The Addition of a New RSDSA Program Offers New Hope

BY LINDA LANG, RSDSA BOARD MEMBER & CO-CHAIR RSDSA SUPPORT & ADVOCACY COMMITTEE

Living with the chronic pain and disability of RSD/CRPS is a tremendous challenge. The loss of who you were before the syndrome struck, the loss of financial security and even the loss of loved ones complicates things further. Add to that the feelings of uselessness, isolation, hopelessness and even deep depression and you have a formula for a life that doesn’t seem worth living. This was my life for many years and many of you may recognize it as yours as well.

Right now there is no one medical treatment that helps everyone. The best treatment we know of for the time being is support. The Support Committee has established a new program we call Peer-to-Peer Conversations. We know that support groups work to help those with RSD achieve more fulfilling lives. This is an individual kind of support that we believe will have the same positive results. Well-screened volunteers have committed to supporting those of you who are struggling with their lives. This will provide a conversation between equals, a conversation that will help you learn from each other to develop more satisfactory lives. You will feel freer to reveal your fears and your concerns because the person at the other end of the line will have experienced them as well. The end goal is to see yourself not as a disease, but as someone who happens to have RSD. RSDSA will help with information, tools and advice.

Science has discovered an interesting fact: your brain cannot process two sets of information at once. This means that you cannot feel pain while you are concentrating on something else. It is a matter of finding those things that can hold your interest. One Veteran with RSD told me he was more surprised than anyone else to discover he loved making jewelry. This has become his passion and he has been able to develop it into a business. With patience and encouragement, each of us can find something we love to do even though we have CRPS. The possibilities are almost endless— it can be photography, art, or writing a story for a child. Some help others as a way of helping themselves. Whatever you find, it will help shape your life with a sense of purpose and a sense of pride. Uselessness and hopelessness will no longer be a part of your vocabulary.

Living with CRPS is a journey. Some of us get stuck at the very beginning, living a life defined by pain. Sometimes change itself is so difficult that we chose to live with the pain we know rather than take the chance on bettering our lives. This is the definition of being stuck. If we announced that medicine had come up with a treatment that would take away a good deal of the pain of CRPS with no harmful side-effects, we would probably all take advantage of it. This is no different. You just need to take a chance on bettering your lives. You need to find the courage to take the first step so that you are no longer stuck.

If you wish to volunteer, you will learn a lot from this experience. Please email me at LindaLang@rsds.org and tell me something about yourself. Include your email and a phone number. We especially need more teens and parents of children with CRPS.

If you wish to take advantage of this program, again email me at LindaLang@rsds.org, provide your email, phone number, and some brief information about yourself. We would like to match teens with teens, men with men, parents with other parents, etc. so that all peers will be able to share the same kinds of experiences.

It is our sincere hope that many of you will find the courage to involve yourself in this program. It is the best hope we have to change our CRPS community from victims to strong human beings, human beings who can come together to help make all of our lives better. Perhaps that strength can even translate into working together to find a cure for this disease.

See more about the new Peer-to-Peer program on the back cover.