



STAR LEGACY FOUNDATION

2013 ANNUAL REPORT

Star Legacy Foundation experienced significant growth and excitement during 2013. Highlights included participating in the development of the Action for Stillbirth Awareness and Prevention (ASAP) Coalition, hosting the first Let's Not Be Still events in the Minneapolis, Minnesota area, welcoming new Champion families and events, and starting planning activities for Stillbirth Summit 2014. These accomplishments and more could not have been done without the many efforts of our ever-expanding team of volunteers and supporters.

STAR LEGACY FOUNDATION

2013 ANNUAL REPORT

EDUCATION

Planning was initiated for Stillbirth Summit 2014 to be held in Medina (Minneapolis), Minnesota June 19-21, 2014. The theme will be *Identifying and Protecting the Vulnerable Baby*. The location and other early details have been determined, and abstracts have been received by dozens of health care professionals, researchers, and stillbirth experts from around the world. Fundraising has also begun and the planning teams are busy continuing with their efforts to make this event a success for everyone who attends.

The education programs continued with several inservices throughout the United States for physicians, nurses, midwives, and nursing students. Plans were also put into place to expand these offerings in a variety of settings and media in the coming year.

The *See Me Feel Me* patient education program continued its success with more hospitals, clinics, and expectant families adopting the concepts and materials for use with their patients and themselves. The 2012 revisions were completed with the most significant change being the inclusion of the kick chart into the brochure itself. This has shown to be a popular feature as it maintains the convenience of the wallet-sized card, but it is a complement to the education components.

RESEARCH

The Study of Trends and Associated Risks of Stillbirth (STARS) Study passed the half-way point of its two-year enrollment period. Participation remains steady and encouraging. In October 2014, the study will finish the enrollment stage so that analysis can begin. We are honored that Dr. Edwin A. Mitchell of New Zealand has agreed to present preliminary findings of the un-controlled portion of the study at the Stillbirth Summit 2014.

“Thank you for the See Me Feel Me pamphlet I received. I felt more comfortable monitoring my baby’s movements after learning why it is important. Most important, it gave me the confidence to talk to my OB about my concerns at the end of my pregnancy. This conversation revealed my daughter was in trouble and needed to be born. I am forever grateful.”

-- Heather M., Boise, ID

“The last summit was by far the best stillbirth meeting I have ever attended, everything presented was new and exciting.”

Jane Warland, RN, RM,
PhD; Adelaide, South
Australia

We continue to build and improve the research library available on our website. Our goal is to be a trusted source of information regarding past and emerging evidence in stillbirth research. We also hope to provide support and recognition for the researchers around the world who are dedicating their careers to stillbirth care and prevention.

ADVOCACY

Our support of families occurs through both formal and informal approaches. Informally, we speak to families and those who work with families on a regular basis. In more structured activities, we continued our fiscal sponsorship and support of *11 Angels* who provide companionship support to families enduring loss in the Minneapolis/St. Paul metro area with plans to expand in the next year. A new fiscally-sponsored activity includes Janelle's Baby Loss Memory Boxes serving the Duluth, Minnesota area.

AWARENESS

Star Legacy Foundation is proud to be a founding member and hold positions on the Steering Committee of the Action for Stillbirth Awareness and Prevention (ASAP) Coalition. In the first year of existence, ___ individuals, researchers, organizations, and health professionals have joined together to unify their voices for stillbirth awareness and prevention. As part of this effort, Star Legacy has been represented this year at several perinatal loss conferences, legislative movements, and meetings with national government agencies engaged in stillbirth activities.

Legislative efforts that we supported during 2013 included (1) the Farley-Kluger Initiative to expand FMLA protection to include parents who lose children from any cause; (2) the Autumn Joy Stillbirth Dignity and Awareness Act in New Jersey; (3) The Sudden Unexpected Death Data Enhancement and Awareness Act (S.314/H.R.669); and (4) The Stillbirth Awareness and Research Act of 2013 (H.R.2365).

Inaugural events for the *Let's Not Be Still!* were a huge success. A golf tournament and Brunch with Miss America raised both awareness and funds for stillbirth issues and our initiatives. As part of the National Stillbirth Awareness Month efforts in October, a 5K Run/1 Mile Walk was held in Eden Prairie, Minnesota. Other Champions events were hosted by the Goodyear and Kvien families (Run for Silas), the Mueller family (Abby's Ride, and Abby's Run in three locations), the VanderWood family (Addyson's Angel Walk), and irun4littlehearts. It appears we will have even more new Champions in 2014.

We were honored to welcome three new members to our Board of Directors.

- Kristi Reinertson is a Founder and Co-Executive Director of 11 Angels. On May 7, 2009 Kristy and her husband Brett's son, Aiden Parker was born into heaven at 38.5 weeks gestation, his death attributed to a nuchal cord. Kristi holds a degree in elementary education and currently coaches gymnastics.
- Erin Fiaturuolo and her husband Angelo have experienced the devastation of miscarriage. As an accomplished photographer, Erin provided perinatal loss photography for her employer, Baby Bloom, prior to moving to Minnesota. Since then she provided photo retouching services

to nurses at those same hospitals for bereaved families. Erin brings a wealth of knowledge and expertise in creating memories for families in a few short hours that must last them a lifetime. In addition, she is a tireless volunteer for our programs and projects.

- Joanne O'Leary, PhD, MPH, MS, IMH-E is well-known in the perinatal loss community for her work with families, particularly in pregnancies after a loss. Joanne holds a B.E.S. and a Masters in Maternal-Child Health from the University of MN. She also has a Masters in Psychology through research from Queens University in Belfast, Northern Ireland which was funded through a Rotary Scholarship. Her thesis title was: Psychosocial factors influencing maternal adaptation in Primiparas and the effect of the Brazelton Neonatal Assessment Intervention. Her Ph.D. is in Work, Community and Family Education and from the University of Minnesota. Her dissertation was The Meaning of Parenting During Pregnancy After the Loss of a Baby: A Descriptive Phenomenological Study of Parenting a Subsequent Baby Following a Perinatal Loss. Her first career as an LPN in Pediatric NICU led into her second career as a birth to five preschool Special Education Infant Teacher in the inner city of St. Paul. She became certified as Neonatal Behavioral Assessment Scale examiner during her MPH course and moved into a hospital setting working within a High Risk Perinatal Center. She does research and writing on prenatal parenting; pregnancy and parenting after the loss of a baby, including its impact on fathers and siblings, including adults who were the child in their family born after the loss of a baby. She also teaches a number of online courses on Prenatal Loss and related issues.

As part of *Let's Not Be Still!*, we created an awareness video that was used in multiple locations as part of October Awareness events and in many social media outlets. We were blessed to have the inclusion of many beautiful babies who were shared with us by their families for this purpose. The video continues to be available at <http://starlegacyfoundation.org/70-stars/> and will be used throughout 2014 as well.

Our monthly newsletter now has a new editor! This change has brought new life to this awareness project. The positive feedback has encouraged us to bring even more material to our community in this way. We are grateful to Alicia Loehlein for lending her talents to us for this purpose. Alicia, too is a stillbirth mom.

Hundreds of people in the stillbirth community came together during 2013 to show their support for the feature film *Return to Zero*. Star Legacy Foundation was excited to participate in this movement as a local leader and continues to support its release in theatres. We hope to continue the work of the directors and maintain the energy created into the next year. In addition, we support another film, the documentary *STILL Project*, as they complete production and use their talents to increase awareness of perinatal losses.

Finally, our blog, *Stillbirth Matters*, continued to reach hundreds of stillbirth families and other interested individuals. We are humbled by the response to our articles as it is proof that so many families, organizations, and individuals want the same answers and progress regarding stillbirth that we seek.

FROM THE EXECUTIVE DIRECTOR

2013 has been an amazing year for Star Legacy Foundation. I continue to be excited and encouraged by the growth and support. So many activities and responses from the last several years have convinced me that the stillbirth community is on the precipice of significant breakthroughs that will

change stillbirth in our country and world. My hope remains that stillbirth will one day be a rare occurrence and that all devastated families will be given answers for their loss. Until then, we will push forward for optimal care for the thousands of families enduring these heartbreaking tragedies and research that brings us closer to stillbirth prevention.

I would like to extend a huge thank you to our Board of Directors, our Medical Advisory Board, our Champions families, all who donated to our efforts, and the many volunteers who contributed in more ways than I could mention. Your support and dedication is palpable and continually provides me with renewed energy to continue and expand our initiatives.

I am looking forward to 2014 with a great deal of hope for what we can accomplish through Star Legacy Foundation and for the babies who provide all the inspiration we could need. Please visit our website to learn more about our 2014 initiatives and priorities.

Lindsey J. Wimmer, CPNP

Lindsey J. Wimmer, RN, MSN, CPNP
Executive Director, Star Legacy Foundation

