

NEW SELF-HELP GROUPS AND GUIDES: A ROUNDUP

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ABSTRACT

New types of self-help support groups continue to develop to meet people's needs for understanding, support, and advocacy. The following information was compiled by the American Self-Help Clearinghouse, which provides information on existing groups and also helps those individuals interested in starting new mutual help support groups and networks that do not yet exist. For more information, contact them in New Jersey at 973-625-3037 or e-mail them at ASHC@cybernex.net

DOMESTIC VIOLENCE ANONYMOUS

Domestic Violence Anonymous indicates it is an international self-help group with thirty-two affiliated meetings that use a twelve-step spiritual approach to help men and women, who have suffered as an adult or as a child, to recover from domestic violence. Their purpose is to overcome domestic violence and to carry the message of recovery to those who still suffer. DVA welcomes members who want to share their experience, strength, honesty, and hope in order to recover from domestic violence. Write to them c/o BayLaw Inc., P.O. Box 29011, San Francisco, CA 94129. Call (415) 681-4850.

INTERNATIONAL REFLEX SYMPATHETIC COALITION

Founded in 1998, the Coalition of reflex sympathetic dystrophy self-help support groups and affiliated members is dedicated to tapping the experience and abilities of patients and families in their efforts to empower and help one another. It was cofounded by Audrey Thomas, who also cofounded the RSD Syndrome Association in the U.S.A. back in 1984. In addition to providing support

and education, the Coalition plans to advocate for needed understanding, treatment, and research of RSD worldwide. Write to them at P.O. Box 771, San Marcos, CA 92079-0771.

HPV SUPPORT GROUPS

In the last several years, sixteen new self-help groups for human papillomavirus (HPV) have developed across the U.S.A., especially in the larger urban areas. HPV is one of the most common causes of sexually transmitted disease (STD) in this country. It is estimated that as many as forty million Americans are infected with HPV, and the incidence of this disease appears to be increasing. Several types of HPV can lead to genital warts, the most recognizable sign of genital HPV infection. Certain other types of HPV have been closely associated with the development of cervical cancer and other genital cancers. For information on HPV and the HPV support groups, call the Center for Disease Control's (CDC's) National STD (Sexually Transmitted Diseases) Hotline from 8 A.M. to 11 P.M. ET, weekdays at 1-800-227-8922.

AIR CRASH SURVIVORS

While there are existing self-help support groups for families of those killed in major plane crashes (e.g., Pan Am 103 or TWA 800 families), "Wings of Light" is a new Mutual Support Organization for any air crash survivor. The support network is actually developing as three separate support networks for those: 1) who have lost a loved one in an aircraft accident; 2) who have survived an air crash, or 3) have been adversely affected by their participation in rescue/recovery efforts. This support, information, and advocacy organization was started by Andrea Waas, who lost her father in a private aircraft accident. For more information, send an SASE to: Andrea Waas, Wings of Light, Inc., Suite 1, 16845 N. 29th Ave., Phoenix, AZ 85053.

In helping several TWA 800 families, the American Self-Help Clearinghouse contacted Betty Polec, who had cofounded the still active "Flight 255—the Spirit Lives On" group, a month after the Northwest Airlines Flight crashed in 1987 on takeoff from Detroit Metropolitan Airport, killing 156 people. Since Betty lost her pregnant daughter and son-in-law in that crash, she and other group members have helped families of subsequent crashes. She said there are no recipes, that the deep-down gut pain will definitely go away, but that some of the pain will always remain. She said that "initially its not that you want to die, but that you just don't know how to live." Finally, she mentioned how her group, after many meetings (where they shared and, in so doing, took away a little of

the pain) and memorials (“honoring them because they lived, not because they died”), now can even laugh together.

LATEX ALLERGY

Suddenly latex allergy has become a serious and sometimes deadly problem for medical professionals and some patients. In response to the problems for which there is no known cause, the self-help organization ELASTIC (Education for Latex Allergy, Support Team & Information Coalition) has developed to provide information and emotional support to latex allergic individuals and their families. The group, which has over a dozen local chapters across the country, is promoting a better understanding of latex hypersensitivity problems. According to one of the founders, Elizabeth C. Borel, a dentist who, like many of the other members, is unable to continue her practice:

One of the most frightening aspects of coping with an allergy to latex is the lack of information and standardized treatment. The people one depends on the most during a medical crisis, physicians and hospitals, often are at a loss of how to provide medical treatment and prevent further exposure to latex products prevalent in the healthcare setting.

For more information, contact Elizabeth C. Borel, DMD, 196 Pheasant Run Rd., West Chester, PA 19380 or at her Internet address: 102246.126@compuserve.com

HEPATITIS C SELF-HELP GROUPS

These are among the latest type of group to develop in the United States. One estimate is that about 150,000 new cases of hepatitis C virus (HCV) infection now occur in the United States annually. Barbara Ramirez and Steve Longello co-founded one of the first groups, which meets weekly in Philadelphia. Being a nurse, Barbara was acutely aware of the lack of information, support, and services available to people living with HCV. The group has become incorporated as the Hepatitis C Foundation, with the hope that one day they may find funding to operate as a national resource. The group’s primary objectives include providing: emotional support (“Never again do we want to feel that people are out there feeling ‘alone’ or ‘isolated’”), information on the disease itself, current treatments, options, statistics, and physicians on the front lines. If one is interested in starting such a local group, the Philadelphia group is willing to help. Call Steve at 215-672-2606.

CHILDREN BORN WITH POTTER SYNDROME

These children are characterized by facial anomalies, limb deformities, and hypoplastic or absent kidneys. Evy Wright has founded a National Potter Syndrome Support Group network for other parents and families affected by this disorder. Contact her at 3501 Curry Lane, #1208, Abilene, Texas 79606; phone 915-692-0831.

THERAPISTS IN RECOVERY

This is not a new 12-step support group. It was started in San Diego, California in 1987 as a local group for licensed therapists in recovery from alcohol or drug addiction. But it has been helping more therapists in other areas of the world to start new TIR groups. Members must first belong to a primary 12-step recovery group before joining TIR. For anyone interested in starting a TIR, contact the American Clearinghouse for current contact information.

SPOUSES OF POLICE OFFICERS

Two new self-help support groups have only recently developed in response to the needs of spouses of police officers—the Police Officers Emotional Support Team in Virginia, and S.E.E.D.S. (Spiritual, Educational, Emotional, Directional, & Social) in Nashville, Tennessee. Laurie Beth Duffy, who had started a “Concerns Of Law Enforcement Spouses” or COLES national newsletter for police spouses, is now working on the development of a how-to guide for starting spouse groups. For updated information, contact Ed Madara at the Clearinghouse.

VARIETY OF GUIDES

Starting and Sustaining Genetic Support Groups is an excellent new resource guide, filled with many practical examples and suggestions. Coauthored by Joan Weiss and Jayne Machta, the 152-page manual was published by the Johns Hopkins Press. One can order a copy in the U.S.A. by calling JHP in Baltimore at 1-800-537-5487 and billing the \$18.95 plus \$3.00 postage to a credit card or write JHP, 2715 N. Charles St., Baltimore, MD 21218.

Dr. Tom Ferguson’s *Health Online* (Addison-Wesley Publishing, 1996) is the first comprehensive guide to exploring the breadth of the online world of mutual aid self-help groups and support networks. Tom, who served as Medical Editor of both the very first and most recent edition of the *Whole Earth Catalog*, now reflects the stories, places, and ways that this new world of mutual help groups is

rapidly-growing. Tom also explains the context and implications for the rise of this new type of grass-roots, "consumer health informatics" resources. It is, as Tom explains, "information shared in the context of community" that is the very foundation of these new online networks.

Self-Help Groups: Getting Started, Keeping Going (2nd Edition, 1998) by Judy Wilson and Jan Myers. Seventeen chapters cover the basics of group development in detail, from "What is a Self-Help Group" to "Evaluating Your Work." It also includes chapters like "Relationships with Local Professionals" and "Ending a Group with Dignity." Judy Wilson is now Director of the Long-Term Medical Conditions Alliance in Britain. Jan Myers is her successor as Director of Self Help Nottingham. Published by R. A. Wilson, Nottingham, 1998. UK price £7.99, or by post, £9.49 postpaid by calling Freephone 0500-47-171. From abroad: Euro 15, order from: R. A. Wilson, Publisher, c/o Susan Davis Marketing, 40 Devon Drive, Sherwood, Nottingham NG5 2EN. From U.S.A., \$US17.50 postpaid from American Self-Help Clearinghouse, Denville, NJ 07834-2995.

The Resource Guide for Those with Facial Differences & Their Families, is annually published by Betsy Wilson, director of "Let's Face It," a national support network for people with facial abnormalities and their families. The fifty-page guide contains a wealth of information on parent support networks for specific illnesses to Internet resources, from patient education guides to autobiographical books written by those "who have been there." The back cover carries a statement by Betsy Wilson that "For many individuals who have felt alone in the world, our support networks offer the first opportunity to meet others who know how they feel. By sharing and caring, we can make a difference in each other's lives." To receive a free copy in the U.S.A., send a 9 by 12 inch mailing envelope with \$3 postage on it, along with a note telling them about yourself, to: Let's Face It, P.O. Box 29972, Bellingham, WA 98228-1972.