



# Capabilities

Communicating the Science of Prosthetics and Orthotics

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## Margaret Pfrommer 1937-1998 The Woman Who Understood No Part of the Word “No”

*Margaret Pfrommer, a crucial member of the Northwestern University Rehabilitation Engineering Team for 25 years and widely known as counselor, advocate, author and teacher who immensely advanced the opportunities available to people with disabilities, died on October 14, 1998. Her friend and colleague, Dudley S. Childress, spoke these words in her memory. This issue of **Capabilities** is dedicated to Margaret and the legacy she left so many of us.*

### ***Margaret Pfrommer, Leader of Angels***

*By Dudley S. Childress*

Margaret always introduced me as “her boss”. But, as Jim Butler observed, everyone knew who really was “the boss”. It was Margaret.

Margaret died on Wednesday, October 14, 1998 — but I saw her coming back to work early on Thursday morning. I was half asleep, half dreaming, half conscious, but for the first time, I saw Margaret walking. In my reverie, I clearly saw her standing outside the east doors of the Rehabilitation Institute of Chicago (RIC). She was waiting for the doors to open — those contentious doors she had tried for so long to get changed so that people without use of arms could operate them.

The morning sunlight streamed through her golden hair. She stood straight, almost six feet tall in her high-heeled black shoes and black pant suit. She was beautiful. She wore a purple scarf and white blouse — Northwestern colors. She had a briefcase in her right hand and a sheaf of papers on her left arm. Like Michael Jordan, she said simply, “I’m back”. Margaret Pfrommer *was* back, taking up new duties as leader of angels.

What could be a more appropriate position? Who knew more about angels than Margaret? There were the

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## Leader of Angels

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Weiss sisters who freed her from the nursing home. There was Mrs. Hartman, Karen Cullinane, Jim Butler, and Dick Calhoun, angels all — perhaps saints — and many others in Chicago, Oak Park, and River Forest.

At the Northwestern University Rehabilitation Engineering Research Center, angels were also abundant. There was Carole Herhold, who in 1973 suggested to me that Margaret might work in our Center. (Little did we know that the work would extend for 25 years.) John Stryzik and Ken Kalan helped develop and maintain Margaret's electronic controllers and communications systems. Edward Grahn kept her wheelchair going and modified her rocking beds. Craig Heckathorne kept Margaret's computer functional.

Ken Kozole designed and built her worksite and interfaced her with assistive equipment of all kinds. Ken gave Margaret her first overnight camping experience. Trinklette Stokes took care of the mail, papers, and schedule and often gave her lunch. Margaret's dear friend, Bonnie Collard, looked after all her needs, private, professional, physical, and spiritual.

A host of graduate students in biomedical engineering learned about disability and rehabilitation from Margaret and in return gave her much affection. Students

such as Laura Miller, Keith Oslakovic and Steve Gard, to name only a recent few, were special angels to her.

**“This is Margaret...she's in charge of everything...”**

There were Margaret's physician's, also angels. Dr. Wu, Dr. Goldberg, Dr. Repasy, Dr. McCarron, Dr. Roth, Dr. Meyer, Dr. Nanninga, and many others come to mind. Especially, there was Dr. Betts of the RIC. No matter who he introduced to Margaret, whether it was Madame Sadat, Patricia Neal, Helen Hayes, Vice-President Bush, or the Mayor of Chicago, it was always, “This is Margaret Pfrommer, she's in charge of everything that goes on here, everything you see in rehabilitation engineering and in technical aids and assistance for the disabled, everything!” And so she was.

Now she's a leader of angels. You'll recognize her in the halls of the RIC, in homes, hospitals, independent living centers, and on the streets of Chicago and River Forest. She's the leader of all angels working to make this a better place for everyone, especially those working for the betterment of persons who have significant disability.

Margaret, we are grieving — we see Fall's “golden groves unleaving”. Your friend Antoinette Krieg noted as she left to return to her native Switzerland that she was crying out of one eye and smiling out of the other. Today, we are crying out of one eye because of your departure but smiling out of the other at your arrival. Welcome back — boss, Boss of Angels! ❖

## ***From Back Room to Congress — Margaret Pfrommer Built a New World for People with Disabilities***

*By Jan Little*

Margaret Pfrommer, like classical music, had warmth and compassion — which made us think of spring days and happy times — combined with crispness, bite and vigor — which made us envision reaching new horizons. Margaret was a young woman filled with life — just entering college — a dancer — an artist — when polio struck one last swath of destruction in 1956. Margaret, one of those most severely affected by the virus, was left with the ability to move her head from side to side, to force air into her lungs using her tongue and soft palate — and the ability to plan how to get on with her life.

In getting on with her life, she touched nearly every aspect of the revolution which would take people with significant disabilities from nursing homes to the main stream of life. To understand the extent of progress for people with disabilities in which Margaret participated, in the early 50s

for the person with a disability requiring use of a wheelchair included many restrictions.

- **He or she would live at home as long as family members could provide care.**
- **Without family care, the individual with a disability would live in a nursing home.**
- **Elementary and high school education was by tutoring or in an “orthopedic school”.**
- **Only one college or university (University of Illinois- Urbana) would allow a person with a significant disability to enroll as a full-time student living independently.**
- **If the individual with a disability worked at all, it was in a sheltered situation.**
- **Life expectancy was five to ten years. Pneumo-**

nia, urinary infections and pressure sores still claimed lives in a short time after onset of disability.

- **Most public and private buildings were inaccessible to those using wheelchairs.**
- **Public transportation was inaccessible. Airlines could and did refuse to allow people with significant disabilities the right to fly.**
- **Little technology existed. Unless a person had good hand and arm function, he or she could not use even the powered wheelchairs available in that era.**
- **An attendant was needed to make phone calls, operate lights and appliances, answer the door, switch the TV channel.....**

This was the world faced by Margaret Pfrommer when she contracted polio.

In a short time, another serious barrier to achieving her goals was thrown in front of her when she was forced to live in a nursing home — the only alternative that seemed open when her mother died a few years after Margaret had polio. She wasn't a very complacent resident of the facility. She refused to fade into the background. Through a series of events, Margaret did leave the nursing home.

As Dudley Childress noted in his eulogy, Margaret soon attracted the attention and assistance of "angels". One angel, whom Margaret, in an article in the February 1975 issue of *Lady's Circle*, identifies only as "Hildegard", spent endless hours searching for an apartment and interviewing people who could assist Margaret. She soon moved into an apartment near a college and two students from the college lived with her as assistants and social peers.

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## The hope of independent mobility

Several of Margaret's friends organized a benefit to raise money for a power wheelchair. The acquisition of the wheelchair, which was to launch Margaret on the product development aspect of her career, is related by her good friend, Chuck Chevillon. Chevillon was manager of a local medical equipment store and President of Medical Equipment Distributors, Inc. (MED), a group of men from across the U.S. who had joined together to solve problems. Although they were relatively untrained in engineering and equipment development, they often "designed" their own solutions to problems.

*"I had a call one day from Miss Pat Kammerer, Chief Physical Therapist at RIC," Chevillon recalls. "She was working with a young woman named Margaret Pfrommer who was classified as "totally paralyzed" as a result of having had polio. Pat told me that the woman was convinced that she could get a job if she could just drive a wheelchair."*

*"I decided that I might be able to let Margaret try a wheelchair put together with components our MED members had devised. Nagle Bridwell, Philadelphia, had found an electromechanical switching device, controlled by sipping and puffing on a tube, which controlled driving the 'chair'. Robbie Robinson and Bud Gage, prosthetists in Vallejo, CA, had developed a powered system to raise and lower the back and legrests of a reclining wheelchair. Dick DeVoe, in Denver, had fashioned shaped, cushioned rests for the head, arms and legs. It took me a couple of weeks to put all these parts together and to learn to drive the resulting 'Sip and Puff, Automatically Reclining Wheelchair'. A meeting was arranged at RIC for Margaret, Miss Kammerer and me to work together."*

*"I'd learned the hard way that it was prudent to get used to the two degrees of sip and two degrees of puff needed to stop, start and steer the wheelchair by disengaging the belts from the motors that drove the chair. Margaret was eager. She quickly became accustomed to the control of the motors. When she puffed hard, the motors started. When she sipped lightly, the right motor stopped and the chair would turn left. Very shortly, she insisted on having the belts engaged and took off down the physical therapy gym, turning right, left, stopping, starting, and — for the first time since she'd had polio — moving independently."*

Now living in her own apartment and able to come and go independently in her wheelchair, Margaret set out to get a job. During a visit to the Rehabilitation Institute of

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## Margaret Pfrommer -- a new world

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Chicago (RIC), she had met Dudley Childress, PhD, Director of the Rehabilitation Engineering Program at Northwestern University. The Program, housed in RIC, was developing a number of electronic devices which could be used by people who had little or no use of their hands.

Margaret wanted to try Northwestern's new technology. In April of 1973, she wrote to Dr. Childress telling him that she was "patiently but anxiously waiting for you to decide whether or not I will be an active candidate for an electrical (sic) device...." She continued to point out her interest although, in a memo in May, she told Childress that she had "decided to stop the pressure tactics". She noted that 17 years of dealing with social agencies and individuals "who do not keep promises or follow through" had perhaps made her a bit aggressive, but she felt his interest in her was sincere. She had judged Childress correctly. Following a visit to the Northwestern labs in July, Dr. Childress proposed that she become a member of his staff.

### **...it might be better if we got to know you better**

In a letter written to Margaret by Childress on July 25, he noted, "I know you are interested in our development of definite things which can assist you. It might be that this



could be done better if we saw you in normal situations and got to know you much better." He continued that he and his staff were exploring the possibility of employing

people with disabilities as significant as Margaret's and were considering modifying a telephone device so that she could work as a receptionist a few hours a day. Carole Herhold, secretary to Dr. Childress, had created a job description for Margaret if she was interested in participating in an experiment.

### **"...I do mind going through life without having tried"**

Margaret was very interested. She replied in a letter to Childress that she was confident she could perform the duties Carole Herhold had outlined. "You have thoughtfully prepared me for the possibility of failure," she wrote. "I do not mind failure; however, I do mind going through life without having tried." She joined the staff at the Northwestern REP in 1973. Her "few hours a week", suggested by Ms. Herhold soon became many hours a week. Ms. Herhold had advised Margaret that she could "use whatever pressure tactics you wished -- as you have with Dr. Childress" to urge John Strysik, one of the lab's most talented electronic technicians, to expedite the project of creating electronic methods for a person to handle office and personal tasks using only sipping and puffing on a tube and slight head movement.

### **Margaret's "Wish List" spurs new developments**

Margaret and John quickly became a team. They were joined by Edward Grahn, Craig Heckathorne, Jay Kaplan, Ken Kalan, Ken Kozole and others. Margaret soon had a work station which allowed her to answer phones, take messages, and be the department receptionist. The team also developed means for her to control lights, television, and appliances and perform other tasks in her apartment. The team didn't just function at the laboratory and during work hours. Various combinations of the team drove Margaret, in her van, to national meetings. Ken Kozole introduced her to camping. John Strysik introduced her to disco dancing. Engineering graduate students at Northwestern including Robert Van Vorhis, James Doubler, Clint Gibler, and Greg Rombola played key roles in assistive device development.

### **Margaret campaigns for constant improvement**

But life wasn't smooth. In May of 1974, Margaret used the fact that her friend Carole Herhold had nearly been injured when Margaret's chair failed to perform adequately on Chicago's busy streets to urge the Northwestern team to modify the system that controlled Margaret's wheelchair. In the process, they caused all manufacturers of commercially available power wheelchairs to adopt such features as controlled acceleration and deceleration, variable speeds controlled by the driver, automatic course control, adjustable speeds when starting and stopping the chair and safety switches. People who marvel at the wheelchair used by Christopher Reeves are seeing the work that Margaret and

the Northwestern staff did in the 1970s.

While progress was made at Northwestern in perfecting the electronic devices that enabled Margaret to work and live more independently, no such changes were occurring in the social system which trapped people with disabilities. Margaret was supported by Supplemental Security Income from Social Security and administered through the State of Illinois Department of Public Aid. When the Illinois Department of Public Aid insisted that her household help must be hired and paid directly by that department, Margaret reacted typically. She wrote to the governor of Illinois — and over 30 other people in various positions of influence — stressing that people with disabilities must be empowered to hire and manage those who assisted them. She won. Today, most states provide funding of personal care attendants (PCAs) that are chosen, trained and managed by the people with disabilities with whom they work.

### **Protective legislation eliminate potential of salary**

Margaret's quest for independence was inhibited by other legislation designed to protect the disabled. Although by summer of 1974, she was working full time at the Northwestern Laboratories, she had to be a volunteer. If she had accepted a salary, her financial support and medical care from Social Security and the State of Illinois would have been discontinued. With costs of personal assistants and special transportation added to the ordinary costs of rent, food, clothing and other living expenses, she could not have made enough money to manage. Margaret began bombarding everyone in health and welfare with her story — pointing out that it was not just her frustrations that prompted her to write, but the thought that there must be others whose plights were worse than hers. There should be a way that people with severe disabilities could re-enter the workplace without losing their benefits.

When Margaret assumed the role of consumer advocate and research associate in the Northwestern Rehabilitation Engineering Program, she did not limit her work to the labs. She shared her experiences, her ideas and her crusade for better living conditions for people with disabilities with many others.

### **“Margaret was my mentor”**

Yeongchi Wu, MD, an attending physician at RIC, recalls some of Margaret's contributions to others. *“For many years, I enjoyed visiting her and watching her give demonstrations with new technology. I always liked to see her showing off what she was able to do with new devices. Through her, one could appreciate the progress of research and development for people with severe disabilities. She was my mentor. From her I learned many issues related to disability. She never hesitated to tell me what problems*

*existed in caring for disabled persons. She provided counseling to many of my patients who considered missing a limb to be the end of life or that working after disabling disease was impossible. Many times, a short visit to Margaret by my depressed patients was all they needed to overcome their initial sad feelings.”*

*“Margaret liked to talk to me about her feelings toward RIC, particularly things that ought to be changed or improved. She passed to me many of her complaints or those she had collected from her friends. This was her way of getting people to follow her and getting things improved.”*

*“There were occasions when I watched her as she was struggling to stay alive. Dr. Goldberg and I stayed up one night doing a study at the RIC of her tolerance of nasal mask assistive breathing. I could not image how I could go through long hours every night in the rocking bed alone. When she was in the ICU a few years ago, many times I looked at her and thought she was not going to recover. Her strong will overcame the fragile body. She not only made it through the illness but also returned to work after a long recuperation.”*

*“One of the difficult parts of providing her medical care was the fact that nobody knew more about her condition than she did. Routine care worked for her only with her approval first. That caused a major problem when she was connected to the ventilator. A special communication board served well to get her connected with the caring staff. When the staff was able to understand her, she started to improve amazingly quickly.”*

*Dr. Wu concludes. “She struggled to live for herself and for others with severe disability. She told and taught many health care providers about what to do **for** the patients rather than what to do **to** the patients. I learned from her the importance of listening. I regretted her refusal of video documentation of her life so that future doctors could learn from my tough friend. I still do not know the reason for her decision, but I feel that future doctors will miss the chance to learn from this great person. Margaret inspired so much for the people around her. She will be remembered. She will be around, like an angel.”*

Companies in Chicago began to invite her to make presentations at their affirmative action sessions. She worked as a member of the Community Advisory Council for the Mayor of Chicago's Office on Senior Citizens and the Handicapped and the Citizens Council to the Center for Program Development for the Handicapped at Chicago City Colleges. She became known throughout the State of Illinois and, in 1976 was elected Chairman of the Illinois Del-

# *“Professional Patients” Add Reality to Teaching of Patient Management*

*By Anthony J. Squicciarini, C.O., C.Ped.*

*Instructor, Orthotics Education*

*Northwestern University Prosthetic-Orthotic Center*

*Instructor in Physical Medicine and Rehabilitation*

**A**t Northwestern University Prosthetic / Orthotic Center (NUPOC) we use a variety of teaching methods in order to help students learn about patient management as it relates to evaluation, assessment and prosthetic / orthotic recommendations. One such method is the use of “professional patient models”. These are individuals who have sustained debilitating pathological disorders, cerebral vascular accidents or limb amputations. Many of the “professional patient models” used by our program have been working with Northwestern University for a number of years.

In order to help facilitate clinical learning, students from our program see patients throughout the course of their studies. Student - patient interaction depends upon which program the student is in. Some patients are seen more than one time during the semester, an example would be an individual who has suffered from a CVA (cerebral-vascular accident) who can be treated during both the lower extremity and upper extremity sections of the Orthotics program.

## **Students studying orthotics sometimes use each other**

In addition to using “professional patient models”, students studying orthotics will often use each other as “student patient models”. They can take impressions or measurements for spinal jackets, conventional or polymer knee ankle foot orthoses and ankle foot orthoses, as well as upper extremity wrist hand orthoses and hand orthoses. This model of patient simulation can be easier on faculty, staff and students. Students develop clinical skills as well as the ability to examine, interview, establish relationships and make appropriate observations in a relatively low risk environment.

There are several benefits and drawbacks to each method. Each type of patient model has its particular advantage and disadvantage in the education of our students.

In using “professional patient models”, many students find this real - life experience to be exciting and motivational. Students learn appropriate communication skills with the patients and develop a deeper understanding of the patient’s problems. In addition students are also intro-

duced to the real pressures and responsibilities of patient care and follow-up procedures. The use of “professional patient models” allows the students to apply technical skills and reassures relevance to the treatment. This method also helps the students gain confidence in their practice.

Some drawbacks to the “Professional patient models” may be seen when unrelated problems may surface during a students clinical assessment. The patient can also be moody and uncooperative. The patient may also be bored since they have done this before. Many times there are difficulties in communications. Students may also be insecure with their skills and distracted in their clinical assessments. “Professional patient models” may become mechanical often repeating themselves over and over. Due to their prior experience as patients, patient history often turns to storytelling and a lighthearted interchange, creating a false atmosphere. While this can make time management difficult it is also a benefit because students are faced with “real - life situations”.

With the use of “student patient models”, there are also advantages. The “student patient models” are available at any time and can be presented as having any pathology. The students have the freedom to make mistakes. The use of students as patients allows students to develop clinical skills in a low risk environment. This method allows the students to practice communication skills with one another, and fosters additional feedback from peers.

## **There are advantages to both systems**

“Student patient models” allow the student to experience the feeling of wearing an orthosis whereas with “Professional patient models”, the student does not have this experience. Finally, the use of “student patient models” does have some financial benefits to the University as well.

“Student patient models” can also have disadvantages. The student-to-student interaction often creates a social environment where professionalism can be easily lost. The students can become unfocused, finishing up quickly without using proper evaluation procedures. Students are

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## **Northwestern Receives NIDRR Grant for RERP in Prosthetics & Orthotics**

Northwestern University was notified recently that it had been awarded a grant to conduct research in various areas of prosthetics and orthotics. In addition to continuation of the studies in the areas of Upper Limb Prostheses, Aided Ambulation and Computer Aided Engineering, Northwestern's RERP has added several new topics for investigation. Located in the Rehabilitation Institute of Chicago, the Northwestern RERP is affiliated with the Department of Physical Medicine and Rehabilitation of the Medical School and with the Biomedical Engineering Department of the McCormick School of Engineering and Applied Science of Northwestern University. These close interactions have resulted in rich resources for research and for applications of the research to those who use prostheses and orthoses. More details about Northwestern's new NIDRR grant will be discussed in future issues of *Capabilities*.

## **Dr. Seelman Dedicates New RERC to Focus on the Needs of Land Mine Survivors**

Dr. Katherine Seelman, Director of the National Institute for Disability and Rehabilitation Research, visited the Northwestern University Prosthetics Research Laboratory and Rehabilitation Engineering Research Center (PRL&RERP), Northwestern University Prosthetic-Orthotic Center and the Rehabilitation Institute of Chicago (RIC) when she visited Chicago on November 19. Dr. Seelman was in Chicago to participate in the opening of the new Rehabilitation Engineering Research Center directed by the Physicians Against Land Mines (PALM) and located at the Lakeside Division of the Department of Veterans Affairs Chicago Health Care System. More about the new RERC and its interaction with the VA and NUPRL & RERP is discussed in the article beginning on page 9 of this issue of *Capabilities*.

## **Cultural Anthropologist, Steven Kurzman, Moves On**

After more than a year, Steven Kurzman, a Switzer Fellow, who conducted a portion of his research for his doctoral program at NUPRL&RERP, is returning to the University of California at Santa Cruz. Following a brief stay,

he will continue his research in India and Cambodia. Kurzman chose an area of study for his work in cultural anthropology that might not occur to other anthropology students. Kurzman, who uses a below knee prosthesis following an amputation, noticed people regarded him as his "disability" related to the local culture. When he was in Southeast Asia, he learned that the fact he could not squat and had to sit with his leg sticking out in front of him caused him to breach standards of polite behaviour in that society. People in that culture also were concerned that Kurzman had little future as a productive member of society since he would have difficulty as a rice farmer.

Returning to the U.S. Kurzman chose to study prosthetics and orthotics in the United States. His adventures in other countries, his goals for his research and his observations about the aspects of P & O he is studying were published in the October 1997 issue of *Capabilities*. Kurzman's cross-cultural studies of attitudes toward prosthetics and persons with amputations will be used in the increasingly important field of provision of prostheses for people in third world nations.

While at Northwestern, Kurzman explored many aspects of how prostheses are developed, fitted to a person, fabricated and delivered. He worked with the research programs at the Prosthetics Research Laboratory and Rehabilitation Engineering Research Program. He worked as a prosthesis demonstrator at NUPOC and spent time with practitioners, health care personnel and amputee support groups.

## **Dr. Seichert Presents Results of Work**

Dr. Nikola Seichert, Director of Research and Development at the SUVA Rehabilitation Center in Bellikon, Switzerland shared his work with NUPRL&RERP staff during his visit on October 21, 22 and 23. He presented a report of his study, "Propulsive and inhibitory muscular activities in human walking as determined from analysis of mechanical energy and power obtained (computationally) from force plate instrumentation".

## **Professional Presentations by Staff**

NUPRL&RERP Staff members continue to share the findings of their research. Steven A. Gard lectured to the Marquette University (Milwaukee, WI) Biomedical Engineering Department Graduate Student Seminar, Dec. 11th. Gard's presentation was titled "Investigation of the Biome-

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## **Margaret Pfrommer -- a new world**

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egation to the National White House Conference on Handicapped Individuals. She served as President of Illinois COPH (the Coalition of the Physically Handicapped) and, with Tom Shworles and others, formed COPH II, which became the Committee on Personal Computers and the Handicapped. Subsequently, she and Shworles formed TAAD (Technical Aids and Assistance for the Disabled), a state-funded organization that had a profound effect on people in Chicago.

Margaret also gained national attention. She received a Certificate of Recognition for Dedicated Service to Bring Independence, Dignity and Full Participation to the Disabled Citizens of this Nation from President Jimmy Carter, a fellowship in the Canadian Medical and Biological Engineering Society and the Everest and Jennings Lectureship Award from the Rehabilitation Engineering Society of North America.

### **Margaret met many influential people**

The Rehabilitation Institute of Chicago attracts visitors from around the world. Margaret's good friend, Henry Betts, MD, CEO and Medical Director of RIC always made sure that the visitors met Margaret and heard her views on independence. As she wrote to Mrs. Anwar Sadat, the wife of the prime minister of Egypt, following Mrs. Sadat's visit, "...you and I share a common bond of interest in improving the quality of life for the disabled....I wish to reaffirm my eagerness to participate in a program of mutual benefit to our countries."

## ***One of Margaret's major goals —and achievements — was to bring awareness of the potential benefits of technology to people with disabilities***

She also was to bring awareness of the potential benefits of technology to people with significant disabilities. An article by Margaret in the November-December 1997 issue of *Paraplegia Life*, titled "Happiness May Only be a Head Switch Away", brought requests for information about how to obtain the powered recline feature Margaret used

on her wheelchair. A doctor in Boston was so impressed after visiting RIC and being introduced to Margaret by Dr. Betts that he returned to his hospital and ordered six wheelchairs equipped with the system Margaret used. The wheelchairs were issued to people who had quadriplegic paralysis following spinal cord injury to demonstrate to them as quickly as possible after their injury that they could take control over their environment.

### **Not everyone admired assistive technology**

Not all of Margaret's public appearances went quite so well. In his letter of December 1, 1981, Dr. Betts wrote, "*You were a great star on the Phil Donahue Show in spite of the obvious, hysterical types there. I think the overall effort was very good.*" Betts was referring to the fact that some people on the Donahue show expressed feelings that technology such as Margaret used was wrong in that it allowed a person to live a productive life despite a disability, rather than forcing that person to spend their life trying to learn to walk or accomplish other commonly accepted symbols of overcoming a disability. But, as Betts continued, "*It makes the handicapped appear at least as 'real contenders' which is what people need to see in this country. A whole hour devoted to the handicapped has done more for the cause than practically any of us. They were lucky to get you.*"

### **So many challenges -- so little time**

While Margaret was frequently an inspiration to those who met her and, certainly, a charming woman as a friend and colleague, she was never afraid to "tell it like it is". She was not shy about expressing her concern when various circumstances seemed to indicate that the Northwestern University Rehabilitation Engineering Program would apparently focus more on service delivery than research. She sent a memo to Dr. Childress which argued, "For the NU Rehabilitation Engineering Program to remain primarily a research and development program, it cannot become overly involved in providing services, particularly of the hands-on type modifications...." Perhaps her influence was partly responsible for the fact that the service delivery program became a service of the RIC rather than a part of the NU research program.

Perhaps it was poetic justice that Margaret, once confined to a nursing home, became the first Public Member of the Professional and Technical Advisory Committee for the Joint Commission on Accreditation. This organization develops standards for health care facilities including nursing homes.

In delivering the Everest & Jennings Distinguished Lectureship before the Fourth Annual Conference on Rehabilitation Engineering in 1981<sup>1</sup>, she pointed out areas that needed to be addressed. It was a long list. It is worth

reviewing because many of the needs continue nearly two decades later.

- **A central source of information about technical aids, including evaluations by users who had disabilities, was needed.**
- **Those who would use technical devices should be involved in their development.**
- **The media should carry more presentations about technical devices for people with disabilities.**
- **More people should be trained in design and application of technology to the needs of those with disabilities.**
- **Funding must be made available so that those who need these devices might obtain them.**

Margaret saw the fruit of her efforts as many more people with significant disabilities acquired technology which made them able to be active participants in their world. She once noted to Dr. Childress that having a wheelchair she could totally control was wonderful, but she got dizzy going around and around the block because curbs prevented her from crossing the street. She never stopped crusading for total access to public and private buildings for people with disabilities. Margaret lived to see the enforcement of accessibility standards in most communities.

### **Shrinking violet was not a role adopted by Margaret**

After testifying before the House Ways and Means Committee on Social Security reform, Margaret finally had the opportunity to take advantage of the work incentive program within the Social Security system, which resulted from the legislation following the hearings. In September of 1997, she was able to accept a salary as Project Co-Director for the Independent Choices Project of the Progress Center for Independent Living. The work incentive program allowed her to earn a small income without losing her supplemental support and health care funding. Although full employment at a significant level of income still isn't possible without threatening the loss of health care insurance, efforts are still being made to eliminate this barrier to employment of the disabled.

For her friends and colleagues, it is hard to accept life without Margaret in it. For many, many people with disabilities, it would be much harder to live life had Margaret not given her gifts of courage, knowledge and perseverance. ❖

**1. The complete text of Margaret Pfrommer's Everest & Jennings Distinguished Lecture, delivered before the Fourth Annual Conference on Rehabilitation Engineering in 1981, is available upon request. Please contact Capabilities.**

## **NUPRL&RERP Staff News**

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chanics of Normal Human Walking, With Implications for the Design of Lower-Limb Prostheses”.

Another review of research into ambulation was given by Andrew H. Hansen as an invited Speaker at the Seventh Annual Visiting Professor Program honoring Dr. H. Kerr Graham at Children's Memorial Hospital, Bigler Auditorium, Chicago, Illinois, September 14th 1998.

The presentation, based on a paper by Hansen, A. H., Childress, D. S, Knox, E. H., (1998), titled, “Foot Shape and Rehabilitation”, basically showed two methods the NUPRL&RERP laboratory uses to measure the roll-over shapes of prosthetic and biological feet during walking. ❖

## **Professional Patient Method of Instruction**

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less likely to rationalize the patient problems, as they know it is a manufactured ailment.

Although there are many differences to both methods, each has its educational and clinical advantages. The student must take many steps before they are ready to treat a patient. The student must be able to address the concerns and problems presented by the whole patient.

Northwestern University tries to address the needs of our students by using both methods of patient treatment. Prior to practicing in the field of Prosthetics or Orthotics it is my personal belief that all students should experience clinical assessment and treatment of a real or “professional patient model”. ❖

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# The VA Presents

News from the  
Department of Veterans Affairs

By: Robert M. Baum, Chief, PTC, VA Chicago Health Care System

## PALM -- Leading the Fight Against Land Mines

By Erin M. Kuhn, Communications Manager, PALM

*The New NIDRR RERC will focus on providing technology to  
persons injured by landmines in many countries*

Physicians Against Land Mines (PALM) received a grant to establish a Rehabilitation Engineering Research Center (RERC) from the Department of Education's National Institute on Disability and Rehabilitation Research (NIDRR). The \$4.25 million, five-year grant calls for a RERC that will develop artificial limbs and rehabilitation programs for land mine survivors and people with disabilities in some of the world's poorest countries. The RERC, named the Center for International Rehabilitation (CIR), will be housed at the Department of Veteran Affairs's Chicago Health Care System - Lakeside Division.

### **CIR will develop wheelchairs and prostheses**

The CIR will research and develop artificial limbs and wheelchairs that can be affordably-manufactured, delivered and serviced in countries plagued by antipersonnel land mines. It will also develop programs in education and training of local rehabilitation workers; publish an international newsletter; and use telecommunication technologies to convey important findings to rehabilitation professionals and people with disabilities around the world.

"NIDRR is pleased to extend its tradition in rehabilitation engineering to solutions to this critical global issue. We believe that this collaboration between PALM — a committed and innovative organization of professional working internationally — and one of NIDRR's most distin-

guished rehabilitation engineering centers at Northwestern University has exciting potential to address problems of children and adults who have lost limbs due to land mines," said NIDRR director, Dr. Katherine Seelman.

### **Center will act as a clearinghouse**

The overall goal of the Center is to become a world-class resource for those engaged in the delivery of rehabilitation services to land mine survivors and other amputees. The RERC will act as a clearinghouse, offering researchers, educators, health care professionals, consumers, service providers, administrators and funders access to information and technical resources that have been developed to enhance the quality of life of people with disabilities.

Dr. William K. Smith, president and founder of PALM said, "This international Center has the real potential to make a difference in the lives of land mine survivors and people with disabilities in the countries that have experienced the most devastating effects of conflict. PALM looks forward to making this Center one more place where Chicago can share the best of itself with the world."

The work of the RERC will be conducted by PALM, in cooperation with a number of partners, including the Department of Veterans Affairs Chicago Health Care System, Landmine Survivors Network/Washington, D.C., North-

western University Prosthetic Orthotic Center, Prosthetics Research Study/Seattle, Rehabilitation Institute of Chicago and Whirlwind Wheelchair International. The Center will also collaborate with many other national and international agencies.

The Center for International Rehabilitation will enable PALM to take its mission to end the death, dismemberment and disability caused by land mines a step further. Established in 1996, PALM strives to achieve its mission through direct programming and public education.

### **A project of Britain's Princess Diana**

Antipersonnel land mines were brought to the public's attention through the work of the late Princess Diana and the awarding of the Nobel Peace Prize to the International Campaign to Ban Landmines (ICBL) and its coordinator, Jody Williams. They strike indiscriminately, killing or maiming someone every 22 minutes. The average victim is not a soldier, but a farmer plowing a field, a mother foraging for fresh water, or a child playing outside. "(Can you) imagine waking up every morning along the edges of a mine field — a death zone, whose hidden hair-trigger sentries never sleep or grow hungry," asks Dr. Smith.

Mines are scattered in some of the poorest countries on earth, making it difficult for most survivors to pay for rehabilitation. Artificial limbs are expensive and must be replaced every three to five years for adults — every six to 12 months for a growing child. Without them, many amputees find it difficult to work, and in many of these countries, work means survival.

Among PALM's programs is the Leadership Award in International Rehabilitation. The Award honors those who have worked internationally to advance the field of rehabilitation, and is presented to organizations or individuals who have shown, through their work and example, that the potential of the individual is limitless and the capacity of the human spirit for renewal is boundless.

This past April, PALM held a dinner awarding land mine survivor, Chris Moon with its first Leadership Award. Moon lost his right arm and leg in 1995 while demining in Mozambique. Less than a year after leaving the hospital, he completed the London Marathon, raising awareness of the land mine issue and money for programs that deliver artificial limbs. Since then, he has become an outspoken advocate for a ban on land mines, and has run 12 marathons, including the world's toughest race, the Sahara marathon. This past February, he ran the Olympic torch into the stadium during the opening ceremonies of the 1998 Winter Olympic Games in Nagano, Japan. Chris Moon is



*Attending the Dedication of the Center are (left to right) Dudley Childress\*, PhD, Director NUPRL&RERP; Raymond Zeiss, MD, Medical Director, VA-Lakeside; Wayne Lerner, DPH, President/CEO, RIC; Henry Betts\*, MD, Past President, RIC; William K. Smith, MD, President, PALM; Ken Rutherford\*, land mine survivor, and Katherine Seelman, PhD, Director of NIDRR. \*Members of PALM Board of Directors.*

an outstanding example of the commitment, dedication and courage which the Award was developed to honor. Mayor and Mrs. Richard M. Daley, Governor and Mrs. Jim Edgar, Francis Cardinal George and Ambassador Jean Kennedy Smith were the honorary chairs for the dinner. John F. Kennedy, Jr. made remarks during a memorable program.

### **More Public Service Announcements planned**

In addition to its leadership award, PALM has launched a Public Service Announcement (PSA) campaign. The first PSA, which features, Former U.S. Surgeon General, Dr. C. Everett Koop, is currently running in select markets. Several more are planned to showcase the issues of importance to people with disabilities internationally.

As part of its work, PALM has engaged, and will continue to engage in consultations with a wide variety of organizations. PALM personnel have conducted needs assessment trips abroad and participated in a number of conferences and seminars. Since its inception, PALM has worked to promote a spirit of cooperation and collaboration among national and international groups engaged in the delivery of rehabilitation technologies and services to people with disabilities. PALM will continue to utilize its resources and challenge rehabilitation specialists in the United States to respond to the needs of people with disabilities — wherever they live. ❖

**Capabilities**

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- ADA List of Publications
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- Association. of Children's Prosthetic-Orthotic Clinics List
- Video List

Bibliographies of NUPRL&RERP Publications Available on the Following Topics:

- Above Knee Prosthetics
- Ambulation, Gait & Posture
- Biomaterials
- Below Knee Prosthetics
- Computer Aided Engineering/Design/Manufacturing
- Pediatric Prosthetics

- Prosthetic Feet
- Prosthetics & Orthotics: General
- Upper Limb Prosthetics & Orthotics

Other Sources for Prosthetic & Orthotic Information:

**Consumer Information:**

National Limb Loss Information Center  
900 East Hill Avenue - Suite 285  
Knoxville, TN 37915  
Toll Free: (888)AMP-KNOW

**Prosthetic-Orthotic Education:**

National Association of Prosthetic & Orthotic Education  
1650 King Street - Suite 500  
Alexandria, VA 22314  
e-mail: opncope@aol.com

**General Information about Prosthetics & Orthotics:**

American Orthotic & Prosthetic Association  
1650 King Street - Suite 500  
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