

# Ohio Polio Network Newsletter

Summer 2009 Issue

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### OPN and the Akron Post Polio Support Group have cherished memories of Fran Willemsen

Fran Willemsen will be remembered as a wonderful friend and very hard worker to many, many people. You did not have to think about becoming her friend. Fran was the type of person who made you feel very comfortable, like you had been friends for a long time. This photo is taken from a trip that Fran made to Alaska. Fran was always on the go. She was very proud that into



her later years that she was still cutting the grass. Fran will also be remembered for her service to the community. For many years Fran served as Treasurer of both OPN and the Akron Post Polio Support Group. Fran brought many new members into both groups. We, the members of OPN, extend our sincerest and deepest sympathy to Sandie and the entire family.

# In Memory of our Dearest and Most Treasured Friend... Fran Willemsen by Fran's Friends from the Akron Post-Polio Support Group

It's so hard for us as a group (the Akron Post-Polio Support Group) to convey what a wonderful friend we had in our precious fellow post-polio member, Fran Willemsen, or to even express how she touched our lives and, most of all, what a special place in our hearts she will have forever.

Having been friends with her since our group began in 1995, everyone will tell you that she was the "light" of our group...our matriarch...always pushing and prodding for the success of our organization, willing to help wherever needed...be it, gathering door prizes for a picnic or Christmas party, constantly dredging up new polio survivors to join our support group...and, the list goes on and on. She was our Treasurer for so many years, we lost count...and she knew where every penny was and how it was spent. She always volunteered to help wherever help was needed, and always worked really hard at keeping in touch with the members. If you missed a meeting, you could count a a call from Fran to check up on

### In Memory of our Dearest and Most Treasured Friend... Fran Willemsen by Fran's Friends from the Akron Post-Polio Support Group

you to see how you were doing and to make sure you were o.k. She had an ever friendly smile for everyone and truly cared about each and every member and their well being.

Fran was also a very vital part of the Ohio Polio Network (OPN) and we're sure the void for them is equally as great. She received a very prestigious award from OPN in 2003 and we were all so, so proud of her, as her hard work was recognized and rewarded!!

Family was ever so important to Fran...then there was her involvement with her church and many commu-

nity activities. She was unstoplived life to the fullest, never alshadow the joys, in particular, young. You'd never know she January of this year...what a

If you had the privilege to know easily how very special she was can only begin to describe the Fran was
unstoppable
....especially in
spirit!!

pable...especially in spirit!! She always lowing any disappointments to overher bout with polio when she was had just celebrated her 90th birthday in lady!!

Fran, you realize it can't be put into words to us and how greatly she is missed. This difference she made in our lives...as indi-

viduals and as a group. A role model for us all...let us always remember Fran with a smile -- she wouldn't want it any other way.

#### OPN Board Meeting Saturday, August 15, 2009 Westerville, OH Library Noon - 3 PM

OPN members are welcome to attend. OPN is always looking for members interested in becoming Board Members. If you are interested or have agenda items for the Board Meeting, please contact Patrick Kelly, pkelly03@sprynet.com

## Ohio Polio Network is on the Web www.ohiopolionetwork.org

Note: OPN is looking for photos and information from past Conferences and Awards pictures. We would like to have photos of the recipients of the People First and Bernice Krumhansl Awards. Please contact Pat Kelly if you have anything to help preserve our past. Also any new ideas for the website are welcome.



2001 Fran taking her Great Grandsons and Nephew for a ride. Fran loved driving her mower.

#### Once Upon A Time by Winnie Walker

It all began one morning when I tried to get out of bed. I had been sick with a fever for a few days. That morning I couldn't stand up to walk. The doctor came to the house and told Daddy to take me to the hospital in Savannah. The doctors there told him I had polio and kept me there for several weeks. First they put me in an iron lung to see if my polio was in my upper or lower body. I was 3 ½ years old and those hot blankets were not my favorite things. Also seeing my mom and dad with masks on their faces was a little scary. I was glad to see them anyway.

From there I came to Warm Springs. I thought it was such a big place with so many kids and all sick like me. I remember crying and begging Daddy not to leave me. He would tell me that if I wanted to get better and walk again, I had to be here, and that he would be back, and to be a good girl. We were in a ward

"President Roosevelt gave us juicy fruit gum"

with 10 beds. The nurses would check our temps and check us all over every day. Then the doctors would do the same. Stretching your legs, arms, and back was a daily thing. Oh yeah, don't forget the hot blankets.

I remember a little boy named Billy. He had polio in his arms and back. Sometimes the nurses would put us in the same cribs together so we could share the toys. I would help Billy, pick up the toys and show them to him. One day I remember this real nice man, like a grandpa, came to see us. He was in a wheelchair just like some of us. There were some people with him. He would talk to us and make us laugh. He would laugh too. Then he would give us juicy fruit gum. We did not know that he was the president.

President Roosevelt died in the "Little White House". The day they brought President Roosevelt by Georgia Hall, the kids, who were able, were taken outside to

#### Once Upon A Time by Winnie Walker

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see him go by

Fast forward to 1950 Back to Warm Springs. Time for surgery. It took the doctors and several trips to get Daddy to agree that I should have surgery. He didn't like the idea of leaving me again or seeing me cry so much. At age nine, I sure didn't like the idea at all. Going into the fourth grade and having surgery didn't mean I was getting out of school, not at Warm Springs!!! Hey, they had that all figured out with a teacher standing by. Her name was Ms Carroll. She was real nice. We really did study and had homework to do. Note: I gave my report card to when I was there for the International Conference in April 2009. Mike was happy to get it.

Warm Springs became my home away from home. The staff of nurses, doctors, push boys, and cleaning help became our family. What a surprise waking up fro surgery in a full body cast. NOW....that put a snag in my plans. GEE! I wanted to be in a wheelchair and ride around and visit all the kids. I wanted to check up on them and try and make them laugh and just visit. I got to go places alright, THE cast room, the movies, school and did I mention....the cast room....oh boy, not my favorite

We had 8 beds in our room, all girls. One day during lunch, a couple of little girls were crying,

younger than me. I thought, hey, no more crying. We had jello for lunch, a straw in our water, that's all I needed to get into trouble. So I took that straw, stuck it into the jello, sucked it up and blew it as far as I could. The little ones did stop crying and ate their lunch. The floor was a mess and I had gotten myself into a mess. It all got cleaned up and I promised to not do that again. I remember one of the girls in the ward had a baby doll, a big baby doll and it could walk all by herself. It was so pretty. We all wanted to walk like that doll and look like her too. It was just another day at Warm Springs, along with going to the cast room and other things.

My best fried Joyce who was a couple of years older than me had polio in her arms and most of her body. So when I got out of the body cast and into a wheelchair I could go over to her bed. I would hold up her books and she would read them to me. She was my family too. One day I told her I was going out into the hall to see where the boys were. I didn't have to go to far, I could hear them cutting up or just having fun, I'd say. Too soon the nurse saw me and just wheeled me right back to my room. No problem. The nurses were so nice and they understood we didn't have our family to be with. They did what they could to fill in.

Learning to walk all over again. By now I had been up and down those steps, there were four sides to the way they were built, go up one side, go down the other, so many times I didn't ever want to see them again. Well I probably wore out a pair of shoes, sure didn't wear out them steps though. The time had passed that I no longer had to have my legs put into warm wax. That wasn't too bad, just different. I was getting stronger, so I could race other patients who were in a wheelchair any chance we got. It seems like I never won. But do you know, the ones who did win, it made them happy and we all had a good laugh. Tomorrow would be another day at Warm Springs, GA.

We were going to have a Halloween party and we were all excited about dressing up so no one would know who we were. The nurse asked me if I would wear the clown outfit, I should have known that.. Going around, trying to get the kids to laugh. That's ok, I felt right at home in that clown suit. It looked pretty good. We had lots of kids in so many different outfits. The nurses did a great job. And to top it all off, I got a new baby brother. Daddy said he had red hair. That made five of us now. I could hardly wait to go home so I could hold him.

Getting ready to go home It was sad to say goodbye to my best friend Joyce. Her mother

#### Once Upon A Time by Winnie Walker

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was good to me and she knew my mom and dad couldn't come see me as often as they wanted to. Daddy would drive many hours to see me for a few hours and then turn around and drive all those hours back to Glennville, GA. Joyce and I promised to stay in touch by letters. Daddy came and stayed for a few days so he could

learn my therapy. He would show Mama what to do because he had to take care of the farm. The nurses gave me a great sendoff. I went to Georgia Hall to get me some silly putty before I left. I had spent a lot of time here visiting with the other kids and their family. Just having fun looking around, no money. I sure will

miss the people in the brace shop. They were so nice and always put your name on the crutches you wore. I am still using the crutches they made with my name on them. They are now 55 years old and good for another 50. After giving lots of hugs and shedding tears, I was on my way

#### Post-Polio Health 10th International Conference Living with Polio in the 21st Century, Warm Springs, GA April 2009 The Wellness Retreat by Warren and Judith Peascoe

Our retreat started with confusion. Our instructions told us to go to Georgia Hall to register. So we got out and looked for the registration desk only to be told that the registration was at Camp Dream about 3/4 of a mile away. As we came out we found we were not crazy as other people were climbing out of vehicles and entering Georgia Hall. As I had been riding for a long time, I decided to walk to Camp Dream while Warren drove.

Camp Dream is separated from the rest of the Warm Springs Institute by a small lake that has a causeway with fishing stands crossing it near one end. The camp has a dining hall, a pavilion, a small boathouse, a small swimming pool, a bathhouse and two cabins, Lanier and Callaway. Each cabin had a large common room, a small kitchenette, and 10 sleeping rooms with 4 beds and a bathroom. Warren reached a check point and received directions but apparently they were incomplete so I caught up with him as he approached the check point for the second time.

Most of the time the retreat staff of 8 had little support from the Warm Springs Staff. The retreat staff had to do the room assignments, check us in, help us unload etc. So Dr. Fred Maynard gave us our room assignments and parking places--for us a room in Lanier. and Dr. Bill DeMayo helped unload cars. He helped me with our huge camp cooler.

In practice only 2 or 3 people could be assigned to each room. For instance each married couple who wanted to room together had one private room. Our room only had two electric outlets. Many of the survivors

used power chairs that needed recharging and some used ventilators. These were assigned two to a room also. So about 25 attendees were in each building. In addition about 15 people found off-campus housing. Unfortunately this meant that we tended to know the people in our cabin and often didn't meet the others. The retreat staff lived in a cottage on the far side of Lake Dream.

We had about 45 polio survivors and 15 care givers. Several of the attendees had contracted polio in the period between the time the Salk vaccine was licensed and the time when it was administered in their community. I think all the survivors were in their mid-fifties or older. I don't think we had any polio victims from the years after vaccination was common.

#### The Wellness Retreat by Warren and Judith Peascoe

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Registration followed check in. We answered a few questions and were presented with a program outline and a complete set of menus. I noticed a service dog who was introducing herself to everyone and got permission to pat her. She immediately befriended all the retreat's participants. Her owner was afraid that one of us would take her home. But when the dog had a door close between her and her owner was she became very anxious.

The Sunday program was dinner, welcome, keynote address and introductions. We also had to sign a release so that the retreat could be videotaped. So there will be a video of the retreat sometime this fall.

We then met the person most responsible and one of the hardest working people in the retreat, Christy. She was the one that made sure that the activities went as scheduled or that people were moved to other events. She kept a big grin on her face even when things were crumbling. Fred Maynard gave the opening address, everyone introduced themselves and we got the first taste that some events were going to take longer than scheduled. During the introductions, a very little lady announced in a very pleasant, well-modulated voice that she was unused to talking to such small groups. This was Wendy, the actor--not actress. Except for me, all the caregivers said they were there exclusively to help their spouse. (I was there to get Warren back in the kayak among other things.)

Christy got to work and had us sign up for the programs we wanted for the next day as some had limited space. This sign-up was repeated each day. She also had people sign up for free manicures, facials and hair cuts. The waterfront was not going to be open on Monday. (Tuesday, free massages were to be available--there was a snafu and Warren missed his massage.)

About 9:30 we all retreated to our rooms and collapsed.

The other three days were:

#### Time Activity

7:00 AM early tea and coffee

8:00 AM breakfast

9:00 AM talk

10:30 AM exercise

12:00 noon lunch

1:00 PM rest--this merged with lunch and activity

2:00 AM recreation

4:00-6:00 PM breakout sessions--talks by various people

6:00 PM Dinner

7:30 PM Program

Our alarm sounded off at 6:30 the next morning. We rushed around and got ready for breakfast. Christy had the unpleasant job of announcing that the pool was too cold for aquatics--although it would be open for swimming in the afternoon. Since this was my first preference, I asked around and found out that the Yoga would be seated and decided not to go there. This was being run by Barbara Duryea. I was so turned off that she was not accommodating normal people that I avoided all her other programs. Warren and I both went to the adapted cardiovascular conditioning.

This was the first of our many trips across the lake to the Center for Therapeutic Recreation (CTR). There was a wooden causeway across the lake from which there was a chance of seeing turtles sunning themselves and at the right time of day a rainbow in the fountain. The first morning there must have been thirty scooters and wheelchairs being led across the causeway. I hoped to get a picture of the parade but there never was another group trip across. The trip to CTR took about 10 minutes. Fortunately the weather was great during the week we spent at the Institute.

On the way across I noticed one of the women had a power

#### The Wellness Retreat by Warren and Judith Peascoe

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chair with the power tilt options Warren wanted but for which he had been turned down. That is how I met Merry, who regaled me with the problems she had had to get the chair she wanted. I introduced them that night at dinner. For the rest of the retreat they huddled together like two conspirators. I hope the huddles will eventually help Warren get the chair he wants.

At CTR, I was turned loose on the exercise machines while Warren and the other patients were given a lecture. Actually I sat in on the lecture for a while and took a couple of pictures.

Then back across the causeway for lunch. And I saw a turtle sunning itself on a stick in the water. Many people made this round trip twice a day. People like me made the trip alright as did people with scooters and power wheelchairs. But the rest had to be ferried. The retreat staff had several golf carts that could carry between one and three passengers. During the retreat the carts made many trips to get everyone where they should be. We noticed a man pushing a wheel chair. One of the survivors commented that she and her husband had attended an Elder Hostel at which there was a man who pushed his wife everywhere. She added that the wife was quite happy with that

but she wasn't at all sure the man was.

Several people pointed out that some man had shown them a rainbow in the fountain. I knew that was Warren. After that people watched for it as they crossed the causeway.

After lunch there was rest and recreation. The rest period merged with lunch and preparation for recreation. Many went to the Little White House but I wanted to go swimming. There was no life guard at the pool and Warren was going to crafts. So I had to find a buddy. I got one but I don't think it was the one I originally started with. The pool was huge (50 meters long and about 8 lap lanes wide.) It was built so that there was a wide rim about two feet high so that a person could slide from a wheel chair on the deck into the pool. The water came almost to the top of the rim. There were also a wide set of steps (approximately 10 ft. long) in the side of the pool with good hand rails and also a lift. At 82 deg. F the temperature was perfect for lap swimming but I don't know how people who were less active survived. The buddy system was handled in subsequent sessions by having one of the staff stay in the pool for the entire pool session.

The schedule dictated breakout sessions. Warren and I agreed that I should go to the session on medical records not the caregiver session. I also attended a session on traveling led by Susan Jones from the March of Dimes in Canada. She organizes group trips and group cruises for post polio people and families. This was followed by a cookout where I introduced Warren to Merry. During the sing-a-long we were all introduced to the Australian contingent led by Mary-ann. She taught us the song *Belle Mamma* which refers to the beautiful earth. (For an Australian point of view see her blog at

www.polionetworkvic.asn.au)

Belle Mamma, Belle Mamma, Yeah

Belle Mamma, Belle Mamma, Yeah

Belle Mamma, Belle Mamma, Belle Mamma, Belle Mamma

Belle Mamma, Belle Mamma, Yeah

This became the theme song for the retreat. We also made So-Mores. Again the program lasted longer than intended.

(Warren and Judith Peascoe's report on the Wellness Retreat will be continued in our next newsletter.

#### Pat Kelly's Message

In this issue, we honor Fran Willemsen, who meant so much to all of us. There is a special article from the Akron Post Polio Support Group. Fran passed away during the Warm Springs Conference. Unfortunately, I did not get back in time to be at the funeral service. Fran's daughter Sandie sent me a number of pictures. They will be added to the OPN Website. We have included Fran's trip to Alaska and Fran on her riding mower in this issue. Fran was always on the move. Fran was devoted to the Akron Post Polio Support Group, OPN, and, of course very devoted to her family.

We have articles from members who went to Post Polio Health's 10th International Conference held at Warm Springs, GA.

Warren and Judith Peascoe of the Mid-Ohio Valley Post Polio Support Group, not only attended the Conference, but also attended the Wellness Retreat, which was held the week before the Conference. Warren and Judith kept very detailed notes and will be sharing them with us through their articles. We are very fortunate to be able to provide this to you and appreciate their hard work. In this issue, we have provided the first part of an article on the Retreat. The second part will be provided in the next issue.

Winnie Walker, of the HELPS Post Polio Support Group, is in a unique position. Winnie at-

tended the Conference and is also an alumna of Warm Springs. Winnie donated her crutches to the Polio exhibit of the Smithsonian Institution, which was temporarily moved to Warm Springs for the Conference. Those attending the conference were able to go through the exhibit and see Winnie's photo when she was a child and her crutches on display. Winnie wrote an article for this issue of the newsletter sharing some of her experiences through her memories of polio at Warm Springs as a child.

Warren and Judith Peascoe provided the Mid-Ohio Valley Post-Polio Support Group with a wonderful organized photo presentation and discussion of the Wellness Retreat and the Conference. They plan to share more about the Conference in future meetings.

In addition to a presentation to the HELPS group, Winnie made presentations to the Akron and Canton Post-Polio Support Groups.

We thank Warren, Judith, and Winnie for bringing back their experiences and relaying what they have learned.

The OPN website is coming along. We keep adding to the links page to provide a central place for resources associated with post-polio. Take some time to explore the website. Ideas for the website are always wel-

come. Our goal is to provide frequent updates as information is available and to keep you up to date as possible. Each support group has a page devoted to their activities. Please consider the information that you would like to see on your group's website page and e-mail it to me.

The website has resulted in several phone calls and e-mails through the Contact Page from people looking for information and "Post Polio Doctors". In response to these inquiries, they are directed to the 2009 Post Polio Directory (links page) and to the contact at the closest Post Polio Support Group to their home address.

The next OPN Meeting will be held on August 15th.

We want to thank all of our members who subscribe to the OPN Newsletter and those who have made donations. These funds allow us to produce the Newsletter and to maintain the Website.

In 2010, we are looking toward bring back the awarding of the Bernice Krumhansl Award. Check the website for more information on the award. Each Support Group should be hinking of nominations for this very special award. In conjunction with this, we are looking toward the possibility of an OPN event next year, probably October. More to come.......

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Please forward letters and articles to the return address on the newsletter or e-mail to pkelly03@sprynet.com

Disclaimer Notice: The thoughts, ideas, and suggestions contained in this publication are those of the writers and do not necessarily constitute an endorsement or approval of OPN. The articles are for information only. Consult your health care provider before beginning any new medications, nutritional plans or any other health related programs.

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