

The week of February 7th to the 14th has become a tradition for our family as Congenital Heart Defect Awareness Week. We celebrate the brave efforts of children and adults with CHDs, and we commemorate Heart Angels who continue to inspire through their bravery in life. We give thanks to supportive heart friends whose expertise as parents has been as valuable as medical advice. It is an occasion for grateful acknowledgment of friends and the community whose support improves the quality of life in an unpredictable world, and the medical staff whose devotion to research and care provides hope.

This letter is in honor of our daughter Cora, and her brother and sister whose patience, love, and care are an intrinsic part of her happiness. We especially want to express gratitude to friends, family, and our community, current and past, who rallied and reinforced our faith and energy as we prepare for Cora's heart transplant. My intention for this letter is to promote awareness and understanding through the listing of resources, and to provide information for other heart families who may benefit.

Awareness brings about understanding that a CHD does not define an individual, but has an impact on daily life. It encourages funding for research and patient support. Undiagnosed heart conditions contribute to unexpected cardiac deaths, highlighting the importance of routine testing for newborns and athletes. The emphasis on volunteering for organ donation is especially prevalent for those waiting for a heart transplant. The need for research, care and funding increases as the number of CHD survivors reach adulthood, and survival and quality of life become integrated.

CHDs are the most common birth defect, and there is a lack of government funding and research allocation. One in a hundred babies are born with a CHD, over 40,000 a year in the US alone. There are 35 different types, some of which may be corrected through surgery. Others require palliative, short term measures that prolong life while patients hope for medical research to extend this. CHDs can occur regardless of ethnicity, race, socioeconomic status, age, and prenatal care.

Children with CHDs can also require other services to assist with other issues such as feeding difficulties, physical and motor delays, and cognitive functioning. Many enlist other medical disciplines to address other physical issues as the lungs, kidneys, liver, and the gastrointestinal tract can be affected.

My hope as a parent is to see the question mark over my daughter's future replaced with an exclamation point. Despite her limited heart function, she completed a 5K thanks to inspiration from friends and coaches who fueled her belief that she could. Cora, like her heart peers, demonstrates resilience, empathy, and optimism. These are a direct result of compassion and understanding from her friends and all whose kindness bolster her belief in herself and her ability to overcome.

We understand that Cora may need another transplant during her lifetime. We believe improved technology could prevent this, which encourages our will to share her story. We want her future to reflect her dreams and expectations.

A proclamation drafted by the Congenital Heart Information Network has been signed by the First Selectmen of Southbury and Middlebury, and the Governor of CT. Participation can be in the form of sharing the resources below, volunteering for a hospital or Child Life Department, or one of the organizations listed. We send these on with thanks to these charities for their advocacy and assistance.

Please continue to keep those with CHDs and other medical issues in your thoughts and prayers. Thank you to everyone for the many forms of kindness we've received over the years. With much love and many thanks,

Val and Mark Guerin

[Adult Congenital Heart Association](#) whose website, print materials, media outreach, educational events and advocacy events allow (them) to reach out to adults with CHD and advocate for the ACHD community. ACHA offers information directly to patients and families, and provides materials and services through health-professional members.

[Children's Hospital of Philadelphia Fetal Heart Program](#) is a national leader in the evaluation, diagnosis and treatment of fetal heart disease prior to birth.

[Children's Heart Foundation](#) is the leading national organization that was created to exclusively fund congenital heart defect research. CHF has published and distributed 35,000 English and 3,000 Spanish copies of [*It's My Heart*](#), a patient and parent resource book.

[Corience](#) is a European network dedicated to congenital heart defects. Patients and relatives can access Corience for in-depth information and useful tips on how to make life with congenital heart defects easier.

[Heart of a Princess](#) emphasizes the importance of organ donation in memory of brave, beautiful Isabelle. Her transplant fund became a memorial that provides nursing scholarships and care packages to families in critical care units.

[Heart Hugs](#) will send pediatric heart compression pillows worldwide with the help of (their) volunteer network. Please contact if you are interested in being a volunteer, or if your child needs a compression pillow.

[Little Hearts](#) is a national organization providing support, education, resources, networking, and hope to families affected by congenital heart defects. You can learn more about CHD facts and how to contact the media with their [PR Toolkit](#).

[Matthew's Hearts of Hope](#) raises awareness to the number one birth defect, offers support to CHD patients and their families, as well as raise funds for research. The founder lobbied successfully for Mandated Pulse Oximetry Screening in both Connecticut (SB 56, Matthew and Faith's Law) and in New York (A 2316). Pulse oximetry is a simple, inexpensive test given at birth that can detect some undiagnosed CHDs.

[Mended Little Hearts](#) provides families and caregivers of children with heart defects and heart disease an outlet through which they can find answers, education, resources and access to local-based peer-to-peer support – building hope for the future.

[Saving Little Hearts](#) is dedicated to helping children with congenital heart defects and their families by providing emotional assistance and educational information primarily through the distribution of Care Packages.