

Margaret Pfrommer and My Career

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BEFORE MEETING MARGARET PFROMMER

I need to go back to my medical school days at Downstate in Brooklyn. In 1967, I was given an opportunity by my medical school and the French Government to visit France. There, my *patron* was Pr. Maurice CARA, a world pioneer of intensive care medicine, mobile intensive care and founding member of The Club of Rome. He offered me the opportunity to make medical transports by land (a stand-up ambulance and mobile ICU) and by air (military helicopter reserved for General de Gaulle) supporting patients requiring mechanical ventilation.

I transported, with police escorts to avoid acceleration or deceleration, several children who were post-operative following open-heart surgery. I picked them up from an operating room in Paris's Laennec Hospital (for adults) and transported them across town to a children's hospital (St. Vincent-de-Paul). There, they were received by Pr. Gilbert HUAULT, who became my life-long professional guide and mentor. I didn't realize I was visiting the *first* pediatric critical care unit in the world and meeting *the* pioneer!

I asked Pr. CARA if I could spend two weeks with Pr. HUAULT. While on rounds, we would often neglect two patients (Aleone and Jacques) in the "back room" where the "lived" for years with no other future living alternatives. They had contracted polio in the early 60s before polio immunization was health care policy in France.

I spent a lot of time with them as they were fascinated with meeting an American and wanted to know about America. (They wanted to know what cowboys were like and if I really ate hot dogs and hamburgers!) I loved being with them, but was discouraged by their situation. They talked slowly despite their tracheostomies and connection to their Engstrom ventilators. (The Engstrom was the first positive pressure ventilator which was developed for polio in the 1950s. One of the first made was used at Laennec.)

My conversations with Aleone and Jacques helped me to perfect my French. It was then and there that I decided to (1) Become an intensivist (become an anesthesiologist) and (2) take care of children (become a pediatrician). But I never, ever wanted to be faced with a situation like taking care of patients like them who had no place to go.

Our lives are always guided. It was not by chance that when I finished my training in pediatrics and anesthesia/critical care, I ended up at The Children's Hospital of Philadelphia (CHOP) with the US pioneer of pediatric critical care, John (Jack) Downes, Jr, MD, FCCP, who had also met and been inspired by Pr. HUAULT.

Dr. Downes and Dr. C. Everett Koop (world pioneer of pediatric surgery) had created the first neonatal ICU and second pediatric ICU in America. And they had a problem: The ICUs were being filled with infants and children whose lives were saved by critical care advances in pediatric medicine and surgery and who required long-term mechanical ventilation to survive and thrive.

As I had trained in anesthesia and pediatrics and took care of children with disabilities in the military, I was given the assignment right after my training to "solve the problem of the disease of progress."

I was given my own intermediate ICU and team and soon was facing my unit filled with 10 children still limiting the CHOP ICU capacity for the Delaware Valley (4-6 million people). With creative and innovative care plans proposed by my interdisciplinary team (optimal ventilation), we soon had smiling happy children on long-term mechanical ventilation with nowhere else to go.

I had always kept close contact with Pr. HUAULT. I wrote to him and asked about Aleone and Jacques. I learned from him that they had moved on from the ICU to a rehabilitation hospital (Garches, France).

So in 1976, Dr. Koop commanded me to go to France and learn more. With Pr. HUAULT, I visited Garches Hospital and Pr. Annie BAROIS (French leader of pediatric rehabilitation) and learned the next steps. I was also told that children and adults like them were being moved into the community where they were supported by *associations* designed for that purpose.

When I returned home and told Dr. Koop about this, he asked where and from whom he could learn more. And so he then travelled to France and met Mr. Andre DESSERTINE, polio survivor and founder of ADEP, an *association* designated to support persons requiring long-term mechanical ventilation in the community. Dr. Koop returned to CHOP and told me to "GET GOING!"

The biggest challenge we faced was the lack of public policy and funding for home care for long-term mechanical ventilation. It was necessary to meet the authorities who determined exceptions to policy. I had one child from NJ and set off to Trenton. But

before I did, I asked the CHOP public relations department to make me a series of photographs (16" x 24") of the children in the ICU happily interacting with their environment. And so I went armed for "The Second Battle of Trenton." (The first battle of Trenton was fought by George Washington on Dec. 25, 1776).

When I arrived at NJ Medicaid, I met a rather small man behind a huge table with an impressively large book: *The Medicaid Regulations*. As I explained the need for the NJ child to go home, he opened the book and threw the regulations at me. When he did, I took out a photo, put it over the book, and he removed it to another place on the table. By the end of 20 photographs, the table (and the book) were covered with photos of smiling children and he caved in...WE WON!

It was sad to think that my work in home mechanical ventilation was soon to be over as I was to move to Chicago and Children's Memorial Hospital (CMH), site of the first pediatric ICU in America. But little did I know, it was just at the beginning of and continuing of my life work.

Just prior to arriving in Chicago, my wife to be (Evi) told me about a PBS program called "Donnie." It was about a child at CMH who had remained at CMH for 4+ years on a ventilator and the challenges for the hospital, the family, and the ethical issues raised for society. Evi was prophetic. She said Donnie would be my first patient! And so he was!! I worked with the Director of Illinois Medicaid collegially and then developed the program which became the "gold standard" in our region. (Note: I have a DVD copy of the movie "Donnie" and the follow-up movie produced at my request after he was home for several years entitled, "Mostly I Can Do More than I Can't".)

I had no idea what was in store for me. I just knew that I was on a path of my life adventure and was grateful for the opportunity.

MEETING MARGARET PFROMMER

It was clear in Chicago that we also needed a regional solution for long-term mechanical ventilation for children and adults. I was fortunate that my Dean at Northwestern was Dr. Jim Eckenhoff. He was also from the University of Pennsylvania and a pioneer of anesthesia. He understood the home mechanical ventilation accomplishment at CHOP and gave me time and money to return to France to propose a plan of action for Northwestern Medical School. My charge was to find out how and what was done for survivors of critical care who required long-term mechanical ventilation.

As I flew over to France thinking about people living long-term with a ventilator in a hospital, I was inspired with a thought: What Ever Happened to the Polio Patient?

When I arrived in France, I met M. DESSERTINE to learn about the role of French *associations* in providing resources and services for patients requiring long-term mechanical ventilation who were living in the community. In addition, M. DESSERTINE and his daughter, Mme SANCHEZ, taught me how to use “*les centres de documentation*” and the role of “*les documentalistes*” in compiling and communicating information to multiple stakeholders necessary to inform and make changes in the health system for mutual benefit.

I asked Mme. Sanchez, “Can you tell me what ever happened to the polio patient in France?” “Can you guide me to learn more about how the French Association System provides services that permit such patients to go home and live independently?”

Even though I was supported by Dean Eckenhoff, all the Department Chairs were fighting among themselves. I never felt like I was able to accomplish what I needed to do in an academic setting. Dr. Koop then invited Evi and me to Philadelphia to meet with his wife Betty at The Union League. There we concluded that we could never accomplish what we needed to do in a medical school setting.

Philadelphia and NYC had many medical schools and they would all benefit by an organization dedicated to solving the challenges that such patient care presented. And so an organization (CARE FOR LIFE) was born and Evi and I were charged with the leadership. Our plan was to make *demonstrations*, provide *education*, and create *documentation*. All our mentors where involved as our Board of Advisors.

This included past Margaret Pfrommer lecturers Drs. Augusta Alba and Dominique Robert as well as Andre DESSERTINE, Gini and Joe Laurie, Dr. Geoffrey Spencer, the UK pioneer for long-term mechanical ventilation (St. Thomas’ Hospital, London) among others.

I had learned from Dr. Alba about the *Rehabilitation Gazette*. This was a source of information for post-polio ventilator users and their caregivers and health care providers. [The *Rehabilitation Gazette* was the organization that evolved into Post-Polio Health International and International Ventilator Users Network (PHI/IVUN)].

We met with founders Gini and Joe Laurie who said we needed to organize an international congress and bring all the world leaders together. And so CARE FOR LIFE, *Rehabilitation Gazette* and The Rehabilitation Institute of Chicago (Northwestern

University) sponsored a conference, "What Ever Happened to the Polio Patient?" in 1981, the International Year for the Disabled Persons. The planning committee included my wife Evi and me, Gini and Joe Laurie and Margaret Pfrommer. Featured speakers included Drs. Alba and Koop (keynote), and Margaret Pfrommer.

Margaret Pfrommer worked at the Rehabilitation Institute of Chicago (RIC) in the Northwestern Department of Rehabilitation Engineering. There she worked with Dr. Dudley Childress and was involved in designing all the technology that permitted her (and others) the mobility and ability to live independently despite disability.

Margaret was a post-polio survivor and quadriplegic who had previously lived in a nursing home. However, some doctor noted her unique capabilities and encouraged her to live independently. With life and living support and first-hand personal knowledge, she was able to contribute both public policy and community-based practices that still benefit persons with disabilities today.

WORKING WITH MARGARET PROMMER

When we created *Care for Life*, we brought together all our mentors who guided our understanding of the challenges we faced. These included Drs. Alba and Koop as well as Gini and Joe Laurie and Margaret Pfrommer. We realized we had a lot to learn from their combined years of experience and wisdom. And so we listened and learned.

Evi and I would often visit Margaret at work at RIC and at home. We experienced first-hand that Margaret was aware of and in control of her body (although she couldn't move her arms, hands, legs, feet) and needed nocturnal ventilation with her Emerson rocking bed (later supplemented with nasal mask).

She knew how to get around her home with an environmental control system developed at RIC to control everything in her home (door locks, alarms, electrical appliances, communication devices etc.). She used a chin-operated wheelchair with a sip-and-puff switch that controlled her wheelchair, permitted her to answer the phone and allowed her to use her computer and write at 35 words/minute.

Although she seemed to be the Rehabilitation Engineering secretary and hostess who greeted people and answered the telephone, she was really an active collaborator with the engineers.

In Chicago, we observed that she encouraged the creation of independent living organizations, e.g., Access Living and The Congress of Organizations of Persons with

Handicaps (COPH), which was the forerunner for the independent living organizations around America and the stimulus for legislation in Chicago and US Congress for transportation and building/housing accessibility. Among her accomplishments was the improvement of awareness for education about persons with disabilities and their ability for living independently (the Americans for Disabilities Act or ADA.)

The list goes on with the benefits from and the impact of what we and others learned by working with her.

One personal experience with Margaret illustrates what and how we learned just how remarkable she was. She was invited to go the National Institutes of Health to review research grants and to the US Senate for testimonies about need for changes in public policy. Unfortunately, Margaret did not have a driver of her adapted van nor a personal caregiver. So, Evi and I volunteered. This is how we got a first-hand understanding of what her day was really like.

When Margaret awoke, she need help with getting dressed. She had no ability to move anything of her extremities. She had, however, totally feeling of passive movement. The caregiver had to use care when moving her and finally putting her limbs in position for the day. Once in that position, they would stay that way all day long.

I drove her disability van (a "for first" experience). The trip to Washington, DC, from Chicago took quite a while. However, we had to make the trip in one day, because getting in and out of the van overnight was to be avoided. The cautious driver that I am, I drove with care. We ate a short dinner on the road and took some sandwiches along with us in case we arrived late and were hungry. And we did arrive late.

By the time we got Margaret settled in her room it was much too late to eat at the hotel in Bethesda, MD. Evi, who by now was in awe of her responsibility as a personal care giver, helped Margaret get ready for bed. Believe it or not, Margaret had a portable rocking bed with which she travelled that she designed at RIC.

Evi put her on the bed and started the motor and it went "hee, haw, hee haw" but it didn't rock! Evi, being "resource-full" remembered the sandwiches! Although she and Margaret were not hungry, Evi remembered that the sandwiches came with mayonnaise. She reasoned that mayonnaise was a lubricant. She used the mayo to help the moving parts of the portable rocking bed and got rid of the noise. Then they both went off to sleep.

The next morning, after several hours dressing, they went to breakfast and told others about the experience. After that, Evi was called Dr. Faure from the MAYO Clinic!

A second personal experience is worthy of note. Margaret had told me that she absolutely would refuse a tracheostomy under any circumstance unless I recommended it. In her later years, she did not seek the medical attention she needed. She developed major abdominal tumors from her uterus which caused her acute respiratory failure and required surgery and post-op ICU care at Northwestern. Her weight was 140 pounds (due to edema) although her normal body weight 80 pounds. She looked grotesque. Those in the ICU didn't really understand who she was. So I took a copy of the CHEST publication she wrote and put it on the bed stand next to my only picture of her with Dr. Koop taken at RIC so others would know.

I knew how to listen to her and talk to her. I explained to her that she had a purpose to fulfill and would be able to do this with her ability to have ventilation which demanded a tracheostomy. She agreed. And lived several more years as a productive person.

She waited until my year of ACCP leadership before passing on at home in 1998, when I was doing travel abroad with Evi. She was in control of her life. She lived what she taught others to understand: her perspective.

Honoring Margaret Pfrommer

Years before, I had a unique opportunity to have lunch with Gini Laurie, Margaret Pfrommer and George Emerson (JH "Jack" Emerson's son). I wish I had had a tape recorder. Most importantly, I learned what persons with disability who require long-term mechanical ventilation were facing. At that time, I made a personal commitment to find a way to get the story out, and I did through my association and commitment to the American Academy of CHEST Physicians (ACCP).

Dr. Koop advised me to "fold" CARE FOR LIFE into other organizations and get myself some more educational credentials and leadership experience in professional associations. The "documentation" function was already being fulfilled by the *Rehabilitation Gazette* and continues to be at PHI/IVUN.

In 1984, I joined the AMA, American Academy of Pediatrics, and was sponsored by Dr. Al Soffer to become a member of the American College of CHEST Physicians. I also was encouraged by Evi and Dr. Koop to get more education in organization development (Loyola University Chicago) and management (Kellogg-Northwestern).

This led to my invitation for leadership at ACCP where I learned first-hand how special the College is with its vision of being “the leading resource for the improvement of cardiopulmonary health and critical care worldwide.”

There, I was able to realize an idea proposed by others and to encourage Curt Sessler to take the leadership in developing ACCP NetWorks (including home care which is now focusing on home-based ventilation and neuromuscular issues).

Dr. Koop knew the ACCP and its CHEST Foundation as a unique organization which is why he shared with me the opening session at CHEST 1999: the “telechat” on “Humanitarianism in Medicine.”

It was also clear to Evi and me that it was the organization that would help me fulfill my promise to Margaret and Gini. That was why we proposed the Margaret Pfrommer Memorial Fund to conduct a lecture at the annual CHEST meeting and for other purposes (e.g., travel for ventilator users and personal attendants at regional CHEST meetings on mechanical ventilation).

It is now 2016 and we are joining with the PHI/IVUN and FCCP members working together to embark on the endowment of the Margaret Pfrommer Endowed Memorial Lecture in Home-Based Mechanical Ventilation to continue these and other educational CHEST activities in continued demonstration of the “CHEST Vision.” ■