



Mended
Little
Hearts

How Our Group Does Things

by Carlie McCorvey • Fresno, California



The McCorveys at Camp Taylor's heart-family camp: Carlie holding Caton, Johnny, Makenna and Zachariah

We asked Carlie McCorvey of Fresno, co-coordinator of the Mended Little Hearts Central California group, to talk about how they organized their group. Carlie and her husband Johnnie are the parents of Makenna, who had the first of three heart surgeries when she was 36 hours old. The Central California group is one of 14 Mended Little Hearts groups chartered since the program was founded in 2004.

Sharing education is an important aspect of the support parents find at Mended *Little* Hearts. We provide educational opportunities to our families in several ways. I contacted The Children's Heart Foundation, and they sent me a case of books titled *It's My Heart* to give to our members and newcomers. This is an excellent resource to guide parents of children with congenital and acquired heart disease. It is very important for each parent to know what their child has and how that differs from a normal heart. This book helps do that.

I also put together a lending library of 20 books that our members can check out. They range from picture books to fictional stories to resource guides. I bring the box of books to each meeting. Members sign a book out and bring it back at the next meeting. I bought most of the books from www.kidswithheart.org, which has a great selection of books about congenital heart defects (CHD).

Another way we offer educational opportunities to families is through guest speakers. We have had a representative from Exceptional Parents Unlimited come and speak about their resources. We also have had meetings where we all shared what community resources we have found helpful. We have had a teacher speak about what resources schools offer, too.

One of the most helpful and inspirational speakers we had was an adult CHD survivor. He gave us a glimpse of what our children may be going through, and he offered hope and encouragement. We also have plans for a cardiologist to come and speak. There are endless possibilities when it comes to speakers.

Finally, in the area of education, our group is working on an informational packet for families in the hospital. They are similar to the Mended Hearts PATH Packs and will be available very soon.

Beyond Educating Parents

We have found that, for our group, being in a non-threatening, easy-going environment promotes more sharing of feelings and experiences. I believe more personal stories are shared at our picnics than at our actual

meetings. We recently had a barbecue at a local park, and it was great to see families sharing and interacting. Adults and kids alike were really coming together and bonding as a “heart family.” I even saw a few tears shed.

Recently we had the opportunity to attend Camp Taylor’s camp for heart families. Three families from our group went. It was a weekend retreat with 40 other heart families from central and northern California, and it was AWESOME! We had the opportunity to meet many other heart families, and it was neat to see that there were as many kids with scars as kids without them. It was great to see my usually very shy 3-year-old daughter make friends so easily (something she has never done). Somehow she realized that these other kids were just like her. I think it’s great that through MLH we have the opportunity to share information about events like this so that everyone has the opportunity to explore them.

Through our newsletter we share information about resources and events in our state.

Everyone doesn’t have to participate in everything, but it’s great to have the information available to have that choice.

Learning by Trial and Error

We have also found many things that don’t work for our particular group, and we have adjusted accordingly. For instance, meeting every month did not work for us. Having meetings in a “meeting room” (similar to Mended Hearts groups) also did not work for us. At first, I was hoping that *all* of the families would come together and share *all* of their experiences at the meetings. I soon found out that others are not as comfortable doing that as I am! This is why we focus on the picnics as a place for casual sharing, and we save the “meetings” for informational speakers.

Now we have quarterly meetings that include a separate activity just for the kids. This allows the parents to give their full attention to the meeting, and the kids get to play and interact with their “heart friends.” It worked out better to have an occasional picnic “meeting” than to have frequent speakers. Now we have two picnics and a holiday book exchange/pot luck.

This is what our group has evolved. I think it’s great that each group can do what works for their particular community and group of families. ❤️



*Top: Mended Little Hearts Central California picnicking in Fresno.
Middle: A group of heart friends enjoy a quarterly get-together.
Bottom: Quarterly meetings include both parents and children.*

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