



What we are NOT: Clarifying Misconceptions about us and our role Care4Dystonia, Inc.

We've received a number of emails pertaining to a few issues.

1) **Sending Donations** : Donations can be sent to C4D by printing out the [Donation Form Page](#) and forwarding it to C4D by mail. We do not, as yet, have a web page through which donations can be made online. Care4Dystonia, to date, has NOT embarked on a full scale fundraising campaign as We recognize the following trends in the nonprofit sector :

- ▶ The pool of American donors is shrinking and experiencing a crisis of confidence in many of the nation's charities, according to recent surveys.
- ▶ Fifty-eight percent of donors say they dropped their financial support of a nonprofit because they felt that the organization was no longer trustworthy or reliable.
- ▶ A shrinking donor pool along with diminished loyalty and trust to specific organizations has created a tenuous situation for the philanthropic sector." The Dystonia sector has not been immune to these trends. You can learn more about current trends in the nonprofit sector in [the NPTimes](#).

While donations are welcomed by C4D our emphasis is on a greater awareness of Dystonia, improved care rather than on seeking a cure for the condition, which realistically will not occur as suggested in 2000 in " 2 to 3 years".

2) **Affiliation with other Dystonia groups** : Several emails have been received which assume C4D " is " The Dystonia Medical Research Foundation (DMRF). C4D does not represent this foundation; neither is it involved in any of its' activities. We are a separate (independent) organization, clearly focused with an entirely different [Mission Statement](#) which involves Public Awareness, Collaboration and Education - setting the [PACE](#). C4D does not fundraise for benchmark research - such activities are carried out by organizations such as the [Bachmann-Strauss Dystonia & Parkinson's Foundation](#) and the DMRF. We applaud their (BSDPF) success in raising in excess of \$1 million dollars during this year's 2004 Annual Golf Invitational. We do assist organizations such as www.spasmodictorticollis.org in their yearly Raffle Golf Tournament if asked by them.

3) **Issues of collaboration vs domination** : At Care4Dystonia, we believe in the spirit of collaboration which we define thru words such as " group effort, alliance, rapport, non-dominance, cooperation and recognition of teamwork". There has been increasing efforts in 2004 to intensify dominance and power amongst the Dystonia Nonprofit sector. Dominance and power will not increase falling membership attrition rates, trust, loyalty, volunteerism, research dollars, or increase public awareness of dystonia. It will only add to negativism surrounding the dystonia arena that already exists due to a large part because of a lack of a cure for all forms of dystonia. As the saying goes " what comes around , goes around". WE will continue to focus on " care until a cure"- a realistic mission.

We have continued to provide selfless promotion of other groups in the area of public awareness to the media; provided media contact information, use of our educational material, and other acts of kindness despite the surging drive for dominance by other groups. Without a doubt collaboration is necessary not only verbally, but also needs to be seen in action; so that the lives of those with dystonia improves quickly.

If you have questions or concerns, always feel free to email us at infoc4d@aol.com.