

13th European Experts Meeting on Self-Help Support

May 13th 2015, Chania, Greece

The Ups and Downs of Self-Help Support in the USA

Edward J. Madara, M.S.

Founder & Former Director

**New Jersey & American
Self-Help Group Clearinghouses**

edmadara@Verizon.net

**Greece is the most appropriate place
for an Int'l Conference on
Self-Help Groups because of it's ...**

1. World's first and greatest epic storytellers who inspired storyhearers with tales of struggle, fear, courage, longing, grief, hope, triumph, and meaning."

2. The World's Cradle of Democracy.

1. The Positive Roles of Storytelling

The **positive roles of Storytelling in groups** has received increased attention over the last twenty-five years – from Ernest Kurtz & Katherine Ketcham’s views on how the practice is a central activity of Alcoholics Anonymous (1992, 2014), to Mark Chesler & Barbara Chesney’s seeing the practice as common to most self-help groups, which they describe as “**narrative communities**” (1995, p15). Keith Humphreys (2000) speaks to the personal stories contributing to the “**community narrative**” of the group itself.

2. Democracy & Self-Help Support Groups

A key characteristic of self-help groups is they are **member run**. This helps create an increased sense of “**ownership**” in the group by members, who then often play a more active (rather than passive) role in “their” organization.

My Own Background

- M.S. degree in Community Development
- As Vietnam veteran – co-founded a local group
- Involved in “Agent Orange” Class Action Suit
- Sought to adopt child – found S.N.A.P. group
in NYC by accident

Early Support for Self-Help Groups in USA

- **1976 National Self-Help Clearinghouse**

Started by **Frank Riessman & Alan Gartner** at the Graduate Center of the City of NY. Ten years earlier Dr. Riessman <http://goo.gl/lfCQZR> had published his noted paper on the “helper therapy principle” (1965). He founded the journal *Social Policy* and the “Self-Help Reporter” newsletter - both of which promoted increased self-help group awareness, research and insights.

- **1978 President’s Commission on Mental Health**

Called for: **joint learning exchanges** between Mental Health services and local community support organizations (which were primarily self-help groups); as well as for **increased linkages by services** to community support organizations.

Dec., 1985 - Dallas, Texas

**The International Network for Mutual Help Centers
Is Formed**

A meeting of representatives of self-help clearinghouses was arranged by Dr. Frank Reissman of the National Self-Help Clearinghouse. Attending were representatives of centers in the US and Canada. On the second day, representatives voted unanimously to create their own “**International Network for Mutual Help Centers**” to promote the continued sharing of program ideas & resources through newsletters questionnaires and conferences, while also having two separate national divisions that would work separately with their own governmental & agency issues.

Funding for Consumer-run Mental Health Programs

- **1986 Nat'l Mental Health Consumers Self-Help Clearinghouse** www.mhselfhelp.org first Federally funded (NIMH) Consumer run Technical Assistance Center aiding mental health consumers **with how-to materials** in development of a variety of peer-run centers, services, & housing programs.
- **1987 National Empowerment Center** (mental health) <http://power2u.org> Federally funded (NIMH) Technical Assistance Center & Training programs aiding mental health consumers via training in development of a range of innovative programs.
- **Later 1980s -1990s Federally funded Local Self-Help Centers and State organizations** (mental health) Additional Federally-funded Technical Assistance Centers started.

1987 - U.S. Surgeon General's Workshop on Self-Help & Public Health

<http://profiles.nlm.nih.gov/ps/access/NNBBCN.pdf>

Called by Dr. C. Everett Koop, it was a 3-day meeting, to determine the top recommendations for how to improve the public health of Americans via self-help groups.

Initially **60 recommendations** were proposed, that were then prioritized down to **16**, of which the top one was:

Priority #1 - “Incorporate information and experiential knowledge about self-help in the training and practices of professionals.” (p. 32)

Other Sample Workshop Recommendations

Priority #3 - “Support collaborative research and demonstration projects using methodologies appropriate to self-help group approaches & values..” (p. 31)

Priority #5 - “Develop, fund, and support a proactive national centralized information center for referral to existing self-help groups and clearinghouses, and for the assistance in the formation of new groups” (p. 30)

Follow-up to Surgeon General's Workshop

A Surgeon General's **“National Council on Self-Help & Public Health”** was created, and worked to help address the recommendations. It published a regular newsletter.

Dr. Koop worked to seek funding (contacting government agencies, foundations, etc.), but was unsuccessful.

He filmed television Public Service Announcements for local self-help group centers/clearinghouses to use.

And he often spoke out, quite elegantly (see next slide)...



"My years as a medical practitioner, as well as my own first-hand experience, has taught me how important self-help groups are in assisting their members in dealing with problems, stress, hardship and pain... Today, the benefits of mutual aid experienced by millions of people who turn to others with a similar problem to attempt to deal with their isolation, powerlessness, alienation, and the awful feeling that nobody understands"

- Former Surgeon General Koop

in Foreword to Self-Help: Concepts and Applications,
edited by Dr. A. H. Katz, 1992, p. xviii.

1992

**International Conference on
Self-Help and Mutual Aid**

Ottawa, Canada

Canadian Council of Social Development

Over 400 attended; many from USA

(A 3-day mutual aid meeting of mutual aid advocates)

“Double Trouble in Recovery” Research

Study of 310 DTR members over 2 years found...

- DTR participation was shown to be "significantly associated with greater drug/alcohol abstinence," as well as "improved health-promoting behaviors i.e. medication adherence, self-care..."
- better medication adherence, in turn, was "associated with lower psychiatric symptom severity and no psychiatric hospitalization during the follow-up period." and
- persons with higher psychiatric symptom severity at entry were more likely than others to attend DTR consistently.

Magura S, Laudet A, Mahmood D, Rosenblum A., Knight, E: Medication Adherence and Participation in Self-Help Groups Designed for Dually-Diagnosed Persons, Psychiatric Services 2002; 53(3): 310-316.

Magura S, Laudet A, Mahmood D, Rosenblum A., Vogel H., Knight, E: Role of Self-Help Processes in Achieving Abstinence among Dually-Diagnosed Persons, Addictive Behaviors 2003; 28(3): 399-413.

Some Federal Funding for Consumer-run Alcohol/Drug Advocacy Groups & Various Programs

2001 - Faces & Voices of Recovery

www.facesandvoicesofrecovery.org

A growing advocacy force of people in long-term recovery from addiction to alcohol & other drugs, their families, friends & allies.

A very informative journal article on this movement is **Addiction Recovery Support Institutions: Mobilizing Support Beyond Professional Treatment & Recovery Mutual Aid** by William L White et al, appearing in the Journal of Groups in Addiction & Recovery, 7:297-317, 2012. It speaks to the serious **Coming of Age of an American Culture of Recovery** and much more: goo.gl/yTMgqY Download is free.

Clearinghouse staff helped Bob Libbey and his wife to develop the first self-help group in the State for families of head/brain injured. For more information, contact Bob at (609) 428-3926.

Son's ordeal leads couple to aid other families

By JULIE BUSBY
Of the Courier-Post

Courier Post
July 11, 1983

CHEERY HILL — Robert and Helen Libbey coped alone with the trauma of being told their 16-year-old son, Rob, had a brain tumor.

They also managed alone aiding their son through two years of chemotherapy, resulting physical problems and then rehabilitation to rebuild his life.

In 1981, after attending a seminar on head injuries sponsored by Our Lady of Lourdes Hospital, the Libbeyes decided it was time for a support group for the families of people with brain tumors or head injuries caused by accidents.

The Southern New Jersey Head Injury Support Group, the first of its type in the state, was formed.

The group, with the Libbeyes serving as co-presidents, meets about every five weeks and has a membership of 40.

"It was not easy for us," Helen Libbey recalled of the dilemmas they faced with their son's illness. "In the beginning we had no idea the problems we would have. If you are just starting with the problems, it's nice to be with someone who's gone through it."

The Libbeyes struggled with their son's migraine headaches, eye, ear and skin problems, chemotherapy and shingles.

Today, after attending a head trauma vocational program at the Elwyn Institute in Media, Pa., Rob Libbey, now 23, is employed with the federal government in Philadelphia. He shares a house in Upper Darby, Pa., with five other men and women his age.

The Libbeyes also have a daughter, Carol, 21, a student at Northeastern University in Boston.

Helen Libbey said the support group usually schedules a speaker at each of its sessions at Our Lady of Lourdes Hospital to discuss topics such as aphasia or new developments in neurological research. The meetings also serve as a sounding board for members seeking advice on how to deal with a specific problem related to a head injury.

Away from the meetings, the Libbeyes and other group members often will speak to families who are going through the experience of dealing with a relative who is in a coma from a car accident or who need help in assisting someone just released from the hospital.

"We are not professionals, what we do is say, 'This is what we've done (to persons desiring counseling). Each person is coming from their own experience and what's right for one person may not be right for somebody else,'" said Helen Libbey.

"Our primary purpose is support and our long-range goal is support, but support in other ways than just talk," she added.

The Libbeyes stress that most families with a head injury victim are stunned at the rehabilitation costs. Often, insurance companies will pick up the \$50,000 to \$100,000 a year needed to assist a person with a brain injury resulting from a car accident. But for those with brain tumors, it is often more difficult to obtain finances for the patient.

The couple also said people recovering from brain tumors or head injuries also may have difficulty receiv-



Helen and Robert Libbey with son Rob, who went through treatment for a brain tumor.

ing services for social agencies from the local to federal level. The reason — in the past, head injury patients didn't survive the car accident or the brain tumor operation. Now, with many recovering, there are often no specific guidelines as to exactly what type of funding or treatment they are entitled.

Another problem a head injured person encounters is that he or she is labeled "retarded" when in fact there is a

different set of circumstances surrounding their brain injuries and different needs for rehabilitation.

Robert Libbey, an engineer with RCA in Princeton, said a support group can be emotionally rewarding but at the same time, emotionally fatiguing.

"I think we have shown some people that there is a better way but it takes thought and patience. And it doesn't always pay off. There are some defeats," he said.

"My goal (for the group) would be always to be no more than a support group. If it got any bigger it would start to detract. The mathematician Pascal said, 'Never confuse activity with progress,'" he added.

The Southern New Jersey Head Injury Support Group aided in the formation of the New Jersey Head Injury Association Inc., an Edison-based group that hopes to promote medical research for the treatment of head injuries and to educate the public about the needs of head injured persons.

The New Jersey Head Injury Association is a chapter of the Framingham, Mass.-based National Head Injury Foundation.

The New Jersey group uses as its headquarters the John F. Kennedy Medical Center in Edison.

Harvey Sanderson, president of the 2-year-old state group, estimated there are 1,700 head injuries a year in the state, most of them involving people under 30 who are in car accidents.

Sanderson's son, Chris, now 17, was injured in a dirt bike accident two years ago.

"This is not a new problem or a new disease. We call it the silent epidemic," said Sanderson, a 47-year-old cable television producer from Branchburg.

The National Head Injury Foundation compiled statistics that include facts such as 100,000 people in the United States die from head injuries each year and over 400,000 have injuries severe enough to require hospitalization. Of this group, 20,000 to 50,000 victims are left with intellectual or behavioral deficits. Two-thirds are under 30 years of age.

Sanderson said the state chapter counts 100 members, 75 percent of whom are the families of head injury victims, the remaining group being medical professionals.

Sanderson said the non-profit group hopes to raise funds to hold seminars and other programs to alert the public to the plight of the head injury victim.

"What people don't realize is that a young guy can go out on a Saturday night, become involved in a car accident and wind up in a coma. He'll never be the same again. It has a traumatic impact on the family," he said.

Marilyn Spivack and her husband, Martin, founded the national organization in 1980.

Their daughter, Deborah Price, was in an accident in 1975 while returning from asking (rip)ina van. The crash resulted in Price, now 23, remaining in a coma for weeks.

Spivack said the national group has chapters in 35 states and support groups in all but a few states. She said the group has served 13,000 people in the past two years and has a paid membership of 3,000.

The group's primary goal is to have agencies at all levels recognize the head-injured person in a separate category and through legislation assist the victims and their families in rehabilitation.

"People read in the paper about a person who is involved in a car accident and is in a coma," said Spivack. "They just assume the person wakes up and all is fine. Well, when the victim wakes up life just doesn't go on. That's when the problems begin."

"This is not only a public health issue," she added. "It is a society issue."

Courier-Post photo by Sam Frazee

Society for Community Research & Action

“Self-help/ Mutual Support Interest Group”

An online international organization of researchers, self-help leaders, and policy makers that:

- 1) promotes research and action related to self-help/ mutual support groups and related initiatives; and*
- 2) provides a forum for researchers, self- helpers, and service providers to communicate and network.*

To sign up their free Listserv Email Discussion Group:
<https://listserv.utoronto.ca/cgi-bin/wa?A0=SLFHLP-L>

Current Effort in U.S. A. to Support Self-Help...

Resolution on Self-Help Groups, pending before the American Psychological Assn.

www.scra27.org/what-we-do/policy/resolution-self-help-support-groups

- It describes **general benefits of self-help groups**, and **cites 92 published research studies** confirming findings.
- Recommends actions that APA and its members can take to **increase awareness, use, and understanding of groups**.
- This proclamation **could be adapted for use** with other professional associations, coalitions, and/or governmental bodies at different levels – if there was interest.
- Suggestions for any additional study, that could be added to the listing, are most welcome. (Contact EdMadara@verizon.net)

“Perspectives on recovery have changed dramatically over the past few years.

It is increasingly plausible that not referring patients to recovery and rehabilitation-oriented groups - to self-help groups, supported employment, supported education, and other similar community participation and consumer-run programs - may now raise liability issues, whereas such referrals may have been viewed as risky decades earlier.”

- from the final “Conclusions” paragraph of the article, “[Law & Psychiatry: Liability Issues Associated With Referrals to Self-Help Groups](#),” by Mark S. Salzer, Ph.D. and Loran B. Kundra, J.D., M.S.S. January, 2010 issue, [Psychiatric Services](#), vol. 61, no. 1, pp. 6-8.

Self-Help Group Utilization Rates

- 18% of U.S. population had participated in self-help groups; 7% currently involved.
- Kessler, R. C., Mickelson, K. D., & Zhao, S. (1997)
- Those who reported having less supportive social networks were more likely to attend a self-help group than those with more support.
- Kessler, R.C, Frank R.G., Edlund M., Katz, S.J., Lin, E., & Leaf, P. (1997)

Lisa Yue fights back

Tenaflly mom works to defeat the disorder that took her sons' lives

BY DONNA NITZBERG

Okay, so most moms are heroes to their kids: wiping tears; stuffing cookies into lunch boxes; staying up to the wee hours waiting for the fever to break, or the dance to be over. That's why we honor them on Mother's Day. But some women are heroes to more than their own kids—by doling out care and compassion to other people's children too. Tenaflly's own Lisa Yue is one of these special women. She suffered through terrible personal tragedy, losing two baby boys to the rare and incurable heart disorder, pediatric cardiomyopathy. But instead of crumbling under the weight of unbearable grief, she turned her anguish into hope for other kids.

Today, Lisa Yue and her husband, Eddie Yu (Lisa kept her maiden name when she married), an executive director at Morgan Stanley, are blessed with two healthy little girls, aged 4 1/2 and 2, who

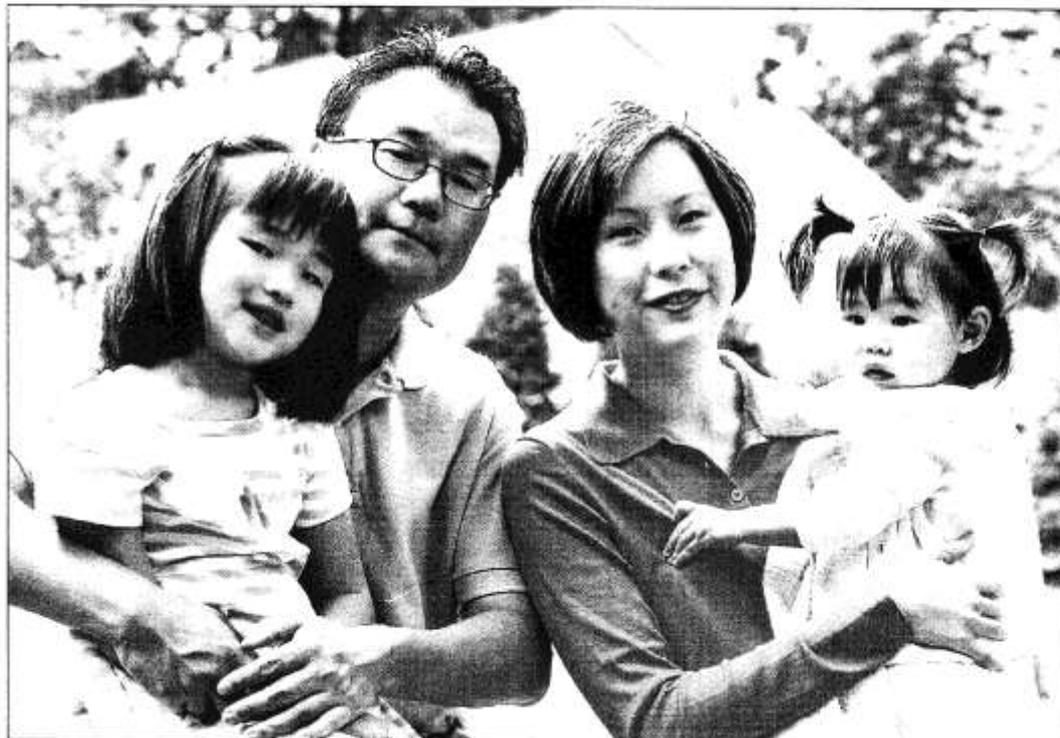


PHOTO COPYRIGHT JIM INVERSO

Lisa Yue, with husband Eddie and their two girls, continues to honor the memory of her sons through the national foundation she founded in her Tenaflly home.

grief and focus their energy like she has. She seems mild-mannered, but let me tell you, she is very tough."

Yue. "He just wasn't himself. He was limp and didn't respond. We rushed him to the hospital, where he died."

It was only after an autopsy that the

In babies, symptoms of cardiomyopathy can include: poor appetite and failure to thrive; upset stomach/gastrointestinal distress; fainting; chest pain; heart mur-

New Jersey Self-Help Group Clearinghouse

A Serendipitous (Accidental) Start

1978 – My Creation of a Simple Group Listing Uncovers People interested in Starting Groups

As a new Hospital Community Consultant, I sought out local support groups for use of Hospital's Clinicians & Social Services staff (Most knew of only AA).

But in addition to groups, my search revealed:

8 individuals who said they wanted to start new groups.

So, I added info on their group to the List, while networking each with a national, distant or model group.

In time, I was surprised to see:

Those 6 eventually started their groups, as did most others who were subsequently added to the list, for a total of...

10 new groups having been started within 18 months.

1980 – The “List” turns into N.J.’s First Group Directory

Identified 112 Local Northern NJ Groups

But decided to add:

19 National/International groups

9 Model groups

**To take advantage of the “Demonstrational Effect” that
national/model groups had in potential group founders.**

Total of 140 groups

Our New Jersey Self-Help Clearinghouse

- 1st State-wide Clearinghouse when started in 1981.
- Published 26 Editions of our New Jersey Self-Help Group Directory from 1982-2011.
- The NJ population served is 8.9 million in 21 counties.
- Provide only a portion of our database online, since we don't yet have Window's software system that can serve both our office and our website too. Office demands are greater, with group contact addresses and data reports and documentation system.
- Staffing is down to 2.75 paid staff and 8 volunteers.

A Modest Start

- 1 **computer** for database management /retrieval
(identified and added 1,750 NJ groups that first year)
- 1 additional **Staff Person & volunteers**
(helped individuals to start over 50 groups that year)
- Statewide toll-free **800 number**
- **Statewide Annual Directory** – started publishing in 1982

NJ Clearinghouse Concept

- **Group Database is Searchable by local, regional, statewide, and national levels. Includes contacts for those seeking to start groups.**
- **Toll-free Phone Access** 
- **Internet accessible 24/7**
- **Multi-disciplinary approach - working with churches, I&R agencies, schools, cooperative extension, funeral directors, newspapers, etc.**

NJ Mental Health Consumers

- In 1982, a state conference with **Judi Chamberlin and other national mental health leaders** was held with NJ consumers and advocates, to encourage and plan self-help group development. Clearinghouse staff began helping consumers organize their own self-help groups.
- With over 16 groups started, in **1984 CSP-NJ, the statewide consumer-run agency** was formed.
- CSP-NJ is now a multi-million dollar agency with a variety of services, and over **30 consumer-run self-help centers across the State.**

- In 1986, the Clearinghouse developed the first guide to starting local **National Depressive Manic-Depressive Association** support group meetings.
- In 1992, the first **Schizophrenic Anonymous** groups in NJ were started after the Clearinghouse brought the founder of S.A. to different areas of NJ for meetings with consumers.
- From 2006 to 2009, the Clearinghouse hosted annual trainings on how to develop **Double Trouble in Recovery** (DTR) groups by it's founder, Howie V.
- Shortly after, DTR was added to SAMHSA's Nat'l Registry of Evidenced-Based Programs & Practices.

1990 - American Self-Help Clearinghouse

- We already had the **database of national groups**
We had been using & expanding for 10 years,
to help us in finding local NJ groups!
- We were provided with free unlimited online
server space, along with free keyword-searchable
software program, that was custom built for us by
Dr. John Grohol who built PsychCentral.org
- All we had to do was to enter & update the national
groups there, and assign keywords to the entry.

National Widowers' Organization

www.nationalwidowers.org

Therefore, with the increased need for peer support just for men who have lost their partners, we've helped the men in their development of their own how-to guide, to encourage more men to start groups. They also now offer a "Widower to Widower" peer support phone call service.

New Jersey Clearinghouse starts

- **1980**, wrote proposal to State Div. of Mental Health for 1 staff person, 1 computer, & a toll-free helpline.
- Mid -**1984**, had identified over 3,000 existing local NJ groups, and helped over 200 individuals to start groups, to include the first NJ groups for depression.
- Staffing increased to 6 paid staff and 16 volunteers.
- Last printed NJ Directory (26th Edition, **2011**) had contacts for 8,200 NJ groups, and over 1,100 national, international, model, and online groups.

When Helping People Start Groups

- **Respond to co-founder(s) “Felt Needs.”**
What would they most want to see the group work on, or to discuss?
- **Emphasize how they should never do it alone – but seek out one or two co-founders willing to help.**
- **Point out how their promotion of a “shared group leadership” approach will help prevent the work from being placed on just one person’s shoulders and their subsequently “burning out.**
- **Cite any National, Model or online Group, and our Clearinghouse’s free services.**

Help for Victims of 'Orphan Diseases'

By CARLA CANTOR

TO LOOK at her, you wouldn't know. An outgoing, green-eyed, blonde child, she looks and acts like any other 4-year-old, snuggling potato chips from her brother and sister and jumping on her daddy's lap.

But Bethany Toughill is different. She suffers from a rare and mysterious blood disorder called histiocytosis-x that some day could kill her.

So obscure is the illness that it is known in the medical community as an "orphan" disease, one that affects too few to inspire public concern or massive medical financing. That means that important research that may save or prolong Bethany's life may not be getting done.

"It's tough to handle the fact that

you might lose your child; it's even harder when you feel isolated and abandoned," said Bethany's father, Jeff, who, with his wife Sally, has organized the Histiocytosis-x Association of America so that Bethany and others like her are not forgotten.

The group is working to find all those touched by the disease, to encourage research and to provide support and information to patients and their families.

Histiocytosis-x is an enigmatic disease with an unknown cause and often uncertain outcome. It is believed to be a malfunctioning of the immune system that causes a type of white blood cell — histiocytes — to multiply uncontrollably and attack the body.

It strikes about 400 children and adults a year and is often fatal in children, said Dr. Michael Osband of Boston, an expert on it who helped the

Toughills set up the association.

Although the disease resembles cancer in some ways and historically has been treated by oncologists with radiation and chemotherapy, histiocytosis-x is not a malignancy.

Unlike cancer, it sometimes mysteriously goes into remission without treatment. It can strike almost any organ of the body, and commonly involves the skin, bones, bone marrow, lungs, liver, lymph nodes and spleen and, in children, the gums.

Bethany's first signs appeared at the age of 3 months, when she developed a severe rash all over her body. Swollen lymph glands on both sides of her head kept her from lying down.

"The lumps were so painful that for four months we sat up all night together in a chair so that Bethany could sleep," Mrs. Toughill said.

It took several weeks for doctors to diagnose histiocytosis-x through a

skin biopsy, which revealed histiocytes eating away at Bethany's skull and legs. She immediately began a chemotherapy program at Children's Hospital in Philadelphia.

"It was a terribly confusing time," Mrs. Toughill recalled. "As we sat in the Oncology Clinic among leukemia patients and other cancer patients, we just couldn't understand the link between them and us. We needed to talk to a parent whose child had histiocytosis-x so that we could know what lay ahead for Bethany — good or bad."

A year of radiation treatments cleared up all of Bethany's bone lesions and her rash. Then, about a year and a half ago, a hospital test revealed a mass of histiocytes behind her eyes and around her pituitary gland.

"We were reliving the crisis all

Continued on Page 22



The New York Times/Carl A. Beitzel/Red

Sally and Jeff Toughill with their daughter, Bethany. The 4-year-old child has a rare blood disease.

The Clearinghouse has helped Jeff to develop the Foundation. This article, which came about when staff contacted the Times and urged they do a story on Jeff and Sally, was carried by UPI nationally. A *Family Circle* magazine editor saw it and subsequently their story appeared in the 11/87 issue.



Marjorie Guthrie, a leading advocate for research on all genetic disease but particularly disorders of the brain and central nervous system.

HELPING PEOPLE HELP THEMSELVES

The sweet sounds of solace: One woman's self-help story

By KAREN LEVEY
News Tribune Staff Writer

Alice Abner is raising three young children in her Piscataway home.

She drops them off at a day-care center every morning before she leaves for New Brunswick, where she is a full-time caseworker for the Middlesex County Board of Social Services.

The two oldest children, ages 11 and 6, walk to school from the center and return there every afternoon, while the 4-year-old stays at the center for the day.

Abner, who is 47, picks up the children in the evening after work. She fixes their meals, bathes them, and plays with them. She takes them shopping for new clothes and shoes.

She is raising them as if she were their mother.

But these children call Abner "Granny."

She is part of a growing contingent of men and women who are caring for their children's children as their own — who are, in effect, raising a second family.

Abner is also one of thousands of New Jersey residents who have found solace and support through self-help groups — groups run by and for their members.

Through self-help, people who have in common a similar life situation, illness, or problem come together to share feelings and experiences. They draw strength, comfort, and knowledge from one another.

Seeking to form a group for other grandparents in her situation, Abner reached out to the New Jersey Self-Help Clearinghouse, a computerized, statewide information bank that keeps track of more than 3,500 meetings of self-help groups across the state.

Based at St. Clare's-Riverside Medical Center in Denville, Morris County, the clearinghouse expects to field close to 14,000 phone calls this year.

When Abner learned there was no support group in the state addressing her particular situation, she moved ahead with plans to start her own, with the help and encouragement of the clearinghouse staff.

Today, only one month after its incep-



Alice Abner, organizer of the Grandparents Support Group.

The News Tribune

Support group is seeking surrogate grandparents

The Grandparents Support Group is a Middlesex County-based self-help group for grandparents raising their own grandchildren.

Generally, grandparents take on this responsibility because their own children cannot properly care for their children.

Organizer Alice Abner of Piscataway is seeking new members for the group,

which held its first meeting last month. She says aunts and uncles caring for nieces or nephews are also welcome to attend.

The group's next meeting is scheduled for Dec. 13 at 6:30 p.m., in Room 162 of the Middlesex County Social Services building, 181 How Lane, New Brunswick.

For information, contact Abner at work, 745-3541, or at home, 356-9402.

ing grandparents more rights in custody disputes.

Generally, she explained, grandparents who assume responsibility for a grandchild are acting as surrogates for dysfunctional children.

Often, these children are crippled by drug abuse or are in trouble with the law, and many are serving time in prison or in

the kids and that was the end of that.

"The setting up at night, giving bottles, changing diapers, the whole routine all over again. I think I cried every single day."

Abner, who left an abusive husband after 10 years of marriage and reared her three children on her own, is still struggling with the guilt that came with her decision not to take in her daughter's

To Identify Individuals who may be Interested in Starting a New Group

- Consider asking those, who request a support group that is not available locally...

“Are you Possibly Interested in Joining with Others to Start a Group?”

- Advise them of any: **Similar existing Self-Help Group at a Distance, or a National Group.**

- Tell them that they don't have to do it alone:
“They can seek out a couple of co-founders. We're willing to help you.”

Phone Call Inquiries – Serve as a Barometer Reflecting New Needs

- **1982** calls for “**Gay Men’s**” Disease
Started first NJ group & **AIDS How-to Guide**
- **Survivors Of a Suicide (Model Group)**
“**Demonstrational Effect**” of newspaper **article/newsletter** to encourage NJ group development.
- **1987 - Lyme Disease**
- **1994 – Latex Allergies of Medical Professionals**
- **2001 – 9/11 Family Bereavement Group**
- **2003 – Holistic Moms**

Interested in an E-mail Discussion List...

“Self-help/ Mutual Support Interest Group”

An online international organization of researchers, self-help leaders, and policy makers that:

- 1) *promotes research and action related to self-help/ mutual support groups and related initiatives; and*
- 2) *provides a forum for researchers, self- helpers, and service providers to communicate and network.*

To sign up their free Listserv:

<https://listserv.utoronto.ca/cgi-bin/wa?A0=SLFHLP-L>

Value of Online Self-Help Networks

For ever-increasing percentage of Americans with Internet access, mutual help is now possible...

- where there is no local community group.
- when the disability or illness prevents travel.
- for those lacking transportation to meetings.
- when 24/7 caregiver responsibility prevents use.
- for rare disorders or stressful conditions.
- 24/7 availability of online support networks.

Examples of Online Self-Help Networks

- *NJ Quitnet* online support groups to stop smoking
- **“Totally Hip”** *those who had or anticipate hip replacement surgery*
- **ACOR.org** (*Assn of Cancer Oncology Resources*)
over 130 e-mail lists for different cancers, to include rarer types of cancer
- *Young Widows & Widowers*
- *Power Surge* *for women having serious difficulties with menopause*
- **Angels of Addiction** *parents of children who overdosed on drugs.*

Most of the National Self-Help Organizations now have message boards, e-mail groups, or social networking.

“One of the most important capabilities of self-help groups is that ordinary people can develop such groups in their local communities when none exist, and subsequently their group serve as an extraordinary resource to many in that area for several years...

A person doesn't need a grant, an agency, or even an office - just the inspiration and a few other people who share their experience and hope.

What significantly helps in providing such inspiration is **a person's knowledge of an existing national organization or a model group**, which can provide them with basic information - so they don't have to ‘re-invent the wheel.’ ”

"Mutual Aid Self-Help Group Developments"
Community Psychologist, 39 (3), Fall, 2006, p. 21.

Encouraging Group Development

- **Telling people they are capable, can do this, & don't have to do it alone was most helpful. A 1983 Survey of first 100 group founders rated simply Clearinghouse staff “encouragement” as most important, over How-to Materials, Training, and Resource contacts.**
- **Inspired through conversation with another peer.**
Hired existing group leaders as consultants.
- **Inspired by a group founder through that person's story - provided in print, or in person.**

Local Heroes: The Rebirth of Heroism in America by B. Berkowitz

- **Having “How-To” guides with personal experiences of**

How We Have Handled Funding in the Past

1. Passing State Legislation – which, after much hard work by us and the many groups that came to the hearings - **gave us funding (But for only one year!)**
2. **Seeking Funding from one State agency for the Blind** – provided some funding, that lasted for several years. But it took up much time.
3. **Sought Foundation funding to write & print an AIDS self-help group how-to guide**. It was not a lot of money but was helpful and supported our work.

Our own epic takes a turn

- Near economic collapse
- Malaise
- Confusion

Near economic collapse

- US Hospitals Struggle
- State of New Jersey Debt
- Decrease of clearinghouse funding, staff and outreach

A “Down”

Decline of Clearinghouses in USA in a Much Less Supportive & More Challenging Environment

In 1990 - 53 local clearinghouses in USA

Today - 10 local clearinghouses operate

Malaise - Perhaps not

- Media fatigue – support groups are less newsworthy
- Hard to get access in newspaper print
- An unintended consequence; support groups have become such an integral part of US culture they only appear less newsworthy.
- New challenge is to break through the Media Malaise to get information on new groups out to the public.

**With the demise of so many clearinghouse, and
with the rise of a so called Google Gap**

- Info on local support groups difficult to unearth.
- Ads are the new priority on search engines.
- Increase extraneous information
- Information on smaller groups doesn't always make it onto Google.

Additional Factors Contributing to the Decline

1. Many local Clearinghouses were affiliated with mental health agencies. So when the mental health **consumer-run** agencies arose, clearinghouses were not needed.
2. Since **printed directories** were no longer sold, that annual revenue was lost, causing programs to close.



To best serve the public and professionals in the present and into the future, an easily accessible online database of groups & resources will be essential.

Among Clearinghouse Values

- **Focus on our Belief in People's Strengths and Abilities to overcome and grow from adversity**, e.g., Nancy Berchtold's development of the first post-partum depression self-help group, which led to over 110 groups nationally.
- **Respect** - In all media contacts, we always highlight **Self-Help Groups first**, ahead of our Clearinghouse programs, and first direct all media reps to groups for best information on self-help groups – because they have the experience and also need to get the media coverage because of their hard volunteer group work.