

PEOPLE FROM ALL OVER THE COUNTRY and the world responded to RSDSA's recent e-mail regarding volunteering with CRPS, and confirmed what I had suspected: people with CRPS might experience physical limitations, but are unlimited in their energy and desire to be part of the world. These responses were as varied and unique as the paths of CRPS. Underlying each response was the common need to interact, to be of assistance, and to put *something* or *someone* ahead of their CRPS—even if only for a few moments.

those who think they can't do anything to do this.

### Christine Kiernan

I HAVE MY OWN NOT-FOR-PROFIT 501(c)3 animal rescue help site. I host fundraisers to offset the high cost of veterinary care needed for abused and neglected animals. I have also started a year-round dog bedding drive, where I



the purest sense of heaven I have ever felt. It makes the fact that I cannot work a little less important, and it keeps me from sinking into a depression. These animals do not see any fault in me or the emotional or physical pain I am suffering from. They see someone who loves them unconditionally, and prays for a loving new home for them. Being there for these animals helps me, and we can help heal each other. That creates a strong bond, which is why I continue fundraising for veterinary care and making my pet beds.

### Rebecca

I AM A CORID VOLUNTEER WITH ALATEEN. I offer rides to people who need to do errands and or get to different types of 12-Step meetings. I collect new and used clothing, household items, and personal goods for kids who are given temporary shelter at a 12-bed RFK Children's Action Corps teen foster facility nearby. I also work with the Cape Cod Time Bank, where I offer services, and in return get time credited to an account. This past winter a friend and I helped teach teens at the facility knitting, and we will hopefully start classes again next fall. I am also waiting to be CORID by the RFK so that I can teach an art class one day a week, help with field trips, and be a nonjudgmental ear for kids who feel they can't read.

### Amber Wiseman

I AGREE THAT VOLUNTEERING GIVES ME A purpose, and it can even distract me from pain at times. There is a quote I heard some time ago that says, "There is tremendous happiness in making others happy, despite our own situations." I find this very appropriate in spite of the pain associated with CRPS. Just last week, I volunteered at my church's vacation Bible school (VBS). In previous years, I had been a classroom assistant or leader, and loved working with the

# Giving Back

*Edited by Stefani Kronk*

From the plethora of unique ideas, the possibilities seem endless! The following testimonials are an excerpt from our upcoming brochure on giving back.

### Lori Launius

I HAD A REALLY HARD TIME WHEN I LOST my dream job to CRPS. I went from a challenging, multitasking position working for the senior vice president of marketing at a life insurance company to being housebound (now mostly bedbound), and not being able to remember things. It's hard on your self-esteem. I have been growing my hair for Locks of Love ([www.locksoflove.org](http://www.locksoflove.org)), a not-for-profit organization that provides hairpieces to financially disadvantaged children suffering from long-term medical hair loss. I have about three and a half feet of hair to cut right now. I would have never been able to grow it this long or have it be so healthy if I was not bedbound. I'd love to encourage

collect old material such as comforters, blankets, towels—anything that can be used or sewn into a soft, comfortable pet bed for an abused or abandoned animal. I then help make beds out of the materials that are donated. To date, I have made 350 dog beds! Items such as crates, kennels, collars, food bowls, leashes, toys, and food are collected as well. Each animal is also immunized, spayed, or neutered, and fully groomed when they first come into the rescue. Their injuries or illnesses are also cared for.

This opportunity has been wonderful for me, because it makes me feel good knowing that I am helping those innocent animals and I can work at my own pace. When a frightened animal that has been abused comes up to me all on its own, it fills me with the greatest feeling of joy and hope. I know they will never be hurt again, or neglected and thrown away like garbage. This is

kids. I knew this year things would be different, because I couldn't keep up with a class full of excited kids, so I volunteered for a calmer position teaching Bible lessons. I actually found that I enjoyed teaching my third and fourth graders about loving God more than I enjoyed chasing them around. Another volunteer activity I do is visiting nursing homes and talking with the residents. Sometimes I bring one of my pets (a dog, rabbit, or cat), but I also like to visit by myself. Some of the residents' stories are fascinating, but we often sit in silence, too. A particular resident who was born with spina bifida and I are doing a Bible study together about living through the tough times, because we both have questions about how God can allow us to suffer. I find in particular that some of the residents can offer me advice from the wisdom they've gained from their years of living. Just the other day, a resident reminded me that I should be living each day for all it's worth rather than worrying about the next day.



I think of other ways to help, particularly with CRPS promotion. Currently, I am working on a website to help communicate information about CRPS to the world. I know I have a higher ability of functioning than some people with CRPS, but I would encourage each person to find something

to help others. It could be as simple as making a phone call, sending an e-mail, or mailing a card. It is amazing how caring for others makes life better.

### Jennifer Kippin

I VOLUNTEER AT MY LOCAL CHURCH. I TEACH a group called Kids Zone for children ages 6 to 12 that meets on Thursday nights. Kids Zone is going into its fifth year in January 2010. Once a month, I also teach a lesson for BGMC—Boys and Girls Mission Crusade, which raises money for missionaries our church supports. Those children are also ages 6 to 12. I have also taught a few younger children as well as teens.

I truly enjoy teaching children. I believe it is a God-given gift. I have taught children for over 20 years now, and even being diagnosed with CRPS seven years ago couldn't take that part of me away. There was a time for a year when I needed to step away from volunteering. But after I

got the CRPS managed and the chronic hives were healed, I was able to continue. I feel it is important to volunteer your time no matter what you can give, a little or a lot. I need to keep my mind on things that matter—and these children all matter to me—not on things that don't

matter, like feeling sorry for myself or wallowing in the pain. I don't have time to waste feeling sorry for myself! I feel like I am offering these kids a piece of myself, the belief that no matter what comes up in life, keep going! Many of



these children come from broken homes, abuse, and poverty. But I can offer them encouragement, love, and joy. I can offer them God's love even when life throws them a curveball. If I can bring these things into a young child's life, they will bring them into their lives as adults. Plus, the smile on these kids' faces fills me with love and joy, and it encourages me to keep moving forward!

### Tammi Crumm

WE HAVE A SECONDHAND STORE in our community of about 300 that serves those going through a hard time. We cooperate on a volunteer basis for workers and donations. The donations can be anything you can think of, from furniture down to a potholder. All items are 50 cents a piece, no matter what. We also provide free food baskets, and provide holiday meals to those who sign up. At school time, we provide haircuts, new shoes, and backpacks full of age-appropriate materials for children. We also offer monthly ongoing classes on topics such as getting out of debt, coupon usage, and family planning.

I volunteer once a month, but because I live close to the store, I am often called upon to assist. There are times I have to leave due to pain, or I might not be able to go in at all, but I enjoy it so much. It goes a long way towards dispelling depression.

### Deb Walsh

I KEEP MYSELF BUSY WITH MISSING PERSONS cases. My interest was first piqued by a missing child in my area. He was 12 years old when he went missing on November 1, 2007. Sadly, he is still missing today, but that boy has touched my heart, and through him I have met people I otherwise wouldn't have met. If you're new to an area, are homebound, and do not work or have children, how do you meet people? It can be very hard, but through the computer and doing what little I can—forwarding e-mails, printing posters, calling companies for help, asking for donations—I have been able to meet people.

I have recently gotten involved with the case of a woman in the next town who

went missing on September 30, 2008. Through this I have met the person who has become my best friend. I have spent many hours helping raise money for benefits, for searches, calling printers

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to do posters, and reaching out to the community for help, which they're willing to do if you just ask. We had a spaghetti supper, which raised money for the case. I have made many calls, and the missing

woman's last place of employment has donated things towards the next search.

I have found that I can make good use of my time by calling and e-mailing. Because of my condition, I've had many days when I've felt useless and worthless, but helping with these cases is a way I can still feel useful. Families of missing people do not know what to do. They are so full of grief, they are lost themselves. Anything you can do to help them is welcome. I thought: this could be my child, sister, aunt, mother, or brother. I know I would welcome any help, so I decided I was not going to sit here and do nothing any longer. I was going to do something, and this work has been very, very satisfying to me. I have learned a lot, and no longer look at missing people as a face on a milk carton. ■

*Support for the Giving Back Project has been received from the Frank J. Anton Foundation, Petit Family Foundation, and Crane Fund For Widows and Children.*

## Join RSDSA

**PEOPLE WHO JOIN RSDSA ARE NOT CONTENT** to be victims, but take an active role in our goals of education, awareness, and research. Our members are people like you—patients, family and friends, healthcare professionals, attorneys, and business people who understand the devastating effects of CRPS and want to make a difference. Your RSDSA membership is important. There is power in numbers and we would like to see our membership, currently more than 6,000, double so that when we talk to the legislature, the pharmaceutical companies, and medical associations, our voice is strong and our message is clear.

As a member, you have a forum to communicate your concerns, share your experiences, and learn about the most recent advances in treatment and research. Fill out the membership application and join today!

### YES! I would like to be a member and support RSDSA

- Patient (US) \$20       Patient (outside US) \$25  
 Can't afford membership       Additional donation

NAME .....

ADDRESS .....

CITY ..... STATE ..... ZIP .....

PHONE ..... EMAIL .....

- Please send me information on starting a support group.

For credit card orders, please complete:

- Visa  MasterCard  American Express

CARD NUMBER ..... EXP. DATE .....

SIGNATURE .....

**Please make check or money order in \$US payable to RSDSA. Mail your check with this form to:**  
RSDSA, 99 Cherry Street, PO Box 502, Milford, CT, 06460

