



NEWSLETTER FOR AMPUTEE
SUPPORT GROUP LEADERS

Communicator

Amputee Coalition of America —National Limb Loss Information Center
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... Dedicated to Enhancing Support Group Leadership Skills

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ACA's Top Ten

By Kathy Spozio

At a recent conference of the Pennsylvania Academy of Orthotists and Prosthetists I had the privilege of speaking on behalf of the ACA to a group of about 80 professionals. The topic of my presentation was “The Top Ten Reasons to Join the ACA.”

It occurred to me while preparing that the reasons I spoke about also apply to membership on all levels, not just for professionals. And, while this newsletter is directed primarily at support group leaders, it is also intended for reprint and distribution to support group members. It is for this reason that I will present a similar version of the ACA’s Top Ten. I know I was surprised to learn some of the facts and information that were given to me by Pat Isenberg, ACA COO, who prepared the Power Point presentation, and I think you may find the material quite interesting as well. Perhaps it may even encourage your group or some of your members to become part of our membership ranks.

The **number 10** reason to join the ACA is our outreach program. The goal of our outreach program is to educate amputees and their healthcare providers about the programs and services available through the ACA. The ACA distributes information to thousands of people each year; builds partnerships with other organizations like the American Diabetes Association and the American Cancer Society; identifies resources that can be passed on to amputees; and identifies amputee needs (such as which materials should be translated into Spanish).

Number nine is our award-winning publications, which continue to grow in number and quality each year. *InMotion*, our bimonthly magazine has a readership of more than 120,000; *First Step: A Guide for Adapting to Limb Loss* is now in its third edition; *the Communicator*, this newsletter, is written primarily for approximately 200 amputee support group leaders and can be received both online and by regular mail; *youth inMotion* is a stand alone magazine for young amputees that is published three times per year; and LLEAP (Limb Loss Education Awareness Program) is our disabilities awareness curriculum for able-bodied kids in the third, fourth and fifth grades.

Our National Peer Network is the **number eight** reason for joining the ACA. In 2002, the ACA revised its peer training materials and standardized its peer training process to include a pre- and post-test and evaluation of skills learned. Peer visitors may now become certified, and 115 peer visitors have been certified to date. Additionally, ACA has 690 previously trained peer visitors in its database. Trainers are also certified to conduct peer visitor seminars throughout the country. Ongoing consultation and a support group leader's track at the Annual Conference are used to enhance leadership skills and provide a link between support group leaders and the vast array of resources at the ACA. Eleven volunteer regional representatives are ACA's ambassadors within the local communities.

Number seven is information and referral. ACA's National Limb Loss Information Center (NLLIC) is a national model for information centers. NLLIC receives requests for information via phone, e-mail and through the ACA Web site. Specially-trained information specialists are on hand to develop customized packets of information to meet the specific needs of amputees and their families or friends, their healthcare providers and the general public. In 2002, NLLIC answered more than 3,000 individual requests for information.

Number six is our limb loss library, boasting the most comprehensive collection of amputee-related information in the country. The NLLIC has an in-house library of journals, books and video resources available for staff use in fulfilling information requests. ACA's online catalog will eventually provide full text access to all ACA materials. Print and video resources are available for sale via the Web site or from its Resource Catalog. Selected articles from *inMotion*, *First Step* and NLLIC fact sheets are available in Spanish.

The **number five** reason for joining is healthcare provider training that, although not targeted toward amputees, directly affects our positive outcome for care. As you are aware, a skilled and knowledgeable healthcare team is essential to successful rehabilitation. ACA's training targets all the professionals involved in individual amputees' care and recovery: orthopedic surgeons, rehabilitation nurses, physical therapists, occupational therapists and prosthetists.

This professional primer is a one-day seminar that covers amputation surgery (principles and decision-making), lower limb amputation (surgery and post-op management); psychosocial considerations of lower extremity amputations; principles of gait analysis; gait analysis; and what to do when professionals return to their practice.

Number four is the Youth Activities Program (YAP), which is experiencing substantial growth. The annual youth camp is a three-day event that allows kids to

network, learn from their peers and adult amputee mentors and increase their self-esteem in an educational environment. This year's camp will host 59 youngsters, ages 10-18, in Boston. *Youth inMotion* is written by and about amputees ages 7-18 and focuses on real-life social and health issues. A new feature of this camp will be youth peer visitor training for those who are interested in providing support to new amputees. YAP Central Station is part of ACA's Web site and is dedicated to issues for young amputees.

Reason **number three** is the annual conference, which is being held this year in Boston. July 2-5 are the dates for a rousing Fourth of July educational extravaganza. From fireworks to fitness, this conference promises to be the most exciting ever! New this year are meals planned by a nutritionist; technology sessions that are clearly identified and do not compete with educational sessions; and support circles for groups such as new amputees, cancer survivors and older amputees.

ACA's Web site is the **number two** reason for joining our ranks. Filled with information about all ACA programs and services, including advocacy efforts and research projects in conjunction with Johns Hopkins University, the Web site is also a link to resources around the country.

And now, presenting the **number one** reason for joining ACA is because the ACA cares about you! And we need you to help us continue to grow and fulfill our mission: ***To reach out to people with limb loss and to empower them through education, support and advocacy.***

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Using the NLLIC Library to Aid You and Your Support Group

By Meredith P. Goins, NLLIC Librarian

Building a library for your support group? Looking for information regarding amputation, rehabilitation or prosthetics and orthotics? Look no further than the National Limb Loss Information Center (NLLIC)!

The NLLIC offers many services that you may already be aware of: responding to questions on adapting to limb loss, referrals to groups, agencies and programs and our information packets. But did you know about the resources we sell, our Library Catalog, or that you can request any item in our library through Interlibrary Loan?

NLLIC Resources

The resources that we offer are selected for their validity and affordability. Many libraries, medical offices and support groups include our information in their personal and organizational libraries.

Due to overwhelming response from our customers, we have added new fitness and lower-extremity books and videos to our 2003 edition of the ACA Print and Video Resources Catalog. Call the ACA to request your free copy today!

For example, we now carry Bob Gailey's *Balance, Agility and Endurance for Lower Extremity Amputees*, *Home Exercise Guide for Lower Extremity Amputees*, *The Essentials of Lower Limb Amputee Running* and *The Biomechanics of Lower Limb Amputee Running*, just to name a few!

ACA members receive a substantial discount and orders can be placed over the telephone by calling 888/267-5669 ext. 8135 or on the Internet at the [ACA Marketplace](#).

NLLIC Library Catalog

Through a grant funded by the Langeloth Foundation, the NLLIC was able to create, develop, implement and maintain a limb loss catalog that is available to the general

public, limb loss consumers, their families, their healthcare providers and to the ACA/NLLIC staff.

Have you ever looked for a book at your public library or at a university through their online catalog? The same searching concepts apply to our Library Catalog. To help you in this process, the main page of the [NLLIC Library Catalog](#) includes three important links: access to the catalog, our tutorial and our newest additions.

The link to the catalog is actually a yellow button that you click to search the catalog. Please note that the Library Catalog is unavailable from 3:00 a.m. to 4:00 a.m. EST each day due to routine maintenance.

The first place to go for help in searching the catalog is the list of Search Tips found on the right side of the catalog search page once you're into the catalog. You can search by keyword, title, author or subject. Note that the [blue hyperlinks](#) (titles, subjects and author) lead you to a listing of all items in the database listed alphabetically by field. These links take you to the title index, the subject index and the author index.

These indexes are most helpful when you don't know how to spell something or the term you are searching for doesn't return any items. Just click on the hyperlink and the index will open. Type in what you are looking for and a list will come up of possible matches, which you can then paste into your search screen!

The second link is our [Basic Training Tutorial](#), which we created to help train users. Note that you must have Flash player on your machine to view the tutorial, but we provide a link to download this plug-in. This runs through the basic steps necessary to complete a search in the catalog.

Finally, the link to the [new additions](#) to the catalog can be found on the right side of the Library Catalog's homepage. This page includes all items, including books, videos, Web sites or magazines, added in over a two week period. When a new list is posted, we e-mail a reminder and description of the new additions. If you are interested in adding your name to the email distribution list, please e-mail mgoins@amputee-coalition.org and request to be added to the OPAC New Additions list!

InterLibrary Loan (ILL)

If you find an item in the Library Catalog that you would like to review, you can always go to your public, medical or university library and request that they borrow the item from us through InterLibrary Loan.

Go to your reference librarian and tell them where you found the information and that you'd like them to request the item through ILL. Most public libraries do not charge for this service, but a few may. Most costs are associated with shipping the item to and from the libraries and normally don't go over \$20.

And as always, if you need further assistance, contact me or any of the information specialists at the ACA. Any of us can walk you through a catalog search, take your resource order or explain ILL further!

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Dear Dee

The Communicator has established this regular feature to help you deal with the common, and sometimes uncommon, questions you may be asked as a support group leader. We hope that Dee's expert and insightful responses to the "model" question each issue will contain will enlarge your repertoire of tools for satisfying your members' informational and support needs.

. . . . Editor

By Dee Malchow

Dear Dee,

My lower leg was amputated last week due to a crush injury. I am only 23, single, fairly attractive and always thought my legs were among my better features. Does this mean I cannot wear short skirts again? What about my shoes? I have a closet full of all kinds of cute shoes. Must I toss them?

Broken Hearted in Brooklyn

Dear Broken Hearted,

My first word of advice is to not toss anything! Some of the clothes and shoes that may not work at first may look fine with a later prosthetic foot or leg. Or you may get to a point where you don't care if shorts or a short skirt reveal that you are wearing a prosthesis. A lot of changes occur during these early weeks and months with your body, your feelings and your prosthesis.

We are all very unique about what is important with our substitute limb. Some want durability while others want high performance. Most want comfort and some want a natural appearance. The reality is we can't have it all. There are definite tradeoffs in this project.

In the beginning, most of us want to look as much like we used to before we had our amputation. We want to blend in and look and walk and function 'normally.' The feeling of loss of our leg is magnified when we think of parts of our previous wardrobe needing to go too. Every aspect of this altered appearance takes much getting used to.

As a young attractive woman, it is not surprising that you express a real sadness as you think of the impact on your appearance. How you look has been a positive part of your life experience. You may choose to put the effort into looking attractive while disguising your amputation. Or you may decide that you can still be an attractive young woman with it looking obvious as well.

For me, looking my best and usually disguising my prosthesis works. I like to move about my day smoothly without constantly answering strangers' questions about my leg. I can bring up the subject when I choose or have the time.

You may find that certain shoes and clothes still look fine as you update your wardrobe with your replacement limb in mind. It happens naturally over time.

I must admit that shoes were an early challenge to me. I don't like to fool with an adjustable heel height so I stick with one low height and have sport and dress shoes to go with it. At first it

seemed like I had to pass over way too many shoes due to wrong heel size, no straps, etc. Long after I accepted my limb loss, shopping for shoes could still drive me to tears. But now I look at it differently. Instead of crying over the shoes I cannot wear, I am delighted when I find a nice pair that I can wear. It's like finding a treasure!

I expect that you will ultimately find what works best for your appearance. It's OK to cry over the changes that you didn't want to be forced to make, especially in the beginning. Being an amputee is always a nuisance, but it doesn't seem like it as much later on.

**Do you have a question you would like Dee to address?
If so, we invite you to ask Dee directly at
deemalco@mindspring.com.**

Dee Malchow, MN, RN, is a nurse case manager who is self employed and specializes in the care of amputations. She experienced a right below knee amputation at age 19 from a boating accident.

Over the past 37 years she has come into close contact with over 2500 amputees through organized skiing and soccer, mission work in Sierra Leone, research for Seattle Foot, and her position as a Clinical Nurse Specialist at the Harborview Medical Center in Seattle, a Level I Trauma Center. In 2001, she retired from Harborview after 34 years. Dee served as the facilitator for the weekly Harborview Amputee Support Group for 22 years and has taught several peer visitor training classes. She has written several related articles and is currently working on a book about the emotional impact of limb loss.

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ACA News and Views

Annual Conference Support Group Leaders Workshop

By Becky Bruce

This year in Boston, the ACA is holding a Support Group Leaders Track on Wednesday, July 3, from 1:00 p.m. – 5:00 p.m. These sessions will be comprised of many different topics, each to be presented by a different speaker. The ACA would like to encourage any support group leaders/facilitators to attend this workshop to learn about the exciting new programs that support groups have the opportunity to be involved in and to learn how the ACA can help you and the members of your group.

Following is an overview of the sessions being presented:

ACA Resources – Presenter: Leslie Duncan

This session will be to inform support group leaders/facilitators about the programs and services that the ACA offers to assist leaders with program development and implementation. This session will include information on how to use the ACA as a resource both for your group and for serving the individual members of your group.

Program for Amputee Life Skills (PALS) – Presenter: Ellen McKenzie

The Johns Hopkins School of Public Health and the ACA are joining forces in the PALS program. This program is an amputee self-management intervention program that will be implemented through local amputee support groups around the country. Please attend this session to learn more about how to become involved and learn more about PALS.

Newsletter Development – Presenter: Marshall Goldstein

Learn more about support group newsletter development and how to make the best publication you can for your members and those on your mailing list.

Landmine Survivor Network Survey Update - Presenter: Beth Sperber-Ritchie

In 1999, at the ACA Annual Meeting in Reno, Nevada, the Landmine Survivors Network interviewed several attendees from the meeting, as well as amputees from other countries that they deal. The purpose of the interview was to gather information regarding the emotional and psychological adjustment to amputation and to learn what makes some people survivors and what prevents others from a complete rehabilitation. The results of the survey have been compiled and will be presented at this workshop.

LLR&SP Research Update – Presenter: Ellen McKenzie

This session will focus on the results obtained and compiled by the Johns Hopkins School of Public Health. Johns Hopkins conducted surveys with 950 amputee consumers to ask what their needs were and what they felt they were lacking in their post amputation care. The results of this study were used to create the PALS program (being presented at this workshop) and will be shared with attendees. The results of this survey will directly relate to the formation of the PALS program.

Peer Visitation – Presenter: Becky Bruce

This session will focus on the ACA's National Peer Network, including the restructuring of the training format, being involved in the network, certifying peer visitors and characteristics of a good candidate for certification as a peer visitor. Other topics for presentation will include the new collaboration between the Walter Reed Army Medical Center and the ACA to assist the military in training peer visitors to help our soldiers who have experienced limb loss in the Middle East and other parts of the world.

The ACA would like to encourage you to attend these sessions. The information being presented has been designed to assist you in your role as a group facilitator and provide information pertinent to support group function.

Please come and join us ... we'd love to have you there!

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