

## NEUROFIBROMATOSIS INC., CALIFORNIA



We are individuals and families whose lives have been impacted by Neurofibromatosis. We have come together out of our personal need for information and support.

[\[HOME\]](#)

[\[WHAT IS NF\]](#)

[\[ABOUT US\]](#)

[\[TAKE ACTION\]](#)

[\[EVENTS\]](#)

[\[RESOURCES\]](#)



## NEW WEBSITE

August 2006

Have you noticed the *new* great look of our website? The new NFC website went live on July 21, thanks to the outstanding job done by Audrey and her team at Cirkadia. We still have a few phases left to complete, but we now have a lot of information on the website about NF, fundraisers, educational meetings and events. What's great about our fundraising programs are they don't cost anything for you to participate, and NFC benefits. If you haven't seen our new website please stop by sometime and check out what's going on in California. We always welcome your suggestions. If you have information that you think others would benefit from hearing, please contact our office at 707-469-0467 or send us an email at [info@nfcalfornia.org](mailto:info@nfcalfornia.org)

With Audrey's help, we finally have an acronym that works for us—NFC. For two years we have been using Neurofibromatosis, Inc. California and NF, Inc. California wondering how we can make it short for those of us who know what NF is. From now on, "NFC" will stand for Neurofibromatosis, Inc. California in all our emails, articles, and mailings.

Now that we have a new look for our website, we would like a new logo. If you have experience designing logos and would like to take on a challenge, let us know.

## UPCOMING EVENTS

**September 30, 2006: NF Symposium** ~ Lunch and Learn Health Fair at Children's Hospital Los Angeles. Do you or someone you love have Neurofibromatosis? This is the place to be on September 30. Detailed information on this event is on the attached registration form. Our website will have the most current information about this event as well. Don't miss out register early.

**October 2006: NF Events** ~ Watch the NFC calendar for October events in your neighborhood (Redding and Bakersfield are making plans now). If we don't have an event going on in your neighborhood and you would like to help in getting one organized, please call Debbie Bell at 707-469-0467 or email her at [dbell@nfcalfornia.org](mailto:dbell@nfcalfornia.org)

NFC is looking forward to having several "Dinners under the Harvest Moon" throughout the month of October. Dinners will be held throughout California as a fundraiser and a way to raise awareness about Neurofibromatosis. NF is not rare, but so few people have heard of it and hosting a dinner is the perfect way to bring positive attention to this essential cause. These dinners can be held at a restaurant, church, home, school, or other community center. Please contact Debbie Bell at 707-469-0467 or by email at [dbell@nfcalfornia.org](mailto:dbell@nfcalfornia.org) for more information about bringing a "Dinner under the Harvest Moon" to your area.

**December 9, 2006: Holidays Around the World** ~ Holidays Around the World is a fun event for all ages and will take place in Vacaville on December 9, 2006 from 10:00 am to 2:00 pm. We want to celebrate the holidays with everyone; which will include activities for all ages. If you celebrate your holiday in a special way and would like to

share it at this event, let us know. If you are a teenager, we invite you to come to our Holidays Around the World. You can participate in all of the activities, or you can be a mentor to our younger kids as they decorate cookies, make fun crafts and eat lots of delicious food! Siblings and friends are always welcome.

**March 10, 2007: NF Steps** ~ Our annual “NF Steps ~ *moving forward with hope*” 5k fun run will take place at Vacaville’s Lagoon Valley Park. If you missed out on last year’s fun you will not want to miss the 2007 event. The “2006 NF Steps” had lots of fun, food, clowns, vendors, live music, and time to make new friends. We are already getting things lined up for March 10, so mark your calendars. We want to see you there! If you would like to volunteer the day of the event or with the preparation work, please contact Debbie Bell at 707-469-0467 or by email at [dbell@nfcalfornia.org](mailto:dbell@nfcalfornia.org)

## MAILING LIST

With our new website we now are able to send our members email newsletters and email blasts. With this great tool we will be able to keep you updated with NF information throughout the year. Do we have your email address? If you did not receive any of the email blasts sent since July 21, 2006 either we don’t have your email address or you need to add us to your email address book to avoid our email being deleted by a spam blocker. Visit the following link <http://www.nfcalfornia.org/maillinglistsignup.aspx> to join our mailing list and receive the most recent information.

There are several ways you can help NFC save money.

- ♥ Are you receiving this mailing at the correct address?
- ♥ Do you have family members or friends who would like to receive information from NFC? Have them join our mailing list by going to the following link: <http://www.nfcalfornia.org/maillinglistsignup.aspx>
- ♥ Do you have an email address and would like to receive all our communications by email? Help NFC save money by electing to receive communications by email only. Visit [www.nfcalfornia.org](http://www.nfcalfornia.org) click on the paperless link.
- ♥ If you don’t have an email address, do you have a family member or friend who would share our emails with you? From time to time we will have time sensitive information that will not be able to wait for our newsletter. An email address will help us keep you current with information from NFC.
- ♥ Everyone who updates or confirms their contact information by using our website or by mailing in a confirmation will be entered into a drawing for \$20.00 gift certificate to Block Bluster. The winner will be drawn on October 10. You can mail the following information to P.O. Box 1234, Vacaville, CA 95696

Full name	Full mailing address	Email Address
Phone Number	Do you have NF1/NF2/ Schwannomatosis	What can we do to help you?
Primary Physician	Who is affect by NF and year of birth	Other Specialist you see?

## ON THE HILL

“Dear Colleague” letters went out to House of Representatives on August 8, 2006. For some you have been helping us with letter signing for two years; however this may be your first time hearing about the “Dear Colleague” letter. This action is crucial to the future of NF research. Some of the most important advances in the fight to find the cure for NF have been made as a result of the Department of Defense Congressionally Directed Medical Research Program (CDMRP). The benefits of this program have been huge. However, due to budget cuts and the war in Iraq we are in danger of losing the DOD’s NF research program. **We need your help to keep this program going.**

We must act now! Please remember, Senators and Congressmen/women want to hear from residents of their state, and the best way to contact them is by fax or email. Visit the following link for samples letter and how to find your representative <http://www.nfcalifornia.org/WriteCongress.aspx> We have a deadline of September 6, 2006 to get as many signed letters to our Senators and Congressmen/women to encourage them to sign the House or Senate letter. Print our letters off and ask family and friends for signatures. If you have any questions or receive any feedback from your Senator or congressmen/women please let us know by sending Debbie Bell an email at: [dbell@nfcalifornia.org](mailto:dbell@nfcalifornia.org) or by calling the office at 707-469-0467.

## RESEARCH

The Department of Defense Neurofibromatosis Research Program (NFRP) is launching a request for information (RFI) regarding NF research and seeks your input. Scientists and Advocates for neurofibromatosis research are being asked three brief questions to target financial support to critical areas of neurofibromatosis research.

To find out more please go to their website for instructions on how to provide your opinions for future research: <http://cdmrp.army.mil/nfrp/RFIPL.htm>. The deadline for sending your response to the RFI is August 31, 2006.

## CORPORATE SPONSORS

We are ready to work on several projects and just received all our quotes. This is where the hard work begins. Our quotes total \$20,000.00; we need help reaching corporate sponsors. Do you work for someone you would like NFC to contact? Do you know someone you would like NFC to contact? With your connections we can make the following projects possible:

**Project #1 *NF Buddies Book*** We are excited about our children's book that will be available soon. "NF Buddies" is a photo essay of a child's perspective of Neurofibromatosis. *It explains why children with NF have so many doctors' appointments, and lets them know a little of what they might expect.* It includes pictures of children with NF and a few of the challenges they face. Written from a child's perspective, "NF Buddies" handles these issues in the way a child would – very matter of fact and full of hope. The book will be an excellent way to introduce families to NF. It also will provide a natural way for children to introduce NF to their friends and teachers. We hope that you also are inspired by this project and are as excited as we are to share it with the world.

**Project #2 *NF Steps ~ moving forward with hope*** 5k fun run We are in need of financing to get this project running! If you have any contacts that may be of help, please contact us. If you are able to provide in kind donations of screen printing, embroidery, printing of walk related materials, etc., please send Debbie Bell an email at: [dbell@nfcalifornia.org](mailto:dbell@nfcalifornia.org) or by calling the office at 707-469-0467

**Project #3 *NF tri fold brochure*** We have designed a brochure that we can send to our NF doctors in hopes that we can reach out to more NF patients. This brochure is very important to all of us, because we all want to meet others in our home towns that are affected by NF. By reaching out to more doctors offices we will be able to put you in contact with others. If you see one or more doctors, we want to send them a packet, to do so we need their names and addresses. Please mail your doctor's information to NF, Inc. California, P.O. Box 1234, Vacaville, CA 95696 or email to [dbell@nfcalifornia.org](mailto:dbell@nfcalifornia.org).

Do you see a project that catches your eye or do they all sound great? Help us move forward by contacting a service group (Rotary, Kiwanis, Lions, Elks), local business or the company you work for!

**Be a Star.....Join the *NFC t.e.a.m. (together~everyone~achieves~more)***

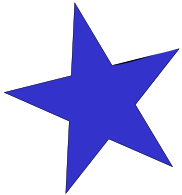
## PAST EVENTS

Most of our time over the past 4 months has been devoted to building our new website and planning for next year, In addition we had the following events:

**July 22 *First informational meeting in Redding:*** What a great first meeting! 5 families showed up for an afternoon gathering. KRCR The Redding TV news station came to the meeting and did a great job covering our NF meeting. We were able to connect with new NF families, and are all looking forward to Redding being on our California NF map for educational and support group meetings, fundraisers, events and more!! Thank you Tracey Ortega for organizing this wonderful event. If you or someone you know interested in the Redding area events you can contact Tracey Ortega at 530-221-5171

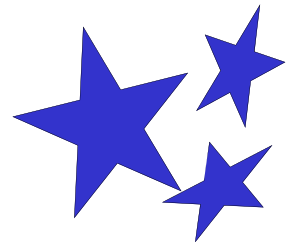
**August 3** was NF night at ***Boomers*** in Fountain Valley. Our NF friends and families had time to talk while playing in the batting cages, bumper boats, gameroom, go karts, kiddie rides, kidopolis, miniature golf, rock wall and the bombers café!. Boomers “A place where the *FUN* rules” was a fun filled fundraiser for NFC. Thru our NF booth we were able to educate new individuals to NF. Thank ***Boomers*** for sponsoring this event!!

**August 5** was NF night at the ***Thunderbirds*** baseball stadium in Vacaville. The Solano Thunderbirds baseball game on was a fun family event. 31 friends of NFC attended the game, including three children with Neurofibromatosis. With record attendance that evening, 2,000 people had the opportunity to learn about NF. Fans who visited our information booth had to say “Neurofibromatosis” to receive a door prize. The door prizes where donated by **local businesses**. During the game two preschoolers from the NFC group were invited to participate in the special between-inning events, and several of the grade school children joined in the Fleet Feet shoe toss game. The fireworks were a special treat, and running the bases after the game was great fun, too. Thank you Solano Thunderbirds for a great evening!



**Be a *Star...***

**Join the *NFC t.e.a.m.***



Start Cartridge Recycling in your home town

Deliver NFC brochures to doctor's offices

Confirm your contact information

Be a coordinator in your town

Spread the word about NF

Volunteer in Vacaville

Come to an NF event

Help with foot work

Collect donations

Write Congress

And more

We have several projects if you are ready to take one on. Big or small project, we can use your help. Donations are always welcome and appreciated. Our biggest expense is photo copying and postage. We can use monetary donations, Frequent Flyer airline tickets, savings for hotels, gift cards for office supplies, copy services. Our biggest need is a full size copier. If you have any leads on how we can get a copier, please contact us. Our own copier would really help us save money for our other NFC events.

Thank you for being supportive over the past few years. NFC has been crawling for a while, and now it's time for us to start walking. We hope that you are as excited as we are about our progress and want to be part of our *NFC t.e.a.m.*