

# The Northern California Chapter of The Neuropathy Association



## 2008 Annual Report

Presented April 27, 2009

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## **NCCNA 2008 Overview**

### **Board of Directors**

*At January 2008*

Bev Anderson, President  
Sandra Vinson, Vice President  
Penni L. Smith, Secretary  
Dick Ward, Treasurer  
Laura Niznik, Director

Charlotte Krale joined the board in May, but had to resign later in the year due to health problems. We greatly appreciated her insights and guidance while she was with us. In September, Sandra Vinson resigned from the board, but she has remained an active contributor as a Director Emeritus. Laura Niznik was elected Vice President. In November 2008, Suzanne Lieban was added to the board.

*Current Board (April 2009)*

Bev Anderson, President  
Laura Niznik, Vice President  
Dick Ward, Treasurer  
Penni L. Smith, Technical Director  
Michael Green, Director  
Amy Considine, Director

(Changes were made in January and April, which will be detailed in next year's report.)

### **Membership and Groups**

At the beginning of 2008, total membership was just under 500. There are always some who do not renew, so the number goes down when we remove them. We set our goal to break the 500 member mark in 2008. To our great surprise and delight, we ended the year at over 750 members. Again, we will lose some for non-renewals, so our goal

this year is to exceed 900. As our organization grows, we will be able to be a more influential and effective voice for hope and education.

In 2008, Penni Smith took on many of the membership chairperson's duties, and developed new ways of tracking membership and income. As a result, we have more comprehensive data about our membership than before. We expect even greater improvements as our information increases. We will be able to learn more about how to effectively meet our members' needs, as well as how to more efficiently administer the organization.

An example of some of this information can be found in appendix A and B.

We started 2008 with 32 support groups. We ended 2008 with 43 support groups. President Bev Anderson labored extensively, arranging for initial meetings and publicity, recruiting leaders, and developing interest in new areas. We are very close to having a group within driving distance of everyone in Northern California.

## **Events**

The NCCNA held its Annual Meeting on April 24, 2008, at the Sierra Health Foundation. With two helpful speakers and a demonstration of using poles for mobility, this became more of a mini-conference, and was well-attended. There was a short presentation of the Annual Report with opportunity given for questions and comments.

NCCNA again had a significant role at the annual Neuropathy Action Awareness Day in San Francisco on June 26. We presented one of the seminars: "Here's Hope – What You Need to Know About Neuropathy." Sue Ingle, Sandra Vinson, Charles Moore, Martha Chandley, and Bev Anderson participated. Bev Anderson received the "You Are Our Hero" award. We also filled a busload of attendees.

We participated in the CalPERS and CalTrans Health Fairs. Local groups also participated in health fairs in their area.

Bev Anderson attended the CalNeuro Alliance conference in March 2008. This includes a time of meeting with state legislators to discuss the issues presented at the conference.

### **Fundraising & Grants**

In 2008, we sent a mailing to members of the national organization (The Neuropathy Association—TNA) to alert them to our support network and ask them to consider joining. In both of our fundraising letters this year, we expanded our mailing to include people who had come to our groups, but not yet joined the organization, and the TNA members. We therefore emphasized membership as well as fundraising, and received a good response. This made a substantial difference in the number of members and the funds available to attain our goals.

Bill Heisinger provided a donation to purchase a camcorder and related equipment. We got it specifically to use at the Neuropathy Action Awareness Day, as well as having it available for other special presentations. We were unable to get an experienced operator for the Neuropathy Action Awareness Day, so we ended up without acceptable footage from that event. We expect to make more use of this equipment in 2009 and to develop some DVDs that can be distributed to our groups.

NCCNA applied for several grants last year, but was not selected to receive any. One challenge we have is that grantors like to fund specific projects, and we most need help with ongoing operations. We hope that having more complete financial information available, including an official 990, will make us more attractive to grantors.

### **Other Activities**

The Board regularly reviews policies and in 2008 updated the standing rules for the Board of Directors. We also approved policies on a variety of issues such as the discount program, mileage reimbursement, advisors, committee reports, and sexual harassment and discrimination.

Our brochure was revised and a major printing produced so that all groups would have brochures to put in locations like doctor's offices, senior centers, shoe stores, and any other place where people with neuropathy might access them.

We discussed other promotional items. Sandra Vinson had a small run of white t-shirts with the logo on them produced. We are also considering a different design on black. We ordered car door magnets for all group leaders. They are available to any member for \$7.

Bev Anderson, Sandra Vinson, and other members engaged in discussions about video projects, including educational material and a public service announcement.

The board deliberated and then decided to raise the annual dues to \$30. We had a special promotion for early renewals to renew at the 2008 cost. We hope to keep the dues at this level for a few years.

Dick Ward made a connection with the Small Business Center at Sacramento State. This is a student-based organization to train people who are taking courses toward a business degree. They will make some suggestions as to how NCCNA, especially the Board, could be more effective.

### **Financial Reorganization**

The most difficult and time consuming business in 2008 was coming to the point of having a budget of more than \$25,000 that triggered a requirement that a 990 EZ form be filed with IRS. We had some questions come up as we considered what this entailed. The Non-Profit Resource Center gave us a list of CPAs and attorneys that deal with non-profit issues, especially financial. We consulted one of the CPAs, and found some issues with how we were handling things.

We specifically learned the extent of our fiduciary responsibilities regarding how our support groups handled their funds. We would need much more extensive accounting procedures. We explored different viable solutions for organizing and managing the finances, and decided on a route that we felt best protected the organization and minimized the burden both on our board and on the groups.

With further consultation and much study, Treasurer Dick Ward approached the reorganization of our financial structure with a plan. Group funds will be handled through sub-accounts within the NCCNA account, rather than through separate bank

accounts (or a shoebox under the bed). This account will include the dues rebates the group gets, plus designated contributions to the group. People giving contributions can then be given a receipt which officially says it is tax deductible. (Individual groups cannot do this with legal authority.) We can track income and outgo with adequate documentation to meet government requirements.

This has been a difficult adjustment for us all. Dick Ward has had a great deal of work and has done a superb job of working this out. Some groups have been delighted that they had a "bank" and wouldn't have to deal with putting money in an account they had to deal with or storing more than they needed in a jar or coffee can. Other groups that had a bank account were upset that changes had to be made. The board has felt the stress, knowing that we had to do what we had to do, but also understanding the feelings of those having to make the changes.

At this point, April 27, 2009, the final touches are being made as the 990 EZ form is being prepared. Dick Ward , Treasurer, and Mike Green, Director and CPA, are teaming together to produce this.

A copy of our support group financial policy is included in appendix E. Please note that this policy is in effect, but we are continuing to refine and develop this, and there will be changes as we go along. We are committed to fully communicating what we are doing and why, so please contact the board with any questions you may have.

## **2008 Goals and Results**

*To use the Strategic Plan to advance this organization.*

The strategic plan was consulted throughout the year to make sure we were on track as we worked. We also had a day-long session in which we focused on the plan, examining what goals we had met and what still needed to be done.

*To organize additional support groups.*

Eleven additional groups were formed or forming.

*To develop the groups we have in place.*

President Bev Anderson made several trips to visit existing groups and provide encouragement and direction. We periodically provided educational and promotional material.

*To do a major project to connect with the health care community.*

In the absence of grant funds, we made a special appeal in our November fundraising letter for money to be able to do a mailing to neurologists in Northern California. The mailing would include information about our organization and a supply of brochures. All the groundwork for this mailing was done in 2008, but the mailing actually went out in early 2009.

*To have more of our members at the California NeuroAlliance Conference.*

Two members attended in 2008, and two are attending in 2009, which is occurring the day of our Annual Meeting. We are continuing this goal, and plan to have more attend the 2010 conference.

*To find more ways to encourage research.*

The newsletter carries announcements of clinical trials as we hear about ones that seem to fit us. Our budget for 2009 reflects a possibility of a contribution of size to The Neuropathy Association to support their research program. The Board chose to give a portion of dues and contributions received to assist with research.

## 2009 Goals

- Review and complete the portions of the Strategic Plan not yet done or due this year.
- Complete the support group structure that will fulfill our goal of a support group within driving distance of everyone in Northern California.
- Enhance our website.
- Fully develop one member of each support group to keep the group records in our membership system and to pull reports appropriate to the local group's need for information.
- Further refine our financial policies and procedures.
- Review and revise our bylaws, standing rules, and all existing policies and procedures.
- Design a handbook to guide and direct our support groups and their leaders.
- Begin work on a new strategic plan for our next few years.
- Produce and distribute a Public Service Announcement (PSA) to television channels and other forums throughout Northern California.
- Continue developing connections with the health care community.
- Examine ways to support research.
- Apply for and receive at least one grant.
- Consider additional ways to increase funding, perhaps including designing and testing a fundraising event and developing appropriate policy to guide its implementation.
- Have more members attend the California NeuroAlliance conference.

## **TREASURER'S REPORT**

Dick Ward, Treasurer

NCCNA started 2008 with \$13,820 in the bank which is an increase of \$7,955 over the previous year. We received \$41,600 and spent \$28,888 during the year, finishing the year with a balance of \$26,531. Memberships accounted for \$21,022 of our revenue in 2008 and contributions and grants provided another \$19,587.

Major expenses were brochures and other printing \$6,019 (21%), newsletter \$4,243 (15%), travel \$3,095 (11%), video system \$2,818 (10%), Support Group rebates \$2,200 (8%) and insurance \$2,000. (7%) These categories accounted for 72% of our expenses.

NCCNA is designated as a 501(c)(3) public charity which permits us to receive tax-exempt, charitable contributions. In the summer of 2008, your Treasurer became aware that the IRS requires these corporations to file an IRS 990EZ form if their annual revenue exceeds \$25,000. In consultation with a certified public accountant, it was determined that the NCCNA support groups did not constitute separate, tax exempt entities, that it was improper for the support groups to use the NCCNA EIN (employer identification number), nor should they use an individual's SSN to identify their business account. The Board decided it was prudent to return the funds kept at the Support Groups, except for a small petty cash fund, to NCCNA for safekeeping. This process has taken place over the last three months of 2008 and the first three months of 2009, and will become operational April 1, 2009.

Our budget for 2009 projects income of \$43,000, which is only 3.6% greater than 2008. Revenue projections are conservative because of the economic downturn. We project spending at \$44,800, including expenditures by the support groups.

The support groups are in the process of returning their surplus funds to NCCNA for safekeeping, and we are crediting their sub-accounts the amount of the rebates due them. Support group funds returned to NCCNA are being held in a support group reserve. This reserve is \$3,203.66 at the end of 2008 and it will be continued into future years at a value determined by the aggregate support group income (including rebates) and expenses.

2008 has been a very active financial year. Revenue is up 66% and expenses are up 63%. We started the year with \$13,820 in the bank and finished the year with \$26,531 there. This includes \$3,204 Support Group Reserves. The NCCNA members have been very generous with their contributions during the year. This has been salubrious because it permits us to budget a \$3,000 contribution toward neuropathy research in 2009 and still maintain a very healthy financial posture if we come close to our budgetary goals.

The NCCNA members deserve a WELL DONE!

See appendix C for our budget, D for support group cash flow, and E for our support group policy.