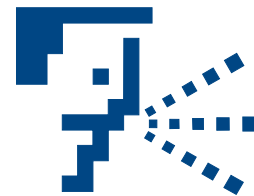




NEWSLETTER FOR AMPUTEE  
SUPPORT GROUP LEADERS

Volume 1, Number 2  
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# Communicator



**Amputee Coalition of America – National Limb Loss Information Center**

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## *Networking - A High Pay-Off Activity For Support Group Leaders*

By Jan Garrett, Executive Director  
Center for Independent Living, Inc. - Berkeley and  
Oakland, California

The universe of organizations providing encouragement, support, education, and advocacy for persons with disabilities is larger than most of us can imagine. While it's important for us to network with our peers in other amputee support groups and with the ACA, we must realize that effective networking outside our own borders is absolutely necessary if we are to bring to our groups the full benefits of information and advocacy our members deserve. To be most effective, our networking should focus on both private and public organizations that are active in our community and state.

Our role as support group leaders is not only to arrange meetings, supervise visitation programs, maintain a newsletter and the like, but to help our members connect with the outside world of disability-related services. The first goal of networking, therefore, would simply be to learn what organizations are out there and what services they offer that might be needed from time to time by our members.

Following are some specific reasons for establishing relationships with organizations representing other disabilities and amputation causes, organizations that focus on disability rights in general, and political organizations that establish public policy and law:

- Networking enables us to refer our members to other organizations for services that would not be feasible for us to duplicate within our own group.

For example, amputee support groups typically have many members who have lost

limbs to diseases, such as diabetes or cancer. Rather than our trying to provide diabetes-related or cancer survivor-related services, effective networking would enable us to refer our members to other groups, such as the local chapters of the American Diabetes Association or the American Cancer Society, for specialized services. We can also invite other such groups to play a part in our program.

Every state has a department of rehabilitation and possibly other agencies that provide vocational retraining and employment services to people with disabilities.

Through effective networking we can make referrals to appropriate officials within these agencies and can bring state officials to our meetings to explain their services to our members.

There are several organizations that provide financial help in obtaining prosthetic limbs for people without insurance coverage. By establishing relationships with these organizations we can make sure our members who are in need of such help have the necessary information and contacts when needed.

- Networking allows us to promote access by our members to activities sponsored by other groups.

Other disability related organizations may have activities in which some of our members may obtain permission to engage. A cross-relationship with Disabled Sports USA or a local affiliated organization, for example, might enable our sports-minded members to access recreational activities that might not be feasible for us to organize ourselves, and for their amputee members to access from us non-recreational services that might not be available in their own group.

- Networking helps leverage our ability to bring informative programs and speakers to our members.

Amputee support group leaders spend a lot of time and energy trying to find interesting subjects and speakers for meetings. When we network effectively, we can expand our meeting horizons. Reciprocal relationships can

enable us also to bring our message to others.

- Networking helps us to get new members.

It is not inconceivable that there are people with amputations in other groups who may not know about our group or the services we offer. By networking effectively, we can have access to those people and we can increase the likelihood that leaders of other groups will be able to refer people to us. We can also offer cross-referrals to them.

- Networking promotes establishment of coalitions to bring about political change.

Examples might be to bring about better enforcement of disabled parking laws or to encourage local businesses to provide better access for persons with disabilities. It only stands to reason that joining forces with others in these kinds of efforts would tend to be more effective than trying to go it alone.

Close to amputees' hearts are issues involving governmentally-provided rehabilitation services and reimbursement for prosthetic services and supplies. We wish we could get our message to the people who establish these rules. Many disability rights organizations have already established close ties to governmental policy makers and legislators. Through networking, these contacts can also be accessible to us.

- Networking promotes improvement of local governmental services our members need.

Just as we can establish coalitions with other disability-related organizations, we can also establish coalitions with local politicians and political groups - city council members and county supervisors, for example. Building these relationships can be helpful in making the politicians more sensitive to the needs of persons with disabilities, for us to know what funding and projects are available that might be of interest to our members, and to enable us to get assistance for our members when needed.

To be realistic, effective networking takes time and patience. But the rewards will be well worth the effort.

# Amputee Support Group Job Descriptions

By Richard L. Mooney, Communicator Editor

Are job descriptions necessary for support group officers? Many group leaders seem to think so. Contrary to popular opinion, however, one cannot simply "lift" job descriptions from one support group and use them in another any more than an accountant job description, for example, can be obtained from Microsoft for use in General Motors. Job descriptions are unique to the organization in which the jobs are performed.

This article, together with the additional information on the Web page noted below, is intended to help support group leaders develop and customize job descriptions for their particular groups.

While job descriptions for support group officers should be kept simple, they do serve several useful purposes.

1. The mere act of developing job descriptions causes support group leaders to think through in a structured way; the work that needs to be done, how it should be done, and who should do it.
2. Job descriptions help incumbents focus on what their principal responsibilities are;
3. Job descriptions are useful in recruiting replacements; and
4. Job descriptions help the President make sure that the team members are doing what they are supposed to.

Whenever possible, the development of job descriptions should be collaborative, involving job incumbents, with advice from other support group members having management experience.

Here is a "formula" for development of job descriptions.

- A. Make a list of every task that must be done to assure that the goals and objectives of the group are attained. Every task statement should begin with an action verb, e.g., write, moderate, supervise, provide, etc.
- B. Divide the task statements among the positions available or desired, e.g., President, Treasurer, Committee Chair, etc.
- C. Add to each task statement a brief description of how the task should be done, e.g.,
  - Keep books in accordance with generally accepted accounting principles,
  - Lead Board meetings in accordance with Roberts' Rules of Order,
  - Approve newsletter advertising in accordance with the advertising policy approved by the Board.

These statements tell when the tasks are performed correctly.

Finally, job descriptions should be reviewed whenever there is a job vacancy, and all job descriptions should receive a general review by the Board at least annually. Jobs tend to evolve over time and this will help keep them up to date.

To help you, there is a list of tasks that are required to support an active group having an educational/social program with periodic meetings, a visitation program, and a newsletter at: <http://www.usinter.net.wasa/guidec2.html>

I have grouped the task statements under "typical" job titles. Naturally, the distribution of tasks should be changed as necessary to conform to the actual numbers and interests of volunteers available in your group.

## ACA People

Leslie Duncan Named Program Manager, Education and Research

In January, Leslie Duncan joined the NLLIC staff, replacing Janice McDonald who resigned to return to academia. Before joining the ACA, Leslie held administrative positions with the Clinch-Powell Regional Library and the University of Knoxville Law Library. At ACA, she will be responsible for the educational program, supervision of the Information Center, grant administration, and for developing ACA's electronic library and bibliographic database.

We're delighted to have Leslie with us!

Leslie Duncan  
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Becky Bruce - New Outreach Coordinator

Becky Bruce, formerly an ACA Information Specialist for almost three years, has been named Outreach Coordinator, replacing Georgie Maxfield, who passed away last December. Becky is a below-knee/Symes amputee and is the possessor of an impressive amount of energy and good humor. Presently, she is deeply involved in conducting peer visitation training seminars and in learning more about you and your groups. Many of you already know Becky. Those of you who don't should feel free to introduce yourselves by phone or email. You will find her a thoroughly delightful person with a deep commitment to ACA and its peer network.

Becky Bruce  
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## Register Now for the 10th Annual Educational Meeting!

July 7 - 9, 2000

Clarion Plaza Hotel - Orlando, Florida

"Bridges to the Future" is the focus of this year's annual meeting. There will be the usual array of stimulating workshops, a cutting-edge technology exposition, and fun social events - augmented, of course, by the wide variety of entertainment and theme parks you will find near Orlando.

This year, our special Youth Initiative invites children from 8 to 18 to participate in an expanded program of educational and fun activities focused on youth interests. See your next issue of InMotion for more program information.

For registration information, call 1-888-267-5669

## "Train the Trainers" Workshop

ACA needs experienced amputees to become qualified to conduct visitation training workshops across the country. Are you doing peer visits through your local support group? Do you want to advance to the next level and become a trainer? Do you enjoy public speaking and meeting new people? Are you willing to conduct training workshops for the ACA in your geographic area?

If your answers are "yes," we invite you to apply for the "Train the Trainers" workshop that will be held before the 10th Annual Educational Conference & Exposition on Thursday, July 6, 2000, from 9:00 a.m. to 4:00 p.m.

If you are interested, please call the ACA toll-free (888-267-5669 Ext. 8113) today and let us know you would like to be involved. The deadline for registering for this workshop is May 15, 2000. Enrollment is limited. We look forward to hearing from you!

## Support Group Leaders' Workshop

Do you sometimes feel you're running your group by the seat of your pants? Would you like to know more about how to expand membership, shape an effective organizational structure, build energetic leadership, assure the group's financial health, and design activities that will keep your members interested and active? If so, you need to attend ACA's Support Group Leaders' Workshop in Orlando on Sunday afternoon, July 9th, from 3:00 p.m. to 6:00 p.m. No need for special registration. Just be there!

# *Chedoke Amputee Peer Support (CAPS) Hamilton, Ontario, Canada New, But On the Move!*

by James F.L. Stewart, CAPS Newsletter Editor

Although I was unaware of it at the time, my personal story is sadly common. It was November, 1991, and I was hospitalized in Montreal due to diabetic foot ulcers, facing an amputation. Things got worse quickly and the choice became my leg or my life. My life won. A below-knee amputation was done.

The doctors were excellent, the nurses knowledgeable and sympathetic, but there was no one to tell me what I could expect next. I knew what a prosthesis was and knew I'd be using one but had never actually seen one. I didn't even know whether it was glued or screwed on! Eventually, as most of us do, I learned not only how to walk but how to regain my active life as an amputee, camping, driving, flying stunt kites, and being employable. I never forgot, however, how dark and uncertain those first few weeks were.

Six years later, when I moved to Burlington, Ontario, I met a number of other enthusiastic amputees at Chedoke Hospital in Hamilton who also remembered those dark and uncertain days and shared my desire to help others bridge that dark gap from amputation to rehabilitation. Through the incredible efforts of these folks and with the support of all the hospital staff we officially formed "Chedoke Amputee Peer Support" (CAPS) in August of 1997. In six months, we'll be three years old.

**Governance** - Early on we decided we wanted to focus on "support," not "red tape." For that reason, it was decided that CAPS would not adopt the structure many other groups had of having By-Laws or an elected Board and Officers. We felt that would be too inflexible for the way we wanted to operate. Instead, we have a rotating "Chair" position, with other volunteers doing the traditional administrative jobs that need doing, each according to their interest and abilities. We only have elections if more than one person wants to compete for a job.

The rotating Chair position helps the members feel more involved. Each gets his or her chance to chair a meeting with the support of the rest of us and the guidance of an agenda. We have found this stimulates a feeling of being of value to the group, much as owning stock in one's company does. It also increases an individual's self-confidence while keeping the focus on the group and its mission. We've found that this method also stimulates new ideas while placing less stress on any one individual, thus reducing the likelihood of burnout.

We make most decisions informally, by group consensus. In the rare event that a vote is required on any matter, each dues paying member can cast a vote.

**Membership** - Since we're still relatively new, we have about 10 paid members (at \$15 per year) and a mailing list

of about 40, including physicians, social workers, and nurses. We meet twice a month on Wednesday evenings. Meeting attendance varies greatly depending upon the season, whether or not we have a guest speaker, and many other factors, but we average about 8 to 10 per meeting. Since our market area is fairly large, we expect our membership to increase. Hamilton, with a population of about 750,000, has five acute care hospitals. It is about a hour west of Toronto and an hour north of the Buffalo/Niagara, New York, area.

Our Relationship To Chedoke Hospital - CAPS is a completely independent support group that uses Chedoke Hospital as a meeting location. Although the Hospital has been gracious enough to provide us with a meeting room, phone, fax, and Internet access and we value the friendly atmosphere, they are not our sponsor. Our relationship with Chedoke is more like a partnership than a sponsorship.

For an example, being at Chedoke brings us into contact with other resident groups, such as spinal chord injury, stroke recovery, and brain injury groups, which, together with CAPS, maintain a shared Resource Center that pools books, videos, and other information that is available to patients, health care professionals, and the general public.

Another example: Chedoke has developed an annual day-long amputation symposium in which CAPS participates that is aimed mostly at health care professionals. Doctors, physical and occupational therapists, nurses, and dietitians attend to learn about gait training, prosthetic developments, skin care, and even the role humor plays in rehabilitation.

The health care system in Ontario does not provide for many "store-front" prosthetic facilities as in the United States. If one needs prosthetic services in Hamilton, for example, one usually goes to Chedoke Hospital. Since most amputees in our area come to Chedoke for rehabilitation services, we find that being close to its prosthetics and orthotics facility to be very helpful.

**Activities** - Other than our meetings, at which we usually have interesting and informative guest speakers, we have parties, picnics, barbecues and outings. We also have a visitation program staffed by trained visitors and an "Amputee Road Show" presentation, which takes us to other local primary care hospitals for short information exchanges with nurses, physical and occupational therapists, and other hospital staff on what new amputees can expect. This also provides an opportunity for us to market our visitation program.

We produce a monthly newsletter to keep our members informed about our activities and about world-wide amputee issues. By publishing our newsletter both in hard copy and on our CAPS Web site, we hope to encourage other similar groups to share ideas. Our web presence attracts an average of 400 hits per month.

The bottom line? We've done our best to keep the need to support each other as our principal priority. Presumptuous as it may sound, we've all decided that what we get back from our efforts far exceeds what we give!

## *Ask the Experts*

"We have a lot of members but we're having trouble getting them to come to our meetings. What can we do to keep them active?"

"We struggle with this like everyone else. Because our members pass away and drift away when they no longer feel they need support, we're constantly rebuilding our core group. Fortunately, many of those who drift away are still available as visitors even though they may not attend meetings regularly.

We've found that making reminder phone calls a few days before each meeting seems to help attendance. I also email everyone who has registered their email address with us. Even if they don't come, they know they're remembered.

"One of the problems our people have is transportation. Since so many of our active members have limitations themselves, it's hard for them to help others with wheelchairs and such. But we try to get the non-disabled people in the group to help.

"Location seems to be an issue as well. Alternating our meetings between two different locations helps people who come from different parts of the city. Also, because good food helps, we have our meetings at restaurants. People seem to look forward to having lunch while visiting. We try to have an interesting guest speaker each month, too. Having a wide variety of topics seems to help satisfy people with a wide variety of interests.

"Of course, we try to make new people feel welcome and part of the group, and we try to encourage their participation. We have recently discussed offering a free LEAPS T-shirt to each person who attends 3 of our monthly meetings a year. This might be a good incentive for them to attend regularly."

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"First, a caution. Interpreting relatively low attendance as a sign of "failure" can be risky! Attendance will be influenced by many things; time of year, location and time of meetings, weather, topics, etc. So the first thing to remember is that even if attendance is low, we are reaching those that are there! Then we can move on to deciding what we can do to reach those that aren't.

"Nothing can take the place of personal contact in trying to build attendance. One idea is to telephone some of those who don't come to meetings, tell them they are missed, and ask them what topics they would like to see addressed or are sorry they missed. Because

popular programs can sometimes be repeated at a different location or time, ask them whether that might motivate them to attend. If they need transportation assistance, you can try to line up a ride for them. If you have a committed core of members, ask them to help with these calls.

"Another idea is to involve folks by asking them to help with such jobs as writing, publishing, or mailing the newsletter, making meeting reminder calls, helping with fundraising efforts, helping to get new members, distributing flyers, or taking information about the group to their doctors, therapists, and prosthetists. It's hard for people to be involved in contributing in these ways and not attend meetings.

"In planning corrective action for poor meeting attendance, don't overlook your group's traditions and culture. For example, some groups may be so used to having a consistent schedule and location that people may not respond well to flexibility. For others, varying the day, time, and location may be the ticket to getting and keeping folks involved. Also, don't overlook geographic issues. For example, having meetings in various parts of the city may work in Denver, but other solutions may be required in a small town." Karen Gardner and Cindy Charlton, Co-Organizers Colorado UnLimbited Connection and Colorado Amputee Support Team "Greater Denver Area"

"For us, program content proved to be the answer to poor attendance. We were having a problem last year getting members to attend meetings. What we found was that we would attract four or five members unless we had a program of unusual interest. The breakthrough came when we were approached by a woman from the Governor's office who came and talked about the Americans With Disabilities Act. That program attracted about 30 members.

"Prosthetists are popular speakers also. We have a prosthetist here who is also an above-knee amputee. When he comes to conduct a gait clinic, we can always count on a good crowd. Any member who is having prosthesis problems can have those problems diagnosed objectively. In selecting a prosthetist to conduct such a clinic for you, the prosthetist must be carefully coached not to criticize other prosthetists, but instead to point out potential problems and suggest ways for the members to discuss the problems with their own prosthetists in a logical way. The members usually become so enthusiastic that they jump right into the spirit of it and want their prostheses looked at also.

"Another way to renew interest is to have a potluck or barbecue once in a while. We sometimes have potlucks at our regular meeting place. If you want to do this, be sure to check with the location's management to make sure you can bring your own food. Our twice-a-year barbecues are usually held at a volunteer member's home. These events usually draw 30 to 40 people.

"Another program feature our members are very enthusiastic about is the roundtable discussion where

each person is invited to ask questions or tell about his or her experiences. This usually degenerates into a very active discussion. Roundtables must be carefully moderated, however, to keep a few people from dominating the discussion.

"Finally, we have found that attendance is better when members are reminded by telephone of the meeting date, time, and subject."

Bill Cozad, President

Southern Nevada Amputee Support Group  
Las Vegas, Nevada

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Website: <http://www.usinter.net/wasa/lasvegas.html>

## Board Banter

by Marianne Rankin, Board Secretary

We haven't had a full Board meeting since the last Communicator issue so there's not much in the way of "new business" to tell you about. As you might expect, the recruitment of a new Executive Director is high on our priority list. Although there's nothing definitive to report yet on that score, we're working at it and we've seen a number of very good people. Also, we can tell you that arrangements for our annual meeting in Orlando are proceeding smoothly. The staff and meeting committee are doing a wonderful job and we anticipate having an excellent meeting featuring many improvements over past years.

We on the Board talk frequently about our "farm teams" of support groups and what we can do for them and vice versa. We are committed to our our peer support groups. We see the relationship between us as a symbiotic one. You, as support group leaders, are an important conduit for bi-directional information flow between the ACA and your members. Our Web page continues to grow and improve, and we hope you are telling your members how to access that site. We are deeply committed to improving access to our peer visitation training and, as reported elsewhere in this issue, we are attempting to leverage the impact of that training by teaching seminar leaders from your groups who can then respond more quickly to workshop requests nationwide.

Incorporating support group leader training into our annual meeting program is an example of our commitment to you and to the groups you serve. This newsletter is still another way we are trying to help you to improve your skills. Our hope is, the more skillful leaders you become, the larger and more successful your groups will become. Another hope is that by bringing training to group leaders we will encourage the establishment of new groups in cities that sorely need them.

The ACA is a large and growing repository of valuable information for people with limb loss. We can provide that information both directly to those who ask for it and through you to your group members. So ask us for what you need. We will do our best to help. Many of the requests we receive are from new amputees looking for a support group. We continue to be successful at referring those individuals to your groups.

We hope that through all of these initiatives, the bond between the ACA and support groups can become stronger. We believe the best way we can become stronger is by doing it together.

## *Better Late Than Never!* *Robert McFarland* *finally finds support* *group benefits.*

"My Harley - unfortunately, with me on it, - got hit 17 years ago and it cost me my right leg just below the knee. At the time, that wasn't my worst injury, though. I actually got to meet God and came back to tell about it!"

In the midst of Robert's anger and depression, he was visited in the hospital by a prosthetist named Rick, who also happened to be an amputee. "He was an inspiration," Robert says, "and we became fast friends."

Robert became rehabilitated and didn't feel the need to hook up with a support group. "Over the years," Robert continues, "I thought about how fortunate I was to have met someone who had been there and who could help me defuse my anger and understand what I'd be going through. I decided I needed to give the support Rick gave me back to others. Getting involved in RASP gave me an opportunity to do that."

Robert got involved in RASP less than a year ago. Now he is the Vice President and sees counseling as his strength. "Today, despite everything Rick did for me, I can see how much I missed by not becoming involved in a support group early on. They gave me some stuff to read in the hospital but, basically, I had to learn how to be an amputee almost by myself. I sure could have used some help in learning about shrinkage, what to do about the ulcers I got on my stump, and everything else."

Today, Robert finds real rewards in bringing support and encouragement to others and in helping others to learn the things he had to learn by himself. In Robert's words, "In the beginning, Rick was an inspiration to me. Now, I'm delighted that I'm in a position to be an inspiration to others!"

Robert McFarland  
Real Amputees Support People (RASP)  
Union City, Indiana

