



Mended
Little
Hearts

How Mended *Little* Hearts Groups Benefit Their Communities



Mended *Little* Hearts of Bakersfield, Calif. organized a community concert that raised funds to help benefit the Children's Heart Foundation for congenital heart research.

With 64 groups in 24 states (and Washington, D.C.), Mended *Little* Hearts groups rarely rest in their efforts to benefit the communities they serve.

"These volunteer-led groups work in local communities to help and support not only their members, but others in the community as well," said Jodi Lemacks, national program director for Mended *Little* Hearts. "Our activities in communities generate awareness that results in improved lives — and sometimes saved lives — when parents recognize signs and symptoms of a heart defect in their child and quickly seek medical attention."

Most Mended *Little* Hearts groups participate in community activities from health fairs to walks to fundraising events. Fundraisers help Mended *Little* Hearts groups hold support group meetings and awareness events, and create care bags for families with children in the hospital. They also provide vital information about congenital heart defects to families living in that community.

We've gathered a small sampling of these activities that are lighting up communities across the country.

For example, every year the Mended *Little Hearts* Tinman Club in Winston-Salem, N.C., displays the spirit of the season by decorating a Christmas tree. It's not just for show. The tree is donated to the local Festival of Trees, which sells decorated trees to local businesses; proceeds benefit the local children's hospital.

October is also busy, with the group participating in the American Heart Association's Heart Walk, which has a significant benefit to the community.

Heart Walk proceeds fund patient education materials and research that could help patients with heart disease as new advances and even cures are explored.

Heart Walk funds are also funneled into critical advocacy efforts that have a direct impact on the lives of heart patients across the country. In addition, with audiences of thousands, Heart Walks are a great way to spread the word about the services and resources Mended *Little Hearts* provides.

The Tinman Club also hosted a fun Halloween photo shoot. "We took pictures of all our heart kids and siblings dressed up in Wizard of Oz costumes for our calendar and sold them for a fundraiser," said Lead Coordinator Valerie King.

In one of its most meaningful efforts, the group is reaching families in need — through their stomachs.

"We're working with the medical center and local restaurants to provide meals for our families who are in the hospital (and their families when they come to visit)," Valerie said. "This means they don't have to take turns seeing the child and can eat together."

Also in North Carolina, another group, Triangle Mended *Little Hearts*, hosts a spring heart-health fair. It's headed by Tommie Polk, a parent who lost her athlete son to cardiomyopathy. Such events spread vital information and share potentially lifesaving services with communities.

"The fair is always held at a local high school," said Lead Coordinator Robin Wilson. "It's primarily a screening and education event for students, athletes and local families. Several Duke doctors volunteer their time to read the electrocardiograms (ECGs).

"We raise awareness and get ECGs done for local athletes to help prevent this type of loss and heartache from occurring," Robin said. "Tommie calls the fair '#42 Heart Health Fair' in honor of her son's football jersey number."



These smiling faces were just a few of the reasons behind the successful benefit concert in Bakersfield, Calif., which included dinner, music, and silent and live auctions.

Because the group is located in the Raleigh-Durham-Chapel Hill/Research Triangle Park area, "We like to think of our "triangle" of care: the child, the family and our supporters such as Mended *Little Hearts*," Robin said. "So we like our name!"

Another activity is the group's annual fall family outing at Ganyard Hill Farms, where members come for a pumpkin patch trip, a hayride and a cotton-pickin' good time. "We pay for the admission from donations and from sponsorship money provided by Dr. Jennifer Li, the Pediatric Cardiology department chair at Duke." Many Mended *Little Hearts* families have limited resources, and social events such as this allow them to get out and enjoy

themselves without having to think about their medical issues. Also, children with heart defects can meet others like them, with the same scars. It makes them feel less different.

In November, the main event is Owen's Trees. "We craft miniature Christmas trees provided by Kjirstin Marlow, Owen's mom, to decorate patients' rooms.

Owen has hypoplastic left heart syndrome, a defect where one of the four chambers of the heart is missing or severely underdeveloped, and has undergone multiple surgeries, but he and his family always think of others, especially around the holidays.

In addition, the group's holiday potluck provides inpatient families a home-cooked meal.

"Mended *Little* Hearts members know what it's like to be in the hospital with their child, eating only in the cafeteria if at all," Robin said. "We set up a countertop full of casseroles and drinks, and a tabletop full of desserts donated by our members, in the Pediatric Cardiac ICU waiting room. Last year the casseroles got rave reviews!"

Joy Byrom, who has coordinated the Mended *Little* Hearts of Bakersfield, Calif., group for five years, got involved after her son Jake was born with a hole in his heart and needed surgery to repair it.

She recently put countless hours into organizing a community benefit concert that was held at Buck Owens' Crystal Palace in August. The event included dinner, music and live and silent auctions. Entertainers Merle Haggard and Eddie Money signed autographs for the live auction.

The event and proceeds helped benefit the Children's Heart Foundation for congenital heart research, a local hospital and Mended *Little* Hearts.

Mended *Little* Hearts of Lynchburg, Va., Lead Coordinator Laura Morrison heads an active group that raises awareness about congenital heart disease by advertising at community and fundraising events and other meetings. Group leaders take their message wherever they can, including to the grocery store.

"In October we offered a CPR class, and in November we discussed the importance of the newborn pulse oxymetry screening and how Mended *Little* Hearts has been a driving force to get this test on the national list of newborn testing," she said.

In December the group will party with a purpose by using their holiday get-together as a chance to look at American Medical Alert samples.



After his third open-heart surgery, a nurse brought Owen Marlow a small Christmas tree. This small act lifted his family's spirits and inspired them to start "Owen's Trees," which has brightened hundreds of other lives with miniature Christmas trees.

Mended *Little* Hearts of Lynchburg's Care Bag program is a major initiative that gives comfort to families of hospitalized kids. Bags contain everything from hot chocolate to lip balm to bubbles for siblings — a huge service to the hospital and the patients it serves.

"We provide help and comfort to families while they are in the hospital," she said. "We delivered 40 bags to UVA Children's Hospital in September along with several nursing covers for moms who are nursing or pumping."

The Mended *Little* Hearts of Greater Rochester, N.Y. group's recent community activities include everything from sharing countless coffee hours with families in the hospital to hosting its first "Hearts Go Wild" summer picnic at a local zoo.

Lead Coordinator Jennifer Kowal said, "We had 274 people attend in support of our heart families, and 52 heart kids came with their friends and families. The event offered them the opportunity to meet someone their age with a similar diagnosis. It was very successful not only for the kids, but also for the moms and dads. They were also able to share stories and learn from each others' experiences."

The group also held a successful silent auction. The icing on the cake? Membership increased by 30 families. ❤️

Many other Mended Little Hearts groups are doing similar great works in their communities—we just don't have space to list them all in this issue. If you have stories you'd like to share about how your MLH events benefit the community, we'd love to hear from you. Email Jodi.lemacks@mendedlittlehearts.org.