL-RET pathway with Hyperemesis Gravidarum confirmed by sequencing families (ACOG, USA)

Trends in cannabis use for hyperemesis gravidarum self-reported to be more effective and more likely to gain weight than other medications. However, we do not recommend cannabis for HG because safety is still an unknown. (ICRS, Israel)

Whole-exome sequencing confirms GDF15 is the greatest genetic risk factor for hyperemesis gravidarum and identifies rare and novel variants in appetite genes GDF15 and GFRAL. This study adds further proof that this pathway is involved in the etiology of HG. (ASHG, USA)

Hyperemesis Gravidarum: Causes, Consequences, Care (RCOG Northzone, India)

Whole-exome sequencing uncovers new variants in GDF15 associated with hyperemesis gravidarum (ICHG, UK)

Patterns of use and effectiveness of cannabis for hyperemesis gravidarum (ICHG, UK)

Large-scale genome-wide association study meta-analysis of Hyperemesis Gravidarum confirms the nausea and vomiting hormone gene GDF15 is the greatest genetic risk factor and identifies additional risk loci (ASHG, USA)

Hyperemesis Gravidarum. (Fetal Medicine Foundation, 150+ countries, 4 languages)

#### Studies In Process

- Trends in cannabis use for HG
- Meta-GWAS analysis of HG
- GDF15 in patients hospitalized with HG
- Fetal GDF15 and recurrence risk
- Trends in HG treatment and outcomes by socioeconomic status.

HER made me feel like I wasn't alone! It provided me with evidence-based research to help me understand the condition. It is a vital support for HG warriors and their families. I refer women and families to HER all the time as it provides crucial information. It's a valuable resource to understand what HG is and the treatment options available.

—EMILY (CANADA)



Focus Area

# PROVIDING CRITICAL SUPPORT TO HG SUFFERERS & THEIR FAMILIES

## IN HER WORDS

I had HG from 7 weeks until birth at 33 weeks. I was hospitalized for dehydration, preterm labor, and a blood clot. I had IV fluids and home health care almost daily. Without HER, my doctors would have had no idea how to treat me. I did my research, so I knew what treatments to ask for and how to advocate for myself. My husband found the website section on how family can understand HG so helpful. He was able to advocate for me and ask the right questions when I wasn't able to myself.

—A (USA)



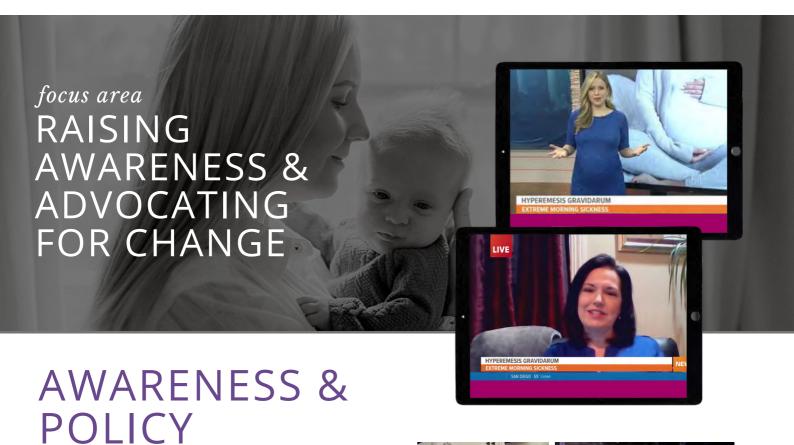


My family wanted me to have an abortion because I was so sick. I went from 75 kg to 49 kg. I felt no one understood my suffering except HER Foundation. I thank God HER helped me and my doctor with information and the algorithm because I'm now the happiest Mum ever with my 9 month old son.

**—U (TANZANIA)** 

I was so sick that I had a termination appointment booked, but 3 days before, my doctor suggested I try a medication we found on the HER Foundation Treatment Algorithm. Within 3 hours of the first dose, I was eating and drinking. I cancelled my appointment, and I got to have my baby. I wish I could personally hug everyone who put together HER's life saving tools.

-R (IRELAND)



Increasing awareness of HG is a key goal for the HER Foundation. HER takes every opportunity to share about HG and presents at conferences, does media interviews and podcasts like Motherly, and engages on numerous social media platforms targeting both professionals and lay persons. HER also has been featured in the *New York Times* and on several news stations such as News 8 in San Diego.

Our Policy Team started a bimonthly advocacy newsletter for Capitol Hill Staffers to inform them about HG and it's significant impact on many mutual concerns related to maternal health, medical care access, stillbirth prevention, and mental health.

HG leads to many preventable complications, and HER collaborates with other organizations and healthcare providers to increase awareness and work together on our 1 MOM is 2 Many campaign.

HER attended the National Association for Psychosocial Obstetrics and Gynecology (NASPOG) to meet with leadership and researchers about HG. We also distributed 200 HG Provider Packets.

HER exhibited and presented abstracts at the American College of Obstetrics and Gynecology in San Diego last May. Our medical advisor, Dr. Brecht-Doscher had the amazing opportunity to reconnect with Secretary of HHS, Xavier Becerra. He remembered us from our 2005 Congressional Briefing on Capitol Hill which he sponsored. We have since met with his senior staff to discuss HG awareness and gaps.





HER has also been collaborating with the Texas HHS department on their new HG mandate to increase awareness and develop policies and strategies to improve treatment. A draft proposal and meetings are underway. Texas HHS is considering our resources and new educational program in their initiative. We hope this is the first of many states to adopt proactive and intentional strategies to prevent complications of HG.

We met with scientists and healthcare providers at the October 2022 meeting at the International Colloquium on HG (ICHG) in London. Leadership passed the conference to the HER Foundation to host in November, 2024 in Ventura, CA. This will bring together brilliant minds for strategic partnerships and learning about HG.

# Focus Area RAISING AWARENESS AND ADVOCATING FOR CHANGE

## **NEW RESOURCES**

HER offers patients and healthcare providers resources to improve assessment, treatment, advocacy and support. We worked with Hebrew and Malaysian health professionals to translate some of our tools, and are now working on French and Italian translations.

Over the last two years, HER released the following:

- Two-sided Treatment Algorithm
- HG Facts Brochure
- Advocacy Brochure
- Psychosocial Impact Brochure
- Patient Treatment Brochure
- Patient Treatment Overview

Our tools and brochures educate specific audiences on HG and the work of the Foundation. Our Advocacy Brochure is being shared with members of Congress to increase awareness of HG.

The new 2-sided algorithm for medical providers gives additional information on HER's innovative strategies for managing HG. The Patient Treatment Overview and Summary help patients manage their care and remember essentials such as taking vitamin B1 and preventing medication side-effects. Our goal is to help patients become self-advocates and understand essentials of HG management.



hyperemesis.org/tools





## **OUR VISION**

HER envisions a world where all pregnant patients have access to compassionate, effective, and safe care for HG, so they and their babies have a healthy future.



Focus Area

# MAKING HG EDUCATION ACCESSIBLE TO PROVIDERS AROUND THE WORLD

## **CLINICAL TOOLS**

Our research finds timely medical intervention benefits the short and long-term health of both mother and child. HER's clinical team creates resources to improve HG care.

Dr. Housholder at Alabama's Morning Sickness Clinic uses our resources and stated "With your treatment protocols we have been able to keep all but one [patient] out of the hospital. After being on your treatment protocols, none of our patients are needing home health! [Patients] submit their HELP scores... so that [I] can adjust their medicines for them on the fly "

Improved care only happens if HER's resources are used, so HER attends conferences and educates clinicians on best practices for issues HG patients face every day. HER tools are freely downloadable on the HER website for all to use, and many are translated into other languages.



Dominique Albrecht, Grant Advisor



#### **HG PRESENTATIONS**

Maryland WIC
Fresno Public Health
Sarasota Hospital
African Health Now COVID Webinar
Partnership for Maternal and Child
Health of Northern New Jersey

#### A WORD FROM OUR MEDICAL ADVISOR

Every year, we are reminded of the need for the education and advocacy we offer. While presenting at an ACOG conference in 2022, we started talking about HG and a doctor in the audience said, "I know what causes HG. It's hysteria." This is why we educate on the genetics of HG.

At a talk for Maryland WIC providers, I was told, "I was completely blown away by this information. I knew a little about HG but had no idea of the impact."

Following Kimber's Fresno Public Health presentation, their leadership team unanimously agreed that all obstetrical professionals should be required to listen to our presentations and asked why HG was not a legislative priority. Our policy and education initiatives are so crucial!



## HER HIGHLIGHTS

With your generous support, here are ways you have provided help and hope for HG since 2000.

#### **IMPACT BY THE NUMBERS**

A Hundreds of thousands helped by HER support groups, peer-to-peer support, and one-on-one guidance by HER advocates and clinicians.



First genetic cause of HG discovered.



Over 2.2 million people utilized HER resources across 95% of countries.



Over 45 articles, peer-reviewed studies & abstracts published.



First HG Care app developed with UCLA which has over 9000 users in 123 countries.



HG brochure translated into 7 languages.



Hundreds of HG Provider Packets distributed.



50+ HER educational LIVEs on social media.



F HG awareness chats across 6 continents.

#### **SOCIAL MEDIA COMMUNITY**

f 22,000+ Facebook followers

20,000+ Instagram followers

in 675+ LinkedIn followers

170+ Pinterest followers

3,700+ Reddit followers

2,700+ Twitter followers



UTILIZED HER RESOURCES ACROSS 95% OF COUNTRIES.



OVER 45 ARTICLES, PEER-REVIEWED STUDIES & ABSTRACTS PUBLISHED



#### **HG PROVIDER PACKETS**

**OUR PROVIDER PACKETS EDUCATE ON TREATMENT AND** ASSESSMENT OF HG.





#### INTRODUCING... AMY!

HER Foundation Executive Director and Co-Founder, Kimber MacGibbon, had the honor in 2019 to film about HG for Amy Schumer's docuseries, Expecting Amy. Amy offered to be on the Board of Directors to assist with media engagement and awareness of HG. We welcome Amy to the HER team!



## 2022 FINANCIAL OVERVIEW

#### Revenues

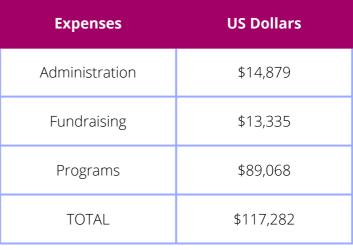
# Expenses

Revenues	US Dollars
Donor Contributions	\$120,000
Grants	\$0
TOTAL	\$120,000

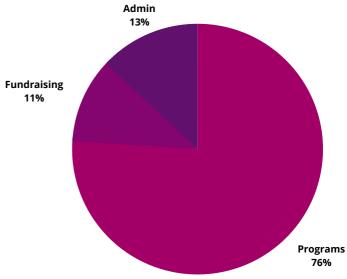
"HER is bringing attention to something that almost killed me and many other women. It brings education and a community to something that otherwise is so dark. Knowing

— MYKAH (USA)

others survived and can help you is priceless."



## **Expense Summary**





## 2021 FINANCIAL OVERVIEW

#### Revenues

### Expenses

Source	US Dollars
Donor Contributions	\$109,548
Grants	\$51,740
PPP Loan	\$13,247
TOTAL	\$174,535

Expenses	US Dollars
Administration	\$13,070
Fundraising	\$11,437
Programs	\$48,718
TOTAL	\$73,225

Platinum Transparency **2022** 

Candid.

#### **GuideStar Platinum Seal!**

In 2022, HER completed the additional metrics and reports required to achieve the Platinum seal of transparency at GuideStar, also known as Candid. HER prides itself on careful management of donor funds. HER's Board of Directors review quarterly financial reports at HER's Board Meetings and a professional Bookkeeper and CPA manage HER's books. Tax reports are available online at the Charity Navigator on the IRS website, GuideStar, and our website.





# PARTNERS IN IMPACT

We greatly appreciate the generous support our business and program partners have provided.































# THANK YOU TO ALL OF OUR VOLUNTEERS WHO COMMIT THEIR TIME AND EFFORTS THROUGHOUT THE YEAR!

#### **AMBASSADORS**

Stella Escobedo
Aijia Grammer
Letitia Hazell
Cindy Montoto
Jen Jean Pierre &
Jermaine Maull
Kathryn & Andrew Romine

#### **VOLUNTEERS OF THE MONTH**

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HER Board Meeting, Los Angeles, CA, May 2022



# OUR DONORS MAKE A DIFFERENCE

The HER Foundation has grown in reach and impact because of the support of the community and generosity of donors who understand the devastation HG can bring and the hope HER offers.

#### WHY WE SUPPORT HER

"I talk about the research HER is currently doing and I try to make people aware of just how serious HG can be. I don't think people are aware that 1 in 3 HG pregnancies end in loss. People should support the work HER is doing because there are so many women who are affected by this disease, not just during the pregnancy, but also after."

-REBECCA (NORWAY)

# Thank You to Our 2021-2022 Donors

#### Benefactors \$5,000+

Amy Kacher
Ann Marie & Jeremy King
Julia & Kyle Moffett
Meagan Mnich
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Philip Sinz
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Tim Opler



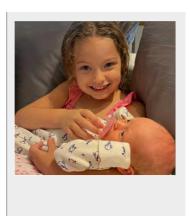


#### Advocates \$1,000-\$5,000

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In memory of Hiraja Ruzaike



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Kodi Sharon

Krista Rogers Krista Fk Kristen Allbritton Kristen Brown Kristin Barry Kristen Land Kristina Wong Kristina McConnell Kristina Pazusis Kristina Cronan Kristopher Brown Kristy Cera Kyla Barrett Kylee Kitch La Ines Lacey Bollino Laila Arnesen Larry Schoenberg Laura Ballew Laura Engel Laura Galley Lauren Gray Laura Harris Laura Timberlake Lauren Marcum Laurie Murdoch Lawrence Sunden Lea Spever Leah Marie Leandra I. Addison Leanne Marie Lee Hunt Lee Hillstrom Leonardo Potì Les Mor Leslie Marlin Leslie Harrison Lewis Luyken Lexy Cruz Young Liane Butitta Lieszl Elle Linda Ottostrand Linda Ramsby Linda Welch Lindsay Bee Lindsayy Kayy Lisa Fields Lisa Lilledahl Lisa-Ann Smith Lizzy Partridge Lloyd Green Loree S.Nauman Loretta Myers Lori Bourque Lori Castoe Lori Debyl Lori Del Negro Lori Gartner Louise Smith Lynda Cass Lynda Thaxton

Lynne Baker Lynn Lina MA Guille Mackenzie Johnson Maddy Weinberg Madeleine MacDonald Majken Heino Malin L. Nording Mandi Moore Mandy Parathyras Mandy Sosbee Marc Mayfield Marcie Sullivan-Marin Margaret Nugent Maria Murphy Maria Verdad Marilynn Thomas Mario Guerrero Mark Koivu Markmarita Lawton Martha Ahrens Martha Gibson Martha Hayden Martha Wolcott Martin Sundholm Mary Konchar Mary Jayne Mcneil Mary McWilliams Mary Ann Plummer Mary Vinopal-Sowers Mary Youtz Maryanne Mize Matt Durbin Matt Hughes Matthew Brown Maureen Day Maureen Lewis Megan Empereur Megan Maultsby Megan Neddow Megan Olson Mel Frank Melanie Courchesne Melanie Smith-Hoffman Melanie Townsend Melanie W. Robinson Melanie Wotherspoon Melinda Leni Melissa Parker Melissa Iohanson Melissa Virginia Melissa Zieglar





Melissa Ward Melissa Dier Mercedes Bell Michael Chirichello Michael Gonari Michael Mann Michael Ramón Michael Raupers Michelle B. Poston Michelle Buchanan Michelle Gregory-Turchi Michelle K. Jensen Michelle Mott Mindy Lyons Mira Dee Missy Babineau Misty Espinosa Misty Steffen Mitch Couzens Mitzi Mosier Monica Palos Murray Shields Naila Kerbal Nancy Pontius Nancy Fiske Nancy Gladding Nancy Mello Nastya Belka Natasha Dupee Nate Knisley Nathan Turcotte Nicole Bird Cheung Nicole Faircloth Nicole Gibson Nicole Grialou Nicole Mello Nicole Wagner Nigel Myall Nigeria Cox Niki Galvin Nina Dougall Noelle Hozumi Norma Wright-Moore Ola Jönsson Olga Rakka Olivia Powley Øystein Pettersen Paige Button Pam Freese Wilson Pam Thompson Pamela Edwards Patricia Afif Patricia Capobianco Patricia Chavez Patrick Boucher Patrik Haggren Patrik Öhman Patrycja Pezán Patti Sinks Pattie Tramontozzi Paul Dawson Paul Moran Paula Sorensen Paula Wise Baker Peggy Nickerson Peter Bouchard Philip Waddell

Phyllis Favila

Poornima Dayalan

Quewaner Kirkland Rachel Apolzan Rachel Boudoin Rachel Lartigue Rachel O'Brien-Morano Rachel McGhee Rachel Walker Randi Thompson (Merritt) RaQuaam Smith Raquel Bonneville Rebecca Andrea Rebecca Saidlower Rebeck J. Gustafsson Regina Millard Ren Raiford Renate Solberg Rhonda Behrens Ria Baker Richard Bernier Richard Wayrynen Rick Schoenberg Ricky Bernard Risa Ray Rita Painter Rita Pozniakoff Rita Blood Robert Bignold Robbie Rickgauer Robert Ir. Robin Gibson Robyn Raleigh Ron Holbeck Ron Kurtz Rory Thompson Rosa Yarbrough Rosalba Broccolo Rose Halverson Roseanne Rawan Rosie Casanova Rosie Luyken Royce Tharp sr. Ruth Burke Ruthann Wilson Ryan Fleming Sadie Chi Sally McMullin Sam Williams Samantha Batson Samantha Greenhow Samuel Austin Samuel Jones Sandi Galavda Sandy Brown Sandy Rose Sanne van Tongerloo Santeena d'Amico Sara Lowe Sarah K. Chubak Sarah Gillespie Sarah Hedahl Pham Sarah Kupas Sarah Sanvictores Sarah Skirvin Sarita Sehdev Scott Hansen Scout Around Sean Ahearn Shadi Mehraein

Shalaya West

Shannon Tobin-Chirichello Sharon C. Caruso Sharon Spires Shaun Bernatchy Shauna Tracey Shea Budd Sheila Holt Shelagh Stratford Shelby Wiltshire **Shelley Thompson** Shelli Patno Sheri Scown Sheri Anderson Sheri Srechsler Sheryl I. Payne Shoshana H. Polakoff Shoushou Y. Selin Sierra Jackson-Yopp Skylee Jones Skyler Cless Sobia Sonia Schenker Sonia Williamson Sonya Rosella Sophie Ackers Sophie Wyn-Evans Stacey Duffy Stephanie Christy Stephanie Isennock Stephanie Malin Stephanie Rae Stephen Thompson Steve Bishop Steve Kennedy Steven Marone Stine Risanger Sueanne Chin Susan C. Cessna Susan Carpenter Susan Comfort Susan Elsner Susan Turturo Susanne Lindberg Susie Speckman Suzanne Charette Suzanne Drapeau Suzanne Rickgauer Sydd Carlisle Sylwia Maliszewski Tabitha Lenius Siniff Talibah El Talleah McGuigan Tamara Williams Tammy Ankney Tammy Burkholder Tammy Majewski Tanisha Landis Tanya Keegan Tasha King

Taylor Hunger Taylor Monaco Taylor Suarez Terri Pinkham Terry Bayuk Tess Jaco Tess Rouvray The Rasberry Family Theresa Douglas Theresa Vandaele Theresa Matson Theryn Engle Thomas Smith Tia Eubanks Tiffany Neddow Tiffany Strickland Tim Searl Tim Swett Tina Ohman Tom Smith Tony Cruse Tony Raio Tori Tori Tracy Bourne Tracy W. Stamper Tracy Van Dolah The Morning Sickness Clinic Tres Hawkins Trish Cuff Tyler McMillin Valentina Guevara Valerie Read Valerie Smith Vanessa Wilson Vasi Billie Vero Mexia-Aguilar Virginia Brooks Vivi-Ann Ohman Wendy Ann Wendy Gilliam Wendy Kobiela Will Farris Yumi Soares Zaj Vidal-Burgie



