



Mended
Little
Hearts

Big Successes for *Little* Hearts

National CHD Awareness Week
Campaign Generates
Overwhelming Response!

“Our goal for Congenital Heart Defect Awareness Week and Heart Month was to raise awareness about congenital heart defects and to make more people aware of the many great services Mended *Little* Hearts provides to help families,” said Megan Setzer, MLH National Director.

Setzer is referring to the successes of the first virtual **Roar ‘n’ Run 13.1** half-marathon and Fun Run races and the first **Rock Your Scar** Instagram photo-sharing contest for survivors of congenital heart disease. Both contests were part of the “CHD: Life with an Open Heart” awareness campaign, and ended on the last day of CHD Awareness Week, February 14, 2014.

Mended *Little* Hearts couldn’t be more pleased at the response for these two new events, which touched more than a half-million people. Each attracted hundreds of participants, who shared their excitement with their families and friends.

Roar 'N' Run

Raise Awareness and Get In Shape

The first annual virtual Roar 'N' Run 13.1 (half marathon) and 1-mile Roar 'N' Fun Run were held to raise awareness about congenital heart defects, the number one birth defect in the U.S., to help people get in shape during Heart Month (February), and to support Mended *Little Hearts* so more families can be reached. This event attracted more than 770 people and many others who participated by fundraising for MLH. Setzer noted, MLH set a goal of 250 registered participants, so the response was terrific.

Participants could walk, jog or run the 13.1 miles, and they could complete it anywhere they chose (the gym, outside, or on an inside track) — anytime during CHD Awareness Week. They could complete some of the miles every day, every other day or all in one day.

“The Roar 'N' Run was a great success because it both raised awareness and much-needed funds for our national organization,” said Andrea Baer, MLH vice president. “The beauty of the virtual race was that it could be done anywhere and anytime. It was a lot of fun too. Also, we wanted to target people who didn't already know about CHDs, and these races were successful in raising awareness because many runners and others outside the CHD community registered.

“The Roar 'N' Run surpassed all goals that we set in the beginning,” she said. “It was really inspiring and exciting to see so many people work together across social media to spread the word and raise awareness.”

Added Setzer: “The medals one of our members designed for this event were a big hit too — with the kids and adults. We had so many participants posting their pictures with their medals to our Facebook event page. It was absolutely wonderful to see!”

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“Rock Your Scar” Also a Big Success

Popular actress and MLH National Spokesperson Valerie Azlynn — an adult CHD survivor who had open-heart surgery to repair an atrial septal defect at age 13 — helped raise awareness of congenital heart defects and showed off CHD “badges of courage” — virtual or real — on the Instagram photo-sharing service.

The purpose of the the Rock your Scar contest (held January 15 to February 13), like the Roar ‘N’ Run, was to raise awareness about congenital heart disease so children and adults with CHDs view themselves in a positive light and see other survivors just like them. Between 2 to 4 million people in the U.S. are living with congenital heart disease today. Many of them have scars, but some of them don’t. The contest was able to show how strong these children and adults are — that they are not defeated by their disease. The purpose was also to empower them to be proud of who they are, scars and all. While not all people with CHDs have physical scars, they all share the scars left from the CHD fight. Unfortunately, a lot of people with CHDs have been bullied, ridiculed or simply don’t feel good about themselves as a result of their scars. MLH also chose “Rock Your Scar” as the theme because so many people don’t know that children have heart surgeries — and the scar is a visible sign of all these kids have been through.

“Once we launched ‘Rock Your Scar,’ we went from about 4,000 ‘Likes’ on Facebook to more than 25,000 in just a matter of a few weeks,” said Donnie Wilson, co-chairperson of the MLH National Awareness team. “There were more than 600 entries in the contest, and it really took CHD and MLH to a new level of visibility.”



**Valerie Azlynn,
MLH Spokesperson**

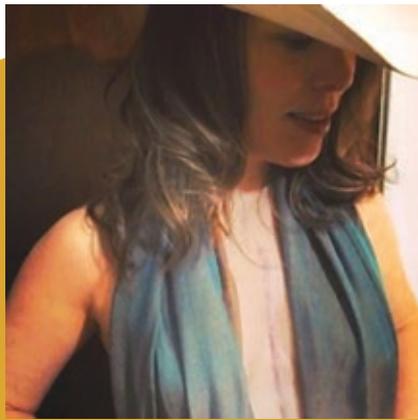
One important factor in the success, Wilson said, is that we made it clear that even those without physical scars could participate with their “virtual” scars. “My five-year-old, Jacob, a CHD member, has no scar. But we are all taking part in the same journey. The response was hugely successful, and we are so grateful.”

That is also the sentiment of Lauren Gray, the other National Awareness team co-chairperson. “The response did surprise us. We easily reached over a half-million people. We have not had this kind of reach, and it is a major step forward for us.”

Gray also credits Valerie Azlynn, the organization’s spokesperson, for helping to drive up visibility. “Valerie is a CHD survivor, and she is very committed and passionate about making sure that these kids have good self-esteem,” said Gray.

Winners in each age category included Carson Haag (0-3 years old category), Ayden Skillman (4-8 years old), Makenna McCorvey (9-12 years old), Lola Serrano-Montilla (13-17 years old) and Kelly Norris (18-99 years old). You can see the photos of the winners at the Mended Little Hearts Facebook page: <https://www.facebook.com/MendedLittleHeartsNationalOrganization>.

“CHD Awareness Week reached more people than ever



18-99 years old—Kelly Norris: From Kelly. "Thank you for putting on this empowering contest! I wish we had had an organization like yours when I was growing up."

0-3 years old—Carson Haag: From Carson's mom, Jamie Haag. "I am so glad that we could be a part of helping to spread CHD awareness, and it was such a fun project for us as well! I cannot express in words how thrilled we are ... after a very difficult first year."



4-8 years old—Ayden Skillman: From Ayden's family. "Thank you for the opportunity to compete in this contest. We are so thankful that so many people were reached!"



9-12 years old—Makenna McCorvey: From Makenna's mom, Carlie McCorvey. "For my daughter, whether she won or not, this was her opportunity to be PROUD and not different! She loved looking at all of the entries. It made her feel like part of a larger community."



13-17 years old—Lola Serrano-Montilla: From Lola's mom, Mari. "Lola's barely 3-1/2 months into her recovery from her surgery ... and a contest like this definitely boosts her confidence. My eyes well up just remembering her telling kids that, in a world where everyone wants to be perfect, her imperfection makes her more beautiful, and stronger, and that no one can take that away from her."

before. I am honored to work with the Mended *Little* Hearts National Organization," said Valerie Azlynn, the official spokesperson for Mended *Little* Hearts. "We had an incredible amount of pictures submitted for Rock Your Scar. We were blown away. To all of my little heart warriors, we are so proud of you. Keep owning who you are. You are the future, and together we are building a community of support."

Rock Your Scar judges looked for the best photo submissions from CHD Heroes, those that reflected a "Rock Star" theme.

"Plans are already in the works for another virtual run to celebrate World Heart Day in September," said Andrea Baer. "And we are looking forward to the annual Roar 'N' Run event during CHD Awareness Week each year." 🍷