

LEAN ON ME:

The Story of Heart Camp



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At the beginning of my career, 50 years ago, I was taught that a good pediatrician considers the entire patient and does not just focus on the patient's presenting symptoms or illness. This is especially true for those children with chronic problems such as diabetes, cancer, heart, lung, kidney diseases, etc. During my pediatric training I was fortunate to have a social worker as part of our care team and this experience convinced me of the need for a team approach to healthcare. These early experiences were further reinforced during my training as a pediatric cardiologist.

One of the great many factors that led me to begin my career in the Pediatric Cardiology Division at the Children's Hospital of Pittsburgh was the fact that for the previous 5 years Ellyn Donovan, a pediatric social worker, had been a full time integral member of the division. Subsequently, our division added additional social workers including Gwen White and Laura Hangard Patton, as well as Kathy Lawrence, a clinical nurse specialist.

In addition to the collaboration with social workers, I found that the pediatric cardiologist needed some additional assistance to help parents and families of our patients to understand the many issues surrounding the care of their children. I was able to explain to parents in great detail what to expect in the management of their child's medical condition – how we would treat heart failure or other problems, or when we would expect to perform heart catheterizations and heart surgery. Our social workers were able to assist families in dealing with their interactions with the hospital and the medical community. However, we were unable to describe to the families what it was like to be a parent or a sibling of a child with heart disease. We had no experience in what it was like living with the anxiety and fear of a child's deterioration, or even death. Nor did we have parental experience in combining the issues of normal childhood growth and development and heart disease.

Initially, with the help of our social workers, we were able to identify families of older children with heart disease who would be willing to talk with families of children with

newly diagnosed heart disease. The feedback from the families was quite positive and we eventually decided to formalize this process as more families participated. This led to the formation of Heart-To-Heart, a parent support group which still exists today. This group provides valuable parent to parent advice and support about the various issues that face the parents of children who are growing up with heart disease. In the mid 1970's Heart-To-Heart began holding an annual September picnic as a means of gathering together many families for an afternoon of fun and fellowship. In 1976 I was very fortunate to meet Mr. Charles Turner the founder of Turner Dairy located in Penn Hills, PA. Mr. Turner offered to host our picnic at the Turner Farm in Slickville, PA and thus began another chapter in the support of our families. Through the kindness and generosity of many Turner family generations, the annual Turner picnic has been held each year in early September for almost 40 years.

In the late 1980's I had discussions with our social workers about the possibility of doing something new for our patients. Most people are surprised to learn that almost 1% of children born in the United States have heart disease. Despite the frequency of this problem, most children with heart problems are not aware of other children like themselves. In the past, these children were over protected by their parents, siblings, teachers and often their peers. Most were not allowed to participate in gym or sports activities in school and often had very sheltered lives. While siblings and peers were able to have sleep-overs with their friends, or even were able to go away to camp, the children with heart disease were not allowed to participate in these activities and usually were not allowed to be very far away from their parents.

In 1989 we decided to look into the possibility of having a short term sleep away camp for our patients at Children's Hospital of Pittsburgh. The social workers and I scoured Western Pennsylvania for a possible location to have this camp and eventually we came across Camp Kon-O-Kwee, a YMCA Camp in Fombell, PA. The Director, Harry Kramer, was enthusiastic about the possibility of our using his facility during the week in June just before their summer season began. It took us about a year or so to work out all of the details as to how to manage this new endeavor and in June 1991, we began with our first Heart Camp experience.

Our vision of Heart Camp was that this would be an opportunity for children with heart disease to get to know a group of other children just like themselves. In their usual environment, they were the only person with heart disease. On the other hand, at Heart Camp, there would be many others just like themselves. In addition to campers, there also would be other older individuals who were junior and senior counselors, nurses and staff who also were patients. These people would be resources for information and also act as grown up role models for these campers.

The cardiologists, nurses, social workers and other staff had no idea what to expect from this group of children in a camping experience. Our only exposure to them had always been in the setting of their visits to Children's Hospital in Pittsburgh. We were told by the parents how limited these children were compared to their siblings and their peers. Almost all of these children had never been away from their parents for any length of time and certainly not overnight without them. Thus, for the doctors, nurses, counselors and staff, Heart Camp was unknown territory.

The facilities at Camp Kon-O-Kwee were ready for their camp season which began on the Sunday of Father's Day. The kitchen staff was in place and the life guards and other personnel were on the grounds. Since there were no other campers in residence as yet, Heart Camp had full access to all of the facilities. Camp began on Wednesday afternoon and we returned to Pittsburgh at around mid-day on Sunday.

That first year we had 32 campers between the ages of 8 and 15, about evenly divided between boys and girls. We had decided that we would gather with the families in the Cardiology Offices at Children's Hospital. This was a familiar place to everyone and might be a somewhat comforting location, especially for the parents, to have this first separation from their children. The children and their parents had a chance to get to meet the other campers and counselors while we finished all of our intake procedures, collected medicines and other necessities for the start of the camp experience. Everyone then said their goodbyes. The campers and counselors were loaded onto one bus, all of the camper's gear was loaded onto a second bus and then we were off for the beginning of Heart Camp.

Harbisson Lodge at Camp Kon-O-Kwee is located in a wooded area and is surrounded by 2 groups of cabins. The lodge has a central meeting area with a large fireplace at one end. At either end of the meeting area is a large room that can accommodate about 12 or more double-decker beds. There is a corridor extending from each end of the meeting room which has a number of additional sleeping rooms and a bathroom at the end. These sleeping rooms were for the doctors, nurses and staff while the camper's and their counselors slept in the large rooms just off the meeting area. One side of Harbisson lodge was for the boys and the other side for the girls.

We arrived at camp in the late afternoon and while the buses were being unloaded, many of the campers said "look, there are cabins! It will be great if we can sleep there". However, there was no way that we were willing to have any of these fragile children out of our sight. Thus, we all stayed in Harbisson lodge that first year. We felt the need to keep a close watch on our precious charges.

Pizza was our first meal and was delivered to Harbisson from the kitchen. Afterward we spent the evening first learning the rules and about what camp will be like. All of the counselors and staff introduced themselves and gave a brief description of their background. We also sang lots of songs, many of which have since become camp traditions. We then started the process of getting everyone washed and ready for bed. Needless to say, this took a considerable amount of time.

After the campers were in bed, the senior counselors, staff, doctors and nurses gathered together in the main meeting room and began what has become a tradition for the first night of Heart Camp. We reviewed the medical history of each camper and tried to identify potential issues that might arise over the next few days. On subsequent evenings, this group also gathered together to review the day's experiences, problems or challenges and discuss what might be anticipated for the next day.

We now began our first Heart Camp experience which in subsequent years resulted in a change of the sleeping arrangements. Can you imagine how difficult it is to get a group of 16 children all in the same room to go to sleep? These campers of various ages, with lots of adrenalin flowing, were all excited about their new experience and would not stop talking about what they were going to do in the next few days of camp. As soon as one group stopped talking and calmed down, another group chimed in. Thus, it was many hours before everyone was asleep and all the counselors and staff were exhausted. And this was only the first night. This continued each night in the first year of Heart Camp and by the end of that week, we all were exhausted. After this first year we also realized that these campers were normal children who just happened to have heart disease. We decided to treat them as normal children in as many ways as possible. In future years, the campers stayed in the cabins, still under close supervision, but this gave them the feeling of having a greater degree of independence.

The next morning almost everyone was up by 7 AM and by 8 AM we all were ready to make our way down to the dining hall for breakfast. While the current dining hall is on the top of the hill near the cabin areas, the dining hall in the 1990's was at the bottom of the hill almost $\frac{1}{4}$ mile away. Almost everyone walked. Some were slower than others but interestingly enough the campers from the same age groups kept together and walked at a pace that was adequate for the slowest member of the group. Those few campers who were unable to walk that distance were driven to the dining hall and their subsequent activities in the car of one of the Heart Camp staff. In subsequent years we rented a van for this purpose and eventually, as camp grew in size, we rented a second van each year.

This experience of the campers sticking together and looking out for each other was repeated frequently and taught us something about the special nature of this group of individuals. Children in this age group can be very cruel toward their peers, especially when they are different from the majority. However, the children at Heart Camp were very different. They tended to look out for each other and in almost every activity would modulate their efforts to the level of their least capable peer. Our interpretation of this observation is that these children are used to being different and being labeled as unable to do certain activities. We believe that because these children have been made to feel different from others, they will go out of their way to prevent doing to their fellow campers what had been done previously to them.

On our first day of Heart Camp the staff had prepared a morning of games for the campers. We all made our way to the top of the hill where the current dining room now stands. When we reached that location the reaction of the campers was "Look, a baseball field. Let's play baseball!" We – the doctors, nurses and staff - were quite concerned because of our perception of their limited physical capabilities. Thus, while the campers clamored to play baseball, we proceeded to guide them through the morning activities of less strenuous picnic games.

After a while, we gave in to the nagging of the campers and chose up 2 teams of 16 children each to play a limited game of baseball. These children with supposedly limited physical capability played baseball for 2 hours straight! How wrong we were! We found out that these campers were willing to try anything to the best of their ability! However, in contrast to their usual peer group, where there were campers who were unable to run the bases, there always was someone else to run for them. When someone dropped a ball, or was unable to make a throw, someone else did it for them. No one was ostracized for not being able to participate and everyone helped out each member of their team. This experience was repeated when the campers went through the Camp Kon-O-Kwee obstacle course. Although this course is physically challenging, it is an extraordinary experience to watch the campers help their friends make their way through this course. The end result of these experiences is that we realized that these are normal children, just like their siblings and peers, who have the desire to try many activities and are limited only by their physical abilities.

Over the years we have found that Heart Campers have a special and unique bond to each other. They are aware of the differences between themselves and others and feel a special kinship with other Heart Campers. In the days before the Internet and e-mail, campers often did not have much contact with each other from one year to the next. None the less, as soon as they saw their fellow campers each year, it was as

if they had only seen each other a few days ago and they picked up where they had left off the year before.

We regularly have had reports from parents when they brought their children back to the office for their checkups after their first Heart Camp experience. They often ask "what did you do to my child at Heart Camp? My child is completely different. Before he or she went to camp my child was very quiet, unsure of him or herself and lacked confidence. After camp, I have a different child who now is outgoing and self confident. This has been a life changing experience!"

Heart Camp has also made a difference in the lives of all of us who have participated as counselors, staff, doctors, nurses and other support personnel. We have experienced the change in our patients and also in ourselves. We have seen the difference that this experience has had in the lives of our fellow Heart Campers and this has given us the resolve to continue this activity for the last 25 years. I personally have hundreds upon hundreds of fellow heart campers who I have played ball with and swam with in the pool. These heart campers have grown up calling their doctors, nurses and other caregivers by their first names and have considered them to be their friends.

There is a special feeling among all of us who have participated in these many years of Heart Camp – campers, staff and caregivers alike. We all have had this unique experience which has changed all of our lives for the better.

This experience is exemplified by the refrain from the Heart Camp theme song "Lean on Me"

Lean on me when you're not strong
And I'll be your friend; I'll help you carry on
For, it won't be long
Til I'm gonna need somebody to lean on.

June 2015 – the 25th year of Heart Camp



