

# PPASS Times

Newsletter of Post Polio Awareness & Support Society of MN

Jan - Feb 2003

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## PPASS MN Granted Tax Exempt Status by IRS

By Larry Kohout

The newly constituted Board of Directors of PPASS MN got together for their first official meeting on Friday January 10<sup>th</sup>. On that day they signed the By Laws of the organization and brought PPASS MN officially into being as a state wide organization. With that complete, we made a copy of the final draft and sent it off to the IRS.

One week later, on Friday January 17<sup>th</sup>, the IRS officially notified us that they had granted our request and given PPASS MN an advanced ruling stating that for the next four years it will treat PPASS MN as a publicly supported organization. We expected this probationary status given that PPASS MN is such a new entity, with no history as a publicly supported organization. We will have to refile our papers after December 31<sup>st</sup> 2006 and, assuming that everything is as we have stated it to be, the IRS will grant us permanent tax-exempt status at that time.

In our dealings with the attorney at MAP (Management Assistance Program for non profits), we had been told that this was the way the

process would work. So we are now on our way. We in the Twin Cities are no longer PPASS MN but a chapter of PPASS MN. Like any other groups that join our organization or are formed under our organization, our chapter is going to have to decide how do we want to be organized, what do we want to be called, and who will be our representative to the state council that will guide the direction of PPASS MN for the next few years.

Up until now we have had a more



formal structure. Initially a three person executive team, this summer the team was increased to four by splitting the office of secretary/treasure into two positions. This was due to the work load that has come with the growth of the group and the efforts to become a state wide organization. It is this four person team that is now leading the corporation and is your elected representation on the Board of Direc-

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## From Where I Sit

By Jane St. Onge, Chair

A few years ago when PPASS MN was just getting organized, the members agreed our mission was to support each other and to educate ourselves, the medical community and the public about Post Polio Syndrome. Last year we decided to broaden our mission to reach out to other polio survivors around the state, help them establish support groups, and create a greater awareness and understanding of PPS. To achieve this we needed to be able to raise funds as a non-profit corporation. Our membership contributed money to get the ball rolling. On July 29<sup>th</sup>, 2002, PPASS MN received its certificate of incorporation. On January 17, 2003, PPASS MN became an official tax-exempt organization. Excellent!

And more good news, Dr. Anne Brutlag, Harold Durrett and Barbara Majerus have volunteered to be on the PPASS MN Board of Directors, committing their time and talents to our organization because they support our goals. They do not have Post Polio Syndrome, but they recognize the need to help people who do by

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## PPASS MN Granted Tax Exempt Status by IRS

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tors.

In the process of crafting the Corporate By Laws, the executive team decided to have Directors on the Board from outside the narrow confines of the group. We have sought diversity in experience, age, and gender. Alphabetically, the first of the three outside members on our Board is Dr. Anne Brutlag who brings with her a wealth of experience in the medical community with specific experience treating those with PPS. Second is Mr. Harold Durrett, a retired Vice President of Network Systems Corporation, who has had a long career in sales in the computer industry. The third member is Ms. Barbara Majerus, Vice President Service & Market Development for ADC - Systems Integration Business Unit.

We hope to be able to profile these individuals in future editions of the newsletter. In the meantime, know that they are bringing their various skills to bear in directing the beginning of your organization. After the initial introductory meeting, the executive committee got together and laid out some plans for where we wanted the organization go in the next six to nine months. We then presented these plans to the outside directors at a meeting on February 7<sup>th</sup>. (See Where Is PPASS MN Headed?) The directors made sound suggestions and offered their assistance in reaching our goals.

## From Where I Sit

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organizing support groups throughout the state. They want to help us create understanding and awareness about PPS in the public and in the medical group of people. Outstanding!

Now what? Well, first of all, we need to celebrate our success in becoming a non-profit organization and what that means. We now have the potential to use the talents of our support group members to reach out and help many others. Our support group, now the Twin Cities Chapter of PPASS MN, will continue as it has. But being the founding group of PPASS MN will give our members many opportunities to be involved in both our local group and the statewide umbrella organization, too. Wonderful!

We all have benefited from being a part of our support group. We have shared our stories, our laughter and some tears. Now we must all share in the work that keeps our group running and also the tasks involved in launching our statewide organization. I ask that each of you consider the opportunities. What can you do? Can you help organize and run the monthly meetings? Can you help with phone calling or planning social events? Have you had experience (or know someone who has) with grant writing, or developing a web site? The possibilities are many.

Remember, we haven't made it this far by saying, "I can't" or "I'm not able to". Just look what we've started. Where we go from here depends on all of us.

## Time For Dues

By Larry Kohout

PPASS MN has always run on a calendar year with dues payable at the first of the year. It is now time for dues again. If you haven't gotten your dues in yet please make your check out to PPASS MN and mail it to our Treasure, Dick Baumer, at his home 4321 Joppa Circle, Savage, MN 55378

Please note your dues and any money you contributed to the non-profit drive are all tax deductible. Our tax exempt status dates from our date of incorporation which is July 29, 2002.

If you are not in a position to be able to afford the \$20 dues, please contact Dick and he will indicate you are paid up. We do not want anyone to miss out for lack of funds.

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# Group Happenings

By Larry Kohout

Our last two meetings have been devoted to support. The January meeting focused on *Caring For Your Care Giver* and the February meeting addressed *Pain Management*. Both meetings were well attended and quite lively.

JANUARY - We started the *Caring For Your Care Giver* meeting by defining who our care givers are. As you might expect in a group our size, the answers to this question were far reaching. A spouse or a relative was mentioned most often while others relied on a neighbor or friend. Some of our members employ professional care givers - personal care attendants (PCAs) but the most unusual care giver mentioned was – would you believe? – a pet. It seems there is an organization that will help train your pet to become a service animal.

Rob, our guide and facilitator through all these discussions, asked what it would be like to be a care giver. Again, opinions ranged over a wide spectrum. Some felt it would be great to be needed, others felt it would be horrible to be pinned down. The general consensus was that caring for someone wouldn't be too bad if the individual wasn't too demanding, and if they showed appreciation for what was done for them.

Some of the suggestions made for enhancing your relationship with your care giver were:

- Be flexible

- Do not allow aggressiveness (either direction)
- Be patient, be patient, be patient
- Have a sense of humor
- Write notes for things that must be remembered
- Remember the other's needs
- Specify a time for when something is needed as everything isn't needed now
- Be appreciative, say thank you, write thank you notes, do something nice

All of us have those that care for us even as we may be caring for others. When we were through it was clear that the session didn't just apply to those who employ PCAs but might be more applicable to the rest of us.

FEBRUARY – We didn't need to start our meeting by defining what pain is. Most of us understood pain. While several in the group do not deal with chronic pain or regular pain, we found a sizeable contingent that does deal with pain on a regular basis. How different people deal with pain was what we were after.

Pain medications of every sort were mentioned--running from a simple aspirin tablet to prescription medications of every sort. Several people mentioned not wanting to take these medications unless they were really needed. Another person took an opposing view and said he'd been told by his doctor that effective pain management required treating the pain before it

became overwhelming. Taking the medication earlier gives it a chance to work and may then eliminate the pain triggers.

However, so often pain is a result of what you did yesterday. This gave rise to the discussion on pacing of activities. Work for some period of time as may be comfortable for you and then rest for a period of time. This can be as simple as walking up a flight of stairs. Take three steps up and then stop and stand for 30 to 90 seconds before you take the next three steps. It takes you longer to get to the top of the staircase but when you do get to the top your legs aren't going to collapse under you. Likewise, you can put in 50 minutes of work on some project and then allow yourself 10 minutes of total eyes-closed rest before you go on. Any of these methods of giving yourself a chance to recover are helpful at holding off the pain.

Other avenues of pain control that have worked for some group members are acupressure and acupuncture. There are a number in the group who swear by chiropractors and have regular adjustments. Along those same lines is a practice called cranial sacral therapy, where most of the focus is on the neck and head.

Another non traditional but very effective way of dealing with pain is with humor. A sizeable number of us agreed that when all else fails you can always just laugh at it.



## Where is PPASS MN Headed?

By Larry Kohout

The Executive Committee held a planning session on Saturday February 1st and put together some directions for where we want to go in the next six to nine months and how we expect to get there. We then presented those plans to the outside directors at a Board Meeting on February 7th. The following is a summary of those plans.

**Fund Raising** – Our treasurer, Dick Baumer has agreed to guide our fund raising efforts and to recruit volunteers from our membership to assist in the various efforts. Dick plans to organize a “Think-Tank” team to brain



storm and research various funding ideas. There

are several opportunities open to us in the near term. These include the possibilities of funding through the March of Dimes, the Rotarians, and the United Way Campaign. We will need people to investigate all of these avenues and to find out what we need to do to be included in these organizations' funding plans.

**Outreach** – Our secretary, Larry Kohout, has agreed to guide our outreach program. Like Dick, Larry wants to form a committee to plan the various efforts. The way he sees things, we should employ a three-pronged approach. First, there have been existing groups in out-state Min-

nesota, and we want to make contact with any remnants of those groups in the hopes of re-energizing them. We are sending out letters to all the groups that once existed in the state to see if they might be interested in taking advantage of the PPASS MN tax exempt status. We sincerely hope that these people will join with us and share what they know about PPS and help us to reach out to the other polio survivors in our state. Second, we would like to put together a web site for all of PPASS MN. Larry has already listed us on four existing web sites dealing with PPS, and that those have brought in one to three new inquiries every month for the past two years. The majority of these people have joined the group. Third, we need to put together a program to help people who want to start up groups. We need to be able to train leaders and outline frameworks that allow these people to establish groups of their own.

Our calculations say that there are between 10,500 and 28,000 polio survivors living in Minnesota. Statistically we would expect between 40 and 60 percent of these people to be dealing with PPS at some time in their lives. We also know from personal experience that some of these people may have no idea what is happening to them because they have never heard of PPS.

It is time to volunteer gang. Choose one of the teams and get on board and help PPASS MN reach out to those who need our help.

## One Psychologist's Perspective on the Polio Experience Part 5

By Margy Hull Ph.D.

Every second of the day our brains are receiving thousands and thousands of tiny pieces of information from our five senses, as well as from receptors throughout our bodies that report on various inner states. (If you want to boggle your said brain with how tiny these pieces of information are, read a psychology text on human perception. And you thought it was just a beautiful sunset!) Each of our brains then has the task of selecting what to focus on, organizing, interpreting, and deciding how to respond to all of this "input."

To me, it is endlessly fascinating how we uniquely make these decisions as we seek to navigate through our worlds, trying to survive and thrive and propagate our species. It occurs to me that we are all Steven Spielbergs making the movies of our lives. Like him, we make many of these "decisions" without awareness in words because of our sense of what works and what makes us feel good. The book of genes and circumstances beyond our control provides much of the raw material for the basic plot for our movie; some books are a whole lot easier to work from than others. But fortunately we have a lot of creative license and directorial discretion as to how the book gets to the screen of our conscious awareness and how the

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# One Psychologist's Perspective on the Polio Experience

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movie turns out.

We want the hero (us) to win the girl, the war, the game and the day. We try our best to get the lighting, the camera angle, the lines that show our hero to best effect. Some scenes we decide not to film at all, and some end up on the cutting room floor. We too love our special effects as our credit card bills sometimes attest. We vary in how long we want a scene to last. Some of us have to get in the car chase scene, though I can do without it, thank you very much. Love scenes are a must, but again we vary in our tolerance for mushiness. One of the trickiest decisions is how scary to let our movie get before we move to another scene and lighten it up.

Discovering an enemy or two among the cast of characters increases the heroic dimension and provides someone to blame when things go wrong.

All this serves as an introduction to a new topic, the defense mechanisms or coping styles. These are processes that we all use, usually without conscious awareness, to buffer the effects of external and internal stressors, so that we do not feel as overwhelmed by anxiety and conflict and can continue to function in the way we see best. Some of them are pretty primitive and end up with the cure being worse than the disease. Others are more flexible, more effective in protecting us in more ways, and

even end up adding something worthwhile to our corner of the world.

Next month we'll start out with repression, denial, and avoidance: the See No Evil, Hear No Evil, Speak No Evil Gang. Do they ever have their place as we deal with this polio thing in its various manifestations over time? We'll look at when they're helpful and when they are not.

Margy Hull Ph.D. is a Psychologist who formerly worked in a community mental health center in Atlantic County, New Jersey.

## Polio Biology Part IV Polio And Limiting Variables

By Eddie Bollenbach M.S.

Editor's Note—This Series was originally written for and published in the Lincolnshire Post Polio Library. It is republished here by Eddie's kind permission. This is the fourth in the series.

In the natural sciences the topic of "limiting reagents" presents a challenge to undergraduate college students. A typical problem involving "limiting reagents" goes something like this: suppose you want to produce the chemical silver iodide. You make the following two elements react: silver and iodine. If you mix 1 gram of silver and 1 gram of iodine together, and they react, which one will run out first? To find this answer calculations must be made by a student with some knowledge of introductory college chemistry. One of the two ingredients will be used up. This will stop the reaction. Some excess amount of the other will remain after the reac-

tion has stopped. The reagent (silver or iodine) that is used up first limits the extent of the reaction because it is gone. Without it there can be no more silver iodide produced.

The aforementioned example can be applied to biological and medical problems too. For example, if a marathon runner runs faster than his ability to provide oxygen to the fuel within his muscles he will exhaust himself. He needs oxygen and fuel (food) but his limiting factor here is oxygen. On the other hand if he doesn't eat for a day or two before his race he may become exhausted and perform poorly not because of a limit of oxygen but because of a limit of fuel. In both cases we can understand poor performance due to the limiting effect of one essential component of muscular performance.

Polio imposes a change to an individual's limiting variables. During the fatigue, exhaustion, and pain of post-polio syndrome something has run out. Because of the damage and remodeling of our neuromuscular system's anatomy and physiology, post-polio fatigue/pain states are caused by different limiting variables than those which stopped our able bodied athlete above in his tracks. I've been thinking about this for a while, particularly when someone barks about performance enhancers like creatine, various amino acids, magnesium supplements, herbs, mestinon, and a host of other products. These could really help a lot if they were limiting factors for the polio survivor. For example, if high energy compounds were in

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## Polio Biology

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short supply inside our muscle fibers creatine could supply the missing energy and restore normal muscle kinetics. But if there are too few muscle fibers with normal energy within them creatine shouldn't help much. So, are any of these limiting? If the answer is no then what is the limiting variable in post-polio syndrome?

A hallmark of human anatomy and physiology is complexity. A good example of this is the fact that pain and fatigue can be often be relieved by small doses of antidepressants. This works for

**To treat this situation properly we must conserve the over-worked motor neurons.**

reasons completely outside of the limiting variable analysis. For example, normal muscle tension may exhaust post-polio muscles but if a drug can drop the muscle tension below that which is normal for an individual he will feel better. There are a number of other examples and some of the chemicals PPS patients use that make them feel better should be used, even though they do not represent limiting variables.

To improve endurance, strength, muscle power, and muscle recovery after exercise for those with PPS we must examine limiting variables. Every credible study done to date implicates the neuromuscular system. That is, the nerve muscle unit that results in

muscle contraction. Whether the trouble in PPS starts deep in the nerve cell bodies inside the spinal cord or at the nerve muscle junction, peripherally, the problem is still the motor nerve and its muscle. There are not enough motor units functioning normally in a person with PPS. The normal fibers are then driven over the threshold of normal function and so they act up. The "acting up" is the pain/fatigue and other symptoms associated with the disability. I believe the limiting variable in PPS is the number of normally functioning striated muscles enervated by motor nerves. To treat this situation properly we must conserve the overworked motor neurons. Then this leads to other problems because of the complexity of human anatomy and physiology I mentioned above.

Some of us feel so bad when we experience the affects of PPS that we get into bed, sit around, and rest too much. Then we don't feel better because we, paradoxically, are on a downward functional spiral. I want to write this again. I believe the limiting variable in PPS is overuse of muscles with too few skeletal fibers normally attached to motor nerves. But what about the muscles which aren't affected to the point where their limiting variable is too few fibers? By over resting them can we impose on them another limiting variable and make ourselves worse? When we rest good muscles day after day they become deconditioned. They then lose essential proteins for normal function, the ability to process oxygen and utilize energy, and even lose the ability to properly burn fuel. They all get

exhausted but not for the same reason our polio affected muscles do. How can we prevent this?

What can we do while conserving our affected muscles? Can we address the limiting factors that contribute to post-polio derived morbidity while restoring what become limiting factors in other muscles due to a lack of conditioning? I believe so and in doing so we can maximize our health while minimizing our symptoms. In the next installment of this column I will share some of my ideas about how this can be accomplished.

## What's Coming Up In Future Meetings?

By Larry Kohout

What's next you ask? Well if you didn't Bill Eddy did. Thank you Bill, great idea. More of you need to feed in ideas like this.

The next two meetings will feature video tape speakers. PPASS purchased a two tape set of the 2002 San Diego Post Polio Symposium. Tape 1, which will be shown at our March meeting, features Dr. Lindsay Whitton and Dr. Sam Pfaff both of whom are research scientists with the Salk Institute in San Diego. We ran one of Dr. Whitton's papers in this newsletter a year ago.

Tape 2, which will be shown at our April meeting, features Dr. Susan Perlman and the late Dr. Anne Gawne. You have also had the opportunity to read papers by Dr. Perlman in our newsletter. These two doctors focus their presentations on the treatment of ordinary patients. Both presentations are very interesting.

## In Memory of ANNE CARRINGTON GAWNE, MD



It is with sadness that we announce the sudden passing of Dr. A. C. Gawne the Director, Post-Polio Clinic and Brain Injury Program at the Roosevelt Warm Springs Institute of Rehabilitation.

Gawne has been at the forefront of the care and treatment of patients with Post Polio Syndrome and has written and presented extensively in the field.

Gawne received her BA from the University of California at Santa Barbara and her MD from Uniformed Services University of Health Sciences, Bethesda, Maryland

Prior to her position at Warm Springs Gawne served as Assistant Professor, University of Alabama at Birmingham, Spain Rehabilitation Center, Birmingham, AL

She came to Alabama from her positions as Director, Post-Polio Clinic and Multiple Sclerosis Clinic, National Rehabilitation Hospital, Washington, DC

### U-M study takes a closer look at polio's lifelong effects

*Study focuses on gender differences, menopause impact as polio survivors grow older*

By Krista Hopson

Reprinted from the University of Michigan Health System web site at <http://www.med.umich.edu/opm/newspage/2003/polio.htm> with the permission of the author.

ANN ARBOR, MI - Polio, a disease that has the potential to paralyze and even kill its victims, was once prevalent in the United States before a vaccine was made available to the public in 1955.

And with no new cases of polio reported in the U.S. for more than 20 years, the only reminder of this past epidemic are its survivors - a group, like many others with disabilities, that is now living longer than ever before.

But despite the growth in this segment of this population, very little is still known about how the effects of aging, and especially menopause, impacts polio survivors' quality of life.

Now researchers in the University of Michigan Health System's (<http://www.med.umich.edu/>) Rehabilitation Psychology and Neuropsychology Division of the Department of Physical Medicine and Rehabilitation (<http://www.med.umich.edu/pmr/>) will take a closer look at the menopausal experience of women polio survivors, including an extensive

study of aspects of both male and female survivors' current health.

The study, "Women with Polio: Menopause, Late Effects, Quality of Life, and Psychological Well Being," is funded through a \$25,000 award from the Gazette International Networking Institute's (GINI) Post-Poliomyelitis Research Grant.

As its name suggests, the study will explore the relationships between menopause, late effects, hormone replacement therapy risks, life satisfaction and emotional distress in the overall quality of survivors' lives.

Past evidence has found that women with a history of polio may have a greater prevalence of late effect symptoms like pain, fatigue and weakness after the age of 50. However, it is not known whether or not those symptoms are influenced by menopause, says Claire Z. Kalpakjian, Ph.D., project manager and co-investigator.

"For women survivors, developing pain and fatigue about 30 years after having polio typically coincides with menopause," she explains. "What we hope to uncover is the influence menopause, if there even is one, has on polio survivors' pre-existing conditions and whether pre-existing conditions such as fatigue and pain make the menopausal transition harder for some women."

To find out more, a group of 800 to 900 women with a history of polio, the majority of whom will be middle-aged, will be recruited from the International Polio Network. The Network will also help recruit 800 to 900 men from the same age group with a his-

tory of polio. The balance of men and women subjects in this study is important since most polio studies tend to report on a greater number of females. Both groups will complete a mailed survey questionnaire.

For the menopause component of the study, the men will serve as the control group to allow researchers to compare the differences between men and women. This will show the impact, if any, that menopause has on female polio survivors.

This comparison between genders will also allow for an in-depth exploration of differences between men and women in terms of late effects of polio and other health problems they may be experiencing.

"As we learn and understand more about how men and women polio survivors differ as they age, we'll be able to help identify the best treatment and health management approaches for both groups," says Kalpakjian.

Other members of the U-M research team include: Principal investigator Denise G. Tate, Ph. D., professor, Department of Physical Medicine and Rehabilitation; co-investigator Elisabeth H. Quint, M.D., associate professor, U-M Department of Obstetrics and Gynecology; and polio survivor and project consultant Sunny Roller, MS, Department of Physical Medicine and Rehabilitation.

Facts about polio

- Polio is an orally contracted virus. Some cases do not cause serious illness, however other cases may lead to paralysis or even death.

- In 1916, a polio epidemic began in the United States that killed 6,000 Americans and paralyzed 27,000 others annually. By the early 1950s, more than 20,000 cases of polio were reported each year. Once the polio vaccine became available to the public in 1955, the cases of the disease began to drop. By 1979, there were only 10 cases reported in the country. However, the disease is still common in other parts of the world.
- Today, polio survivors are one of the largest disabilities groups in the U.S. A 1987 survey conducted by the National Center for Health Statistics found that 1.6 million Americans had contracted and survived polio. About 640,000 of those cases resulted in paralytic polio, which increased the risk for post-polio syndrome.
- Post-polio syndrome occurs about 10 to 40 years after the initial onset of polio. It can cause fatigue, muscle weakness, joint pain and muscular atrophy. The severity of post-polio depends on how serious the polio attack was initially.

## Editor's Note

The following article was written by a friend I made over the internet. We had known one another a few years when I began to have my breathing problems. Deborah was most supportive to me during that time. She passed away unexpectedly on October 14, 2002. This story has been special to me since the time she wrote it. Her family has granted us permission to print it.

## Just One More Thing

By Deborah Gately-McKeen

I am awake. I can hear their rubber-soled shoes padding up and down the hall outside my room. Some people sound big. Their feet make a heavy thud as their heels hit the corridor linoleum. The littler people make rustling noises as their dresses whip back and forth. They all carry breakfast trays, medicine, and bed pans. I can't see anyone this morning. Last night the nurse turned my mirror away. She said that I shouldn't keep watching everything that's going on in the hall because I should be asleep.

"But I'm not sleepy." I said, as she stood out of view and twisted the mirror away.

"That's because you're nosy. Now close your eyes and think of nice things. You'll go to sleep soon."

"But I'm not sleepy." I protested again.

"Don't be difficult, Debby. Little girls are meant to be asleep by now."

She left me then. I wanted her to talk to me some more. The room was almost dark; only the night light was left on so the nurses could write things from the dials on my tank. I have my own tank. The doctor told me I could keep it as long as I stay in the hospital. I asked him if I could bring it with me when I go home. He laughed at me.

"What would you do with a great big iron lung in your house?"

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## Just One More Thing

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"I could be with my Mommy and Daddy and Chrissie and Stephan." I responded definitively. He laughed at me again and left my room. I felt kind of silly. It seemed like a good idea to me. I can't breathe without it.

I hope they come and bring my food soon. I'm hungry. I have to go to the bathroom too. I hate it when they reach through the sides of my tank and put me on the bed pan. It's cold and terribly hard. I don't think it was made for someone as little as me. It pinches my skin and digs into my back and legs. The nurses forget me when I'm on it because they're real busy. Sometimes they forget to cover me back up when I'm on the bed pan. I feel kind of silly then too because there are windows on the top of the side of my tank. Other people can walk right in my room and look in the windows. I don't like that.

My mother never forgets to cover me up. She always says, "I'm going to cover up my little girl's skinny bones so she won't get cold." When the nurse forgets, I try to make believe that I don't know there are windows on my tank or that nobody can see my skinny bones. It isn't that hard to do. I haven't seen my body in a long time. It's inside the tank, below the plastic collar around my neck. They wrap a diaper around my neck so that the collar won't hurt. At night it slips and burns sores on my skin. The collar leaks once in a while too, blowing air in my face, taking my breath away. Bells go off and everyone comes running.

They fix my collar so I can breathe again. Then they go away. I'm still scared, but they go away anyway.

I can move my right hand a little. If I work at it, I can crawl up my stomach and over my chest to the underside of the plastic collar. My stomach sinks in a lot now. It used to be round and stick out some before I got sick. My daddy used to poke his finger in my belly-button and I would giggle. Then he would tickle my ribs. As I creep up to my ribs, they feel hard; kind of like there's no skin there. It hurts when people touch me. I can't laugh when they press in all the places that used to tickle. Sometimes I cry when they do that. They tell me I'm very brave but I don't think so. When I get my fingers to the top of my chest, I can pull my chin in real tight and see my fingers beneath the filmy plastic. My fingers look pinkish and real little. I remember they looked kind of pudgy before. When I think about my fingers, I can tell they are little. They can feel the pleated underside of the collar. They want to touch my face but I say "No!" to them. They can't get through. I pretend they belong to someone else. These are someone else's skinny pink fingers that don't do much. Mine are chubby and can squish a caterpillar just like that! That doesn't bother me or my fingers.

Waiting for my food, I can look at the big round end of my tank. It's painted an ugly yellow color. Pieces of the paint have chipped off. One spot looks like my cat, Sugar. I can see her with her paw up to her mouth, licking it. The other chipped space is real big and can look like a monster.

He has giant teeth and a great big head. I try not to look at him too much. When I do, I try to see if he can be something nice but he always turns out scary. I make myself look away from him most of the time. I am counting the little holes in the ceiling this morning too. "One, two, three, four," I can count pretty high even though I'm not in school yet. I would have gone to school in two weeks but I got sick. I don't feel sick anymore. I just can't move or breathe too well. I wish someone would bring my breakfast.

"Good Morning, Debby. Are you ready to eat?"

"G'morning. I'm hungry."

"Good." The nurse sits down next to my head and balances the tray in her lap.

"Now, here let me give you a bite of egg. Turn your head this way. There you go."

"Yuck. I don't like runny eggs. Do I have to eat them? Can't I have Wheaties?"

"You have to eat what the kitchen sends you. I'm very busy. I can't get anything else. Now be a good girl. I don't want to have to tell the doctor you wouldn't eat." She looks mad to me so I smile at her. I don't want her to go away and be mad at me but my stomach feels sort of queasy from the runny egg.

"I'm not very hungry anymore," I smile.

"How about a drink of juice?" she suggests.

"Apple?"

"Yes, apple and a little glass of

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## Just One More Thing

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prune juice. Which do you want first?"

I know she will make me drink the prune juice. "Prune juice first," I say, to get it over with. "That's a good girl. Drink it all up. Good. Here's your apple juice now. "The nurse puts the same bending straw in to the apple juice so that the first few sips taste awful. I don't make a face though because she's smiling at me. I feel full.

"I have to go the bathroom."

"What do you say?"

She's not smiling any more.

"Please?"

"O.K. I'll put you on and be back in a few minutes." She gets up and puts the breakfast tray away somewhere. Then she disappears down the side of my tank. Suddenly, she pops open two portholes in the side of the iron lung. For a few moments I can't breathe. The great gushing in and out sound, that is steady and reassuring, changes. Then she pushes the bed pan and her arms through the portholes. The steady noise returns as the vacuum is resealed. She is moving my legs and rolling me on my side. My head can't turn very easy so the movement hurts. I say, "Ouch!"

"Now don't be a baby, Debby. It will be over in a minute."

I make believe my body belongs to someone else and that helps some. I'm quiet.

"I'll be back in a couple of minutes." She walks quickly out of the room. She didn't cover me

and my mirror is still turned. I wish my mother were here. She'll be here later today. She promised. It seems like the nurse has been gone a long time. My back and legs ache. I can't talk loud enough to call anyone. Maybe if I think hard she'll remember me. Oh, I wish she'd remember me.

"Debby, Debby. So sorry. My, my you must have been here for half an hour." She's reaching in the portholes and rolling me on my side. It hurts more this time. The bed pan has dug deep in to my flesh and is stuck to me.

"Ow!" I'm starting to cry.

"Debby, you're such a cry baby. You've really got a ring-around-the-moon here." She laughs a little. I don't know what she means by that but I'm biting my lip so she won't call me a cry baby again. I'll make believe this is another person inside the tank. Someone I don't know. This way I won't feel the hurt. I'll be kind of just a head lying on a pillow that is propped up on a tray. The head can smile when the body it doesn't know hurts. "Would you fix my mirror, please?"

"Sure. Do you want to look at your funny face or out in the hall?" She is smiling at me again. She tips the mirror that swivels over my head and I see the sunken eyes and hollow cheeks of a little girl I vaguely remember. "No, no. Outside, please," I smile.

"O.K. There you go. Can you see now?" She bends down and looks in to the mirror that reflects her image.

"Yes. My mother is coming soon. She promised. She's

bringing me bacon today. I love bacon. She's making it for me right now, I bet."

"I'm sure she is." The nurse leaves my room. I am alone again; a head with a phantom body attached somehow. I think of my house and of my family. I wonder what they are doing. Chrissie is probably playing with my dolls and Stubby, my teddy bear. I asked Mommy to bring Stubby in and she said she would when I get better. When I get better I'll go home and play there with Stubby. He's a panda bear with blue button eyes. We'll play together and I'll go out and put him on the swing with me and he'll ride my scooter with me. When I go home, that is. I don't feel really sick so I'll be better soon. The time goes by quick here sometimes. I don't do anything but think a lot. That seems to make time move fast. I make believe I have a doll house with tiny real people and I can make them do anything I want and anything I say. I can put them in any room and I can make them sit, stand, lie down or just whatever I want. They like me but they know I'm the boss. What I say goes. My mother has finally arrived. She's brought me bacon like I asked. It smells so good. I think I can smell it even before she unwraps the Saran Wrap. She's cooked it just the way I like it, a little chewy. It's nice when she feeds me. I don't feel so much like only a head when she's here. She smiles and talks to me a lot; even when I cry. She doesn't care if I have to go to the bathroom and, as I've already said, she never forgets to cover

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## Just One More Thing

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me up. She tells me what's going on at home. I'm afraid to ask her when I'll be better enough to come home with her and Daddy. The nurse just came in and told my mother that visiting hours were over for the afternoon. I don't want her to leave so I start to cry. She puts her warm soft hand on my forehead and tells me she promises she'll be here tomorrow. I want her to stay now. "Please?"

"The nurse says I have to go. I promise I'll be in tomorrow. Daddy will be in tonight."

"I know, but can't you stay? Please?" I want her to tell the nurse that she is staying no matter what they say. I want her to tell them they can't make her go.

"I want to, Baby," she strokes my head again, "but they have their rules and I have to follow them."

"When can I come home with you?" I dare to ask.

"Soon, Honey, soon." She looks a little sad to me. "Now I have to go." She gathers all her things and starts for the door.

"Mommy? Just one more thing?"

"What is it?" She turns and steps in to my view again.

"What time are you coming?"

"About one o'clock. Just like today."

"O.K."

"Goodbye, Sweetheart." She kisses my forehead and I start to cry again.

"Mommy? One more thing?"

"What Debby?" She stays where

she is.

"Can I have bacon again?"

"Yes, Honey, I promise. Now I'm going to leave and I can't stay for any more questions." She walks out the door.

"Mommy? Mommy? Just one more thing? Please? I forgot to tell you one more thing." My heart is racing but I know she is at the elevator and won't come back. "I love you," I call soundlessly.

----- "Deborah, Deborah, wake up!" Paul is rocking me gently back and forth in our bed.

"What! Huh? Oh. Oh, I was dreaming again, wasn't I?" I answer faltering, out of breath. My heart is thudding visibly and the pounding in my temples is confusing.

"You stopped breathing again. You were gasping! Jesus, that scares me when you do that." He has his arm around my shoulders and is helping me to a sitting position. My right hand keeps rising to my face. Seemingly of its own volition, I gratefully brush fingers against my cheek. I can feel myself calming down as my breath comes more slowly and clarity of thought returns.

"I don't really remember, Paul. I just felt like I was floating away from my body. God, I've got the shivers."

"Well, it's no wonder, you're covered in sweat too. Here, lie down so I can cover you up. You'll be warm in a minute." Paul slowly lies me back down and helps me to turn damp atrophied limbs so that I can rest on my side. He pulls the covers up over my

shoulders and folds himself warmly around the contours of my scoliotic back.

"Better?"

"Mmmm. That's much better. One thing, Paul?" I speak softly.

"What's that?"

"I'm sorry."

"Don't be ridiculous." He answers quietly in my ear. "You can't help it if you have a nightmare."

"Thank you, baby. One more thing?"

"Mmmm?" He is beginning to drift off to sleep.

"Don't ever leave me, O.K.?"

"O.K." He answers, barely audible.

"Paul? Paul? Just one more thing?" There is no answer. Merely the slow even breathing of my husband of twelve years and the security of his warm body enveloping all of me.

"There's just one more thing I forgot to tell you."

"What's that?" he mumbles.

"I love you." I whisper.

"I love you too."

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