

# Facing Forward



A B O U T F A C E

## An Honour to be a Pioneer

By: Elise J. B. Levitt

...continued from newsletter

It was not unusual for me to awake from a nightmare. However, in the winter of 1976, when I was twenty-three, I realized the nightmares were related to growing up with a cleft lip and palate in the 1950's and 60's. I began to wonder if I was the only one with this residual feeling from all my hospital experiences.

I decided to give The Hospital For Sick Children (aka Sick Kids) a phone call, but I did not know who to ask for or really what to say for that matter. Eventually I was connected to Susan Barclay in the Social Work Department. I told Ms. Barclay some of my thoughts around the idea of helping other people with cleft lip and palate. She was very interested and very supportive. We decided to meet.

On the day of our meeting, I drove down to Sick Kids with great trepidation and excitement. I hadn't been there in years. I parked inside the same familiar parking lot where I had been with my parents so many times before. Once inside the hospital, it was very strange for me to walk those halls and smell the many familiar odours again. Seeing doctors, nurses and sick young patients everywhere was upsetting and stressful for me. But I pushed on, since I had an agenda. Ms. Barclay was wonderful as she listened to me with great interest and compassion. She said she would talk with the other members of the Maxillofacial Team and tell them my desire and plan to help others through setting up a self-help group. I told Ms. Barclay that I would like to begin by writing to other hospitals in Canada, and around the world, for any and all the materials they might have on cleft lip and palate.

I was so excited in the following months to check my small apartment mailbox every day after work for all the replies to my requests. My mailbox was overflowing, as was my anticipation and hope for what lay ahead. Every night I would read all the letters, pamphlets and booklets that I received.

I met with many of the plastic surgeons, dentists and otolaryngologists at Sick Kids, along with a psychiatrist and a geneticist, to get their input on my plans and began to map out a strategy. We decided to have an opening meeting for the public in a large auditorium at Sick Kids that held about three hundred people. We needed to see how much interest there would be in this self-help group. With the date of September 20, 1977 arranged for our opening meeting, I set out to inform the media. I was very encouraged to see the interest of the media as I began to be invited for interviews about my cause. I was interviewed by the Toronto Sun and the Toronto Star newspapers, CTV News, CBC television, Sick Kids' own news bulletin and the March of Dimes. Through this process, I began to get inquiries for information from parents of children born with a cleft lip and/or palate, as well as from older patients.

I later decided to name our group The Canadian Cleft Lip And Palate Family Association. It was very important to me that this group we were forming would include the whole family because in reality, every family member is affected.

I did not know it at the time, but my speech for the opening meeting would be the first of many public speaking engagements and interviews for me. I also did not know at the time that I had a severe anxiety disorder (like my mother's), which would explain my nerves, shaking and sick stomach before every event. The media wanted to attend our opening meeting, but it was suggested by the professionals at Sick Kids that many of the guests attending the meeting would probably not want to be photographed. I agreed and the media listened.

It was also suggested that I not use myself as an example of how the end result would be after surgery for everyone. Apparently my repair was exemplary and would not be the same result for everyone. I was very fortunate to have been one of the last repairs ever done by Dr. Arthur LeMesurier, a plastic surgeon whose revolutionary technique came to be known by his name, the LeMesurier Repair. We are all fortunate now that all the plastic surgeons at Sick Kids do amazing work with very difficult cases.

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Cleft lip and palate being the second most common birth defect (1 in 700), after club foot, meant that many people were affected by this challenge. Once the big day came, there was standing room only in the auditorium. It was estimated that almost five hundred people showed up. I reserved the front row for all the professional staff and my family. Many of these professionals had been my doctors. I



told the audience all about my experiences with the many doctor's appointments, surgeries, treatments, ear infections, difficulty with speech and being made fun of at school and camp. It was the emotional impact all of this had on me that I wanted to express the most. When I was finished speaking I looked up to the audience and all the professionals in the front row had tears running down their cheeks. They had never really heard the deep agonizing pain that being born with any facial challenge could cause. I then asked anyone who wanted to work with me in this self-help group, to please come to the front. I was overwhelmed with people coming forward, shaking my hand and some hugging me, then asking me what committees they could volunteer for. The Canadian Cleft Lip And Palate Family Association was truly born.

I had cards ready for anyone who wanted to fill out their contact information and I began to think of the next get-together. The opening meeting could not have gone any better. My year of preparation paid off. Over the Fall I met many times with those interested in getting involved, picking a leader for each committee and writing up the goals of each committee. Some of our committee

titles were: fund raising, media, newborns, teens, and psychology. I will be forever indebted to all those people who did so much for our Association. I loved working with the teens who had often felt so much shame in their lives, but were such energetic and caring people.

Some time in 1978, the Association was given two offices in the old Sick Kids nurses residence at 170 Elizabeth Street, with a telephone. A friend of mine, who worked in office supplies, brought me a new filing cabinet, chairs and a brand new electric typewriter. During one of our early meetings in our new office, we decided on whom to ask to join our board of directors and our advisory board. We also began the process of acquiring a tax registration number for s, as well as filling out the application to be listed in the directory of self-help groups. The day we were accepted in this directory was definitely a milestone for us. We had arrived! I believe it was through this directory that I began to get calls from other people wanting to set up self-help groups for their own disabilities or challenges.

One of these people was Betty Bednar (Elizabeth Ross), who was the second person to come to me regarding setting up a self-help group to encompass all facial birth defects. Betty was able to succeed in her quest to help others by later creating AboutFace and I welcomed her to use one of our offices while she was setting up. Today, those who are reading this article know Betty set up an amazing organization that is helping people across Canada with all facial differences from birth defects to facial accidents and/or traumas to facial diseases. I was very resistant to my Association losing its unique identity by amalgamating with hers. I felt cleft lip and palate needed its own place on the world stage. However, several years later, that was exactly what happened: we merged and cleft lip and palate is now looked after by AboutFace.



Meanwhile, donations were coming in from all over Canada, our committees were set up, meetings were being planned; I began to be invited to several cities to tell our story and sometimes help set up a branch of our Association. Our first branch was set up in London, Ontario. I met and assisted the leader in this region many times. When I was in Saskatoon to speak at a medical conference, I was invited to speak on radio regarding this birth challenge and our Assocrn.

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I worked for The Canadian Cleft Lip And Palate Family Association for five years including weekends and all my vacation time. I would teach at many professional and lay events by passing along information, visit new parents to help them with their disappointment and fears by giving them hope, and try to build self-esteem amongst teenagers. But my life was moving on. A wonderful woman took over for me in the early eighties as I went on to have my own family.

Now, in 2013, it is with gratitude that I say the functions of The Canadian Cleft Lip And Palate Family Association are still in the caring hands of AboutFace. It was an honour to be a pioneer.

Elise J. B. Levitt (Lisee)  
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