



MOVING FORWARD

LIMB LOSS SUPPORT GROUP

NEWSLETTER

1st Edition – September 2013



MOVING FORWARD

FEATURE STORY

Philip's Story – Part I

-- Written by Julie Randolph

Philip Randolph was born April 9, 1987, in Louisville, KY. At a birth weight of 8 lbs. 3-1/2 oz., Philip was born strong & healthy. We took him out for a stroller ride when he was 3 weeks old. We had him covered well but it was a breezy day & Philip became congested. Apparently, this weakened his immune system because on May 15, 1987, the day Philip turned 5 weeks of age, I awakened at 6:00 am to feed him as usual & found him listless with not a sign of his normal crying to be fed. At that point his skin had a gray mottled appearance & his fontanel (soft spot on top of his head) was swollen. I didn't know until later that this is an immediate indication of brain-spinal infection. I called our pediatrician & he calmly told me to take Philip right away to the Emergency Room at Kosair Children's Hospital in Louisville. I took him to the hospital as quickly as I could. Philip's father, Roy, prepared to go to work as usual, neither of us realizing yet the graveness of the situation.



Philip, 2 yrs. old

As soon as we arrived at the Emergency Room & the intake nurse saw his swollen fontanel, she immediately whisked him away. They started him on 4 IV antibiotics, Phenobarbital & Dilantin to prevent seizures, steroids, heart & blood pressure medication. When the doctor came out to talk to me, he told me that my son was seriously critical, that he was between life & death, and that his father needed to get to the hospital right away. I was stunned, and when I called Roy to relay the doctor's message, it took some convincing for him to believe that this was really happening to us. He called his mother to come & stay with Joy, our 3-year-old daughter, & called his job so he could get to the hospital quickly. The stark reality & graveness of the situation slowly penetrated our consciousness as we waited at the hospital for 3 days & 2 nights. Philip was placed in the PICU, Pediatric Intensive Care Unit, and Roy & I dozed in chairs in the PICU waiting area.

During those first days at the hospital, we were never without support. Leaders & special friends from our church family came & prayed with us, talked with us, sat with us, & encouraged us. Through that first night that was oh! so long, a dear older couple we knew, the man being an amputee

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AMPUTEE COALITION ADVICE

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Tips for Taking Care of Your Limb

-- by Paddy Roszbach, RN, Former Amputee Coalition President & CEO, & Terrence P. Sheehan, MD

Proper limb and skin care is essential to your health and mobility. Prosthetic sockets trap sweat and prevent air from circulating around your residual limb, which can create a virtual paradise for bacteria. Bacterial and fungal infections can lead to skin irritation, abrasions and eventually skin breakdown. Left unchecked, this could lead to infection and ulcerations, leaving you unable to use your prosthesis for an extended length of time.

The following tips can go a long way toward keeping minor problems from turning into a crisis.

Limb Care

- If you are a new amputee, it's better to take a bath or shower at night rather than in the morning, as your limb will swell in hot water or when dangling as you sit or stand to shower, making it difficult to put on your prosthesis. In the beginning, you should use a shrinker at night, and put on your prosthesis when you get up from the bed – in other words, don't let your leg hang down or it will swell. As time goes by, this will become less necessary.
- If you have a transtibial (below-knee) amputation, never sit or sleep with a pillow under your knee, as this will lead to a contracture (inability to straighten the knee).
- If you have a transfemoral (above-knee) amputation, do not sleep with:
 - Your limb resting on a pillow, as this promotes a hip flexion contracture (inability to completely straighten your hip)
 - A pillow between your legs, as this lengthens the inner thigh muscle that helps you keep your legs together when you walk, and shortens the outer thigh muscles so that you walk and stand with your feet apart.
- Do not rest your limb over the handle piece of your crutches.
- Do stretching exercises daily to make sure that you can straighten your knee and hip; this makes walking, and even lying in bed, more comfortable.

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Philip's Story – Part I (cont'd)

himself, sat up with us in the waiting room & kept us company, telling humorous stories & experiences that they had been through, helping us to laugh & to get our minds off the situation, if only for a few moments.

During that first night, we were told that the nurses on duty were whispering among themselves that Philip was not going to live through the night. A special friend, who was a nurse in the Neonatal Intensive Care Unit on third shift, checked Philip's chart & came to tell me that he wasn't going to die during the night, that his labs were too good. That first night passed & Philip was still alive.

Philip was listed in seriously critical condition for 3 days & nights. We knew that he had some type of meningitis but his condition was too unstable to do a spinal tap to determine the exact type of meningitis. Instead the doctors did a blood culture which took several days to develop. At the end of the third day, our pediatrician came & explained to us that Philip had Haemophilus Influenza Type B meningitis, which was the worst type of bacterial meningitis, and that the infection was also in his blood stream, causing the capillaries in his extremities to collapse. This is why his hands & feet were turning blue, then purple, then black, and he was being treated as a burn victim.

He also explained to us that the meningitis affected the frontal lobes of Philip's brain, which meant it would probably affect his reasoning & creativity, but we wouldn't know the extent of the damage until he went to school. Our pediatrician told us that he would have long-term & short-term memory loss as well. He told us that Philip was not out of the woods yet but that he was somewhat stabilized & the doctor wanted us to go home that night & get a good night's sleep in our own bed. That we did, gratefully!

Since first being admitted on Thur., May 15th, Philip's arms & legs had been wrapped in bandages. The dressings were changed every day but we could not see what was going on under those bandages. I was told that if I wanted to talk to the pediatric plastic surgeon to find out the status of his limbs, I would need to be at the hospital very early the next morning. Early that Tue morning, I met the plastic surgeon. He told me that at best Philip would lose his right hand, and at worst, he would lose all 4 extremities. From then on it became a waiting game to find out how much of Philip's limbs could be saved.

Finally, after about 2 weeks, a line of demarcation around Philip's ankles became evident between the living & the dead tissue. Philip had amputation surgery on June 10th. The surgeon had to remove his right hand at the wrist, all the fingers & part of the palm on the outer side of his left hand, and both his legs about mid-calf. They wrapped palm skin around his right wrist so that he would have the advantage of palm sensitivity at the end of his right arm. A week later, Philip had skin grafting surgery. The surgeons took a square of skin from his thigh to cover some needed areas on his hands.

We were told that Philip could be fitted with prosthetic limbs as soon as he had healed adequately & that he would

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Tips for Taking Care of Your Limb (cont'd)

Skin Care

- Wash your limb with mild soap and water every day (more often if you sweat heavily) and pat it dry with a soft towel. Be patient and allow it to dry completely. If this is not done, you will be at risk for fungal growth that could lead to infection or abrasion.
- Check your limb for red pressure patches that last more than a few minutes after you remove your prosthesis; these may be a sign that the socket needs checking. If left untended, these red patches may result in skin breakdown.
- Check for skin breakdown twice a day – if you can't see the end of your residual limb, use a mirror. This is particularly important for people with diabetes.
- Softening cream should only be used if the skin is extremely dry and at risk of cracking. It should only be used temporarily unless cleared by your doctor.
- Do not use talcum powder on your limb, as it can ball up and create an abrasion. If you must use a powder, cornstarch is better.
- Do not use alcohol or unknown chemicals/creams on your limb.
- Remember – your limb is covered all the time, so be very careful if you expose it to the sun. Use sunscreen SPF 30 or better.
- Do not shave your limb; the resulting short hairs get pushed back into your skin, becoming ingrown hairs that can become infected.
- If the skin of your limb opens, go straight to your doctor and prosthetist.
- If you are having a fit problem with your socket, causing skin breakdown, go to your prosthetist for an adjustment. If the breakdown is infected, you will need to go to your physician as well. Stop using the prosthesis; have crutches and a wheelchair for backup.
- If you have a skin breakdown, don't use prosthesis. Put a clean dressing/band-aid on the area daily and see your doctor or prosthetist. Don't "pad" a pressure area, as that creates additional pressure and will make it worse.
- A red spot that turns into an ulcer can mean weeks without being able to use your prosthesis. Stop using the prosthesis and call your prosthetist/doctor.
- If you have reduced or no sensation in your residual limb, check your limb more frequently during the day and don't put it in hot water or expose it to the sun – it will burn and blister.

Prosthetic Care

- Wash anything that makes skin contact (liners, socks, the inside of the socket, etc.) every day with mild soap and water and allow plenty of time to dry. Follow manufacturers' instructions for care of liners. Unless specifically instructed, do not use anything containing alcohol or unknown chemicals.
- You should know the landmarks of when your

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Philip's Story – Part I (cont'd)

probably do very well, that it would work to his advantage having this trauma happen at a very young age because he would grow up with prosthetics and this condition would be all he had ever known. We held this hope dear to our hearts.

Philip remained in the PICU for 2 weeks, and then was moved to a private room on the fourth floor for 5 more weeks. He was having a build-up of fluid on his brain. The nurses monitored it closely by measuring the circumference of his head daily. The measurement of his head grew to the point that the doctors were about ready to put in a shunt to drain the fluid off his brain. Just before they did that, his head circumference miraculously began to decrease so this procedure was not necessary.

During the 5 weeks that Philip was in his fourth floor room, members of our church family organized a "meal pool" so that someone brought a hot meal up to us & someone else brought a dessert for each evening meal, Monday through Friday, during the entire 5 weeks. I had gone back to work. Roy or I would pick up 3-year-old Joy & we would all come up each day to Philip's room as soon as we got off work and stay all evening. The meals were a godsend so we didn't have to waste time or spend money picking up meals on the way to the hospital. We had plenty of moral support during this time. A steady stream of family & friends flowed through Philip's room.

Philip was discharged from the hospital on July 3, 1987, so we celebrated "Philip's independence"!

Philip had had seizures for the first 3 days of his illness, so he continued to take both anti-seizure medications for a while. When he was 12 months, doctors did an EEG and, miraculously, the results were normal so he could be taken off both medications. Since that time, Philip has rarely taken medication of any kind.

When Philip was around 5 months old, a prosthetic shop in Louisville made him his first prosthetic right arm. It was mechanical with a metal hook hand. At first, the goal was just to get him used to wearing it. Then as the months passed, he learned to operate it quite well. By tensing muscles in his shoulder, he could open & close the hook and hold objects.

We traveled to the Child Amputee Center in Grand Rapids, Michigan, to have Philip's first set of prosthetic legs made in the months before he turned 1 year old. This involved 2 trips to Grand Rapids, the first appointment for casting of the legs & the second visit a month later for fitting, finishing, & bringing the legs home. Even though Philip wasn't walking on the legs yet, the hope was to have him get used to wearing them & crawling around in them. The legs were made with sockets of wood, feet of some type of foam with a vinyl covering, and they were held on with a neoprene sleeve that pulled up onto his thighs.

After we brought the legs home & started having him wear them for short periods during each day, Philip would pull off the prosthetic legs as soon as we put them on. To him, it was much easier to crawl around without them. But I knew that

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Tips for Taking Care of Your Limb (cont'd)

socket fits correctly; if you don't, ask your prosthetist to show you. If your socket is too big or too small, visit your prosthetist immediately.

- Make sure your shoe height is correct for your prosthesis or your alignment will be wrong, putting a strain on your residual limb and surrounding joints.
- Keep a "leg" bag handy with items you might need in an emergency (stump socks, pull socks or bandages, antibiotic ointment, antihistamine ointment, etc.).
- Remember – the fit of your prosthesis changes during the day, so add socks when needed.
- If you are having trouble with the prosthesis or liner, do not make your own adjustments or alter the prosthesis/liner – call your prosthetist immediately.

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## SPOTLIGHT

Each month in our spotlight section, we will get to know one of our members a little better. This month the spotlight is on:

Name: Philip Randolph

Age: 26

Hometown: Charlestown, IN

Hobbies: Playing drums, listening to music, playing basketball

Favorite TV show: ER

Favorite Sports Team: Not a big sports fan

In one word what do you like about our support group? Friendship

In more than one word what do you like about the group? We talk about and help each other solve our problems, and the outings are fun.

What has helped you to move forward? The Lord, my Mom, my Dad, my friends, and our group

What activity would you like for the group to do? Get together and play board games

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Q & A



In this column we ask you to submit questions pertaining to limb loss, & then we will get responses from members of Moving Forward Limb Loss Support Group.

We are not offering medical advice, but will share tips & information to try to make living with limb loss easier. You may submit your question by email to belindajacobi@yahoo.com or by calling 812-620-3694.

Remember, you don't have to be a member of **MOVING FORWARD** Limb Loss Support Group to attend meetings or events. **EVERYONE** is Welcome!

Philip's Story – Part I (cont'd)

his ability to eventually learn to walk depended on him getting used to wearing the legs, so I thought to myself, "This is going to be a battle of wills, & Bubby, you are not going to win this battle!" I took a small chest harness that the prosthetist had made for Philip & attached it to the top of his neoprene sleeves so he could no longer pull off the legs. That was a turning point for Philip and his legs.

A Physical Therapy Assistant came to our home 2 days a week & worked with Philip, using a toddler size walker. The sweet taste of victory came when Philip walked completely on his own without the walker at the age of 21 months. From then on, you could not hold him down!

~~~~~ To be continued in the Oct. Newsletter ~~~~~

## UPCOMING EVENTS



**Sat., Sept. 21:** Ice Cream & Pie Social at the Okolona Fire Station, 8501 Preston Hwy., Louisville, from 2:00 – 4:00 pm. Ice cream & drinks will be provided, but please bring a pie or your favorite ice cream topping. Mike will be making homemade low sugar ice cream. Please label the pies that you bring in as far as sugar free or low sugar for the diabetics in our group. Allen Jones & Philip Randolph will be providing musical entertainment on the guitar & drums. If anyone else plays an instrument, please bring it with you to the Social. This is a great opportunity to showcase some of the talent in our group. We will have games & activities for the children in attendance.

**Thur., Sept. 26:** Meeting at Baptist East in the Education Center from 6 – 8 pm. A rep from Premier Compounding Pharmacy will be at this meeting to answer questions about how various compounds can help to relieve phantom pain & sensations.

**Sunday, Sep. 29:** Brunch Cruise on the Belle of Louisville will board at 1:30 and runs from 2:00 - 4:00 pm. The cost is Adults - \$ 31, Seniors - \$30, Children - \$21. Everyone needs to order their own tickets for the event by calling 502-574-2992 or 866-832-0011 or online at [www.belleoflouisville.org](http://www.belleoflouisville.org). Click on Buy Tickets. The cruise is handicap accessible. Please let them know when ordering tickets if you will be using a wheelchair or scooter so they can accommodate you & be sure to tell them that you are with the Support Group so we will be seated together for the brunch.



### Other Activities Being Discussed:

- Walk-and-Roll-A-Thon / Picnic in Oct.
- Dance
- Bowling

We are researching adaptive sports and would like to see the group offer various sports clinics (tennis, golf, bowling, softball, etc.) as well as plans to start a program for children with limb loss. For more info or to offer ideas or suggestions, please call or email Belinda Jacobi.

## RECAP OF AUGUST



Our Support Group held a Fundraiser Yard Sale on Sat., Aug. 17. It was a huge success! We raised over \$600 for our support group treasury.

We tried a new format at the Aug. 22 meeting. For the first half hour we had "Meet & Greet", giving members a chance to socialize & meet new members.

This was followed by a discussion on childhood limb loss, which was led by Kelly Reitz. Our President Belinda Jacobi presented an Amputee Storybook & Moving Forward T-shirt to our newest member, 4-year-old Reid.

Mike Portman discussed medications for phantom pain & a new shower leg called "Water Gait", developed by a prosthetist from Chicago.

Sam Gaylord gave a legislative report, and talked about Dr. Hugh Herr & the technological advances he is making in the world of prosthetics.

We discussed the newsletter. A sample was passed out to get everyone's feedback on it. We plan to email or mail the newsletter out the first week of each month.

The meeting concluded with a discussion of our upcoming events.

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FACEBOOK PAGE

Kelly Reitz has set up a page for our support group on Facebook under the name **Moving Forward Limb Loss Support**. Add your name to our friend list & keep up with our group's activities.

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## CONTACT INFO



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-- Edited by Julie Randolph