



Rehabilitation Gazette

International Journal of Independent Living
by and for Persons with a Disability

January 1990

Vol. 30, No. 1



Glimpses of Gini and G.I.N.I.

Gini Laurie

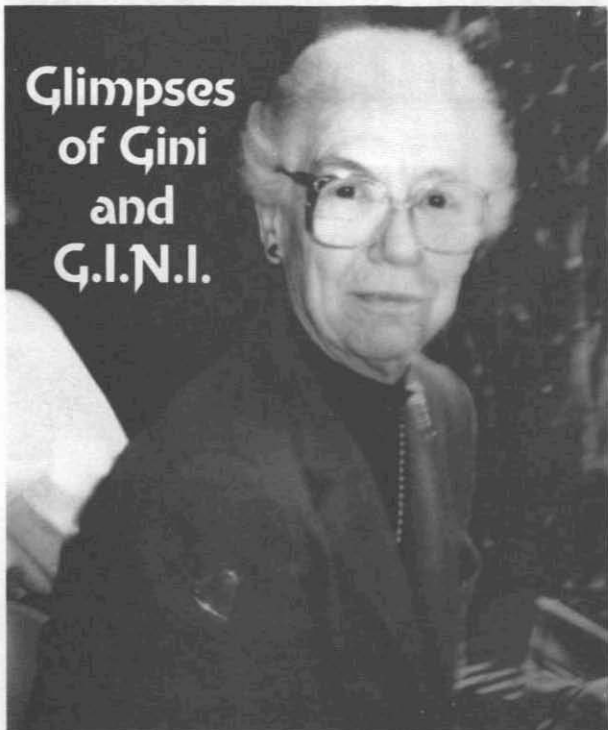
June 10, 1913 — June 28, 1989

*"The story of the Rehabilitation Gazette
is interwoven with my life."*

— GINI LAURIE (1989)



Glimpses of Gini and G.I.N.I.



"Have you ever heard a rooster crowing, or a fire engine's siren wailing in a hospital corridor; have you ever walked into a

hospital room and seen balloons being blown up or a 'Howdy Doody' night light being plugged into a respirator;

have you ever seen kids' faces light up when they were handed toys and gadgets no one else has ever been able to find? If you ever have experiences like these, you know Gini Laurie is there. We're glad to have you as our Volunteer of the Month."

"Well I will never forget mine. The hostess was that super party giver, my friend Gini Laurie, ably assisted, as they say, by her husband Joe. Who but Gini, would have a Chinese motif, invite over fifty people and make arrangements for perfect (not too hot) weather?" —Susan Ambrecht

TOOMEYVILLE GAZETTE
(Sept.-Oct. 1955)

福

"...the GAZETTE'S Volunteer-Editor is now working full time and will be unable to give as many hours to Toomey.

"So, with humility, we two Thursday volunteers and an Out-Patient have gathered news

Gazette International Network Institute 福 (G.I.N.I.)

4502 Maryland Avenue
Saint Louis, Missouri 63108 U.S.A.
Telephone: 314/361-0475

Written by individuals with a disability, *Rehabilitation Gazette* (formerly *Toomey j Gazette*) has been published since 1958. Its aim is to reach, to inform, and to dignify individuals with disabilities throughout the world.

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January 1990
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ISSUED IN JANUARY AND JUNE

from patients, staff, volunteers and keyholes, which we are rushing into a JUNIOR edition.

"We cannot foresee just how Jr. will evolve."

TOOMEYVILLE JR. GAZETTE
(1958)

福

"WE WISH TO THANK: Mrs. George I. Martin and Mrs. Joseph S. Laurie who donated the printing of this issue in memory of their sisters and brother - Virginia, Grace, and Robert E. Wilson, Jr. - who died of polio because they lived too soon."

TOOMEYVILLE JR. GAZETTE
(August 1958)

福

"Gini Laurie's herb garden is peacefully asleep, the harvested herbs are automatically drying in the back room or preserved in vinegars, while her typewriter clacks away into the night while turning out JR."

TOOMEYVILLE JR. GAZETTE
(1958)

福

"Sometimes, when I am digging in the garden, or walking in the woods, I feel a sadness because my respiratory friends cannot participate.

"Then I cure these thoughts with my memory of volunteer work at a mental hospital and

recall the excessive mobility in the disturbed wards.

"How different is the emotional climate of respiratory polio people. Their living has been filtered of much of the fluff and the best of humanness remains." —Gini Laurie

TOOMEYVILLE JR. GAZETTE
(Summer 1959)



"We are not pleading for unending help from the NF (National Foundation)

We are pleading for
TIME
To make a transition"

"By the time this issue is in circulation, TOOMEY j GAZETTE will be incorporated as a non-profit organization. We have named our non-profit organization 'Iron Lung Polio Assistance, Inc.'"

TOOMEY j GAZETTE
(Fall-Winter 1959)

"A+ requires an equal number of horizontals and verticals."

"The first Radio Moscow report on the drug, called galanthamine, (erroneously reported at first as 'karatonin'), said it cured polio paralysis.

"But a later Associated Press dispatch said that doctors emphasize the drug does not produce a complete cure. Destroyed nerve centers cannot be made well again."

TOOMEY j GAZETTE
(Spring 1960)

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"OUR AIM: To reach and advance respiratory polios all over the world and to share the problems, experiences, thoughts and adventures that would be of value to know about each other."

TOOMEY j GAZETTE
(Indian Summer 1960)

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"Although our present frightening financial problems have arisen because of the precipitous withdrawal by the National Foundation of its support of home care attendants, we are still most appreciative of the astounding care of polios by the former NFIP. No other group of handicapped ever fared so well. We survived - because of the respiratory centers, care, and equipment it then supported. We thrived - because in a

dramatic experiment to save hospital costs, it pioneered returning us to our homes with respiratory equipment and attendant care.

"Our continuing survival and expected longevity involve financial needs that greatly exceed those which can be borne indefinitely by a volunteer organization. Clearly, the responsibility now lies with a coordination of assistance from County, State and Federal governments."

TOOMEY j GAZETTE
(Springtime 1961)

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"Educators have learned that quads still have their heads. Lawyers, teachers, doctors, business men and graduate students have proved that physical disability, even the inability to breathe or move, is no bar to higher education and success."

Toomey j GAZETTE (1962)

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"Morally, institutionalizing young people with so many potentialities for service is wrong. One answer lies in small co-operative residence homes in which the residents have freedom and privacy to live—not merely exist."

Toomey j GAZETTE (1963)

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"FIVE YEARS HAVE GONE BY since The National Foundation-March of Dimes initiated its policy of withdrawing financial support of attendants for respos (polios who are quadriplegics and dependent upon mechanical breathing aids).

"WHAT HAVE WE DONE? Hundreds of TjG readers wrote to their Senators and to their Representatives, to the Health, Education, and Welfare Department, and to our various State officials.

"WHAT HAS OUR GOVERNMENT DONE? As a result of our letters, the Health, Education, and Welfare Department tabulated and published the information gathered by TjG on our Census forms. The published findings were entitled REPORT ON A SURVEY OF RESPIRATORY AND SEVERE POST-POLIOS.

"IT'S UP TO US. Now is the time for each one of us to start

hammering away on our local level. Rejections must not stop us. Keep hammering away."

Toomey j GAZETTE (1964)

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"A CHANGE IN SOCIAL SECURITY—In October, 1964, President Johnson signed into law (P.L. 88-650) Social Security amendments, one of which removes a restriction on the retroactivity of applications for disability insurance benefits. Previously, disabled workers who did not apply for disability insurance benefits until after June 30, 1962, were ineligible for more than 18 months of retroactive benefits, or were eligible for only reduced amounts."

Toomey j GAZETTE (1965)

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"Tremendous rehabilitation potential opened to the severely disabled with the enactment of the 1965 Amendments to the Vocational Rehabilitation Act.

"One of the most significant provisions of the Act is that a State rehabilitation agency can provide services before vocational rehabilitation potential is determined.

"Another change of fundamental significance is the elimination of the Federal requirement that an individual's financial need be determined before certain services are provided."

Toomey j GAZETTE (1966)

"Since much of the mail to Toomey j GAZETTE is addressed impersonally to 'Gentlemen' it would seem that too many of the readers are under the impression that it is published by a rehabilitation center or a well-funded organization which has no need of their financial help."

Toomey j GAZETTE (1967)

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"...The 'readers' becoming the 'writers' with Gini to edit all this material, and then type and lay out the pages for the printers.

"As the *Gazette* became the 'clearing house' for all the severely disabled, with its operations centered in our house, there became less and less room for me and our furry friends. In the spring of 1962 we had some experts build a little pool in the garden, with heated water, and there I would recline on an inner tube or two away from the mad clackety-clack of the busy IBM's.

"...I hate to admit it, but it has enriched my life to have had it so beautifully disrupted, and the many people who have helped over the years have become our dear friends, and in retrospect the troubles are now all remembered joys." —Joe Laurie

Toomey j GAZETTE (1968)

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"NATIONAL CITIZENS CONFERENCE ON REHABILITATION OF THE DISABLED AND DISADVANTAGED. About 1,000 professionals and lay persons discussed rehabilitation of the physically and mentally disabled as well as those disadvantaged by poverty, drug addiction, criminal records, racial minority, etc. It was a vital 'happening,' an eye-opening experience for TjG's editor."

Toomey j GAZETTE (1969)

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"*Rehabilitation Gazette* is now the name of our former Toomey j GAZETTE. We feel the new name more clearly reflects our present aims and the evolving interests of our readers worldwide."

REHABILITATION GAZETTE (1970)

"When we finish typing this issue, have it printed, and send it off to you, Joe and I will start packing to move back home to our house in St. Louis. We've lived here in the 'snow belt' in Chagrin Falls for over 20 years; but now that Joe has retired, we would rather live in a warmer climate and be near our families. The GAZETTE is crowding us out of this house. We'll have much more room in St. Louis for the cats, books, and GAZETTE 'treasures.'"

REHABILITATION GAZETTE (1971)

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"CHAGRIN FALLS TO ST. LOUIS. The REHABILITATION GAZETTE was transplanted with us when we moved from Chagrin Falls to St. Louis in September 1971. After more than twenty years away, we moved back into our house here in St. Louis and we've spent an exciting year redecorating the house, redesigning the garden,



settling ourselves, the cats, and a new basset hound, rearranging the GAZETTE files, keeping up with the GAZETTE mail, looking up old friends, and getting to know wheelchair St. Louisans."

REHABILITATION GAZETTE
(1972)

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"Our 'family' was happily increased with the addition of two long-haired blondes: Kem Mahan, an old friend from Chagrin Falls, now a student at Washington University majoring in Spanish - the GAZETTE's assistant editor, and Shiva, an afghan hound, a ludicrous companion for our basset hound, Beaugard, and the three cats."

REHABILITATION GAZETTE
(1973)

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"A productive three-day workshop session to formulate By-Laws for the proposed 'American Coalition of Citizens with Disabilities' (ACCD) was held the weekend of June 22-24 in Fort Sumner, Maryland...."

"The intense nature of the discussions was relieved at time by the enthusiasm, often approaching exuberance, about the significance of this long-awaited meeting.

"Agreement was reached quickly on three basic premises: the necessity for control to be placed and remain in the hands of persons with disabilities, the

need to fortify state and regional coalitions and organizations at the local level, and for the watchword of 'Positivism' in all areas of the Coalition's operation."

"Rehabilitation Act of 1973, Public Law 93-112, Sec. 504. Nondiscrimination under Federal grants. - 'No otherwise qualified handicapped individual in the United States shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.'"

REHABILITATION GAZETTE
(1974)

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"Our book, HOUSING AND HOME SERVICES FOR THE DISABLED, ELDERLY, AND RETARDED, will be published by Harper & Row in late summer of 1976. This book is not about buildings. It is about people—people who happen to be physically disabled, blind, deaf, retarded, or elderly and who have problems with housing and home services. It is about their essential people-ness—their differences as well as their common needs; independence, integration, self-direction, acceptance, dignity, love, and a choice of life-style. It is about their individuality, adaptability, potential, and humanness. It is about the skills and special techniques of living that make a disability less disabling. It is about the world-wide awakening to the need for

integrated housing, supportive home services, and an hospital environment."

REHABILITATION GAZETTE
(1975)

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"ACCD functions as a catalyst for unity in pursuing solutions to the problems that confront all members of the nation's disabled population. With one 'token' exception—the GAZETTE's editor—all of the officers and board members are disabled."

REHABILITATION GAZETTE
(1976)

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"Of first importance is the right to freedom of choice to live as normal a life as possible within the community—either through one's own impetus or with the supportive services of appropriate independent living and other community programs.

"SEGREGATION IS UNNORMAL. Harmonious group living is extremely difficult for even the most homogeneous, with a common bond such as religious vocations. It is relatively impossible for groups with nothing in common except the dubious bonds of disability and low income."

REHABILITATION GAZETTE
(1977)

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"...I went once or twice a week to Cleveland City Hospital's contagious ward, the Toomey Pavilion, which became the regional respiratory polio center. I loved being with the patients. I came to know their families, their problems, and their joys. I shopped for them and ran errands. I fed, bathed, dressed, toileted, shampooed, shaved, manicured, read to, and wrote for. I did whatever needed doing and I tried to relieve the boredom and to make life as much fun as possible by giving birthday parties and decorating the wards for every holiday.

"The most exciting part of the GAZETTE has been watching so many people go forward from the initial stages of disease or injury, seeing them gather their forces and cope, going back to work, or changing work, or going on to finish school, getting PhDs or MDs or MAs in engineering, psychiatry, medicine, psychology, or social work, marrying, acquiring homes and families, traveling, living it up! It has been like having a worldwide family of friends.

"I am still the catalyst, the catcher of straws in the wind, the gatherer and giver of facts."
—Gini Laurie

REHABILITATION GAZETTE
(1978)

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"New volunteer at 4502. Last fall we divided up the house to make an apartment for Gini's sister, Mickie Martin, who moved here from Miamisburg, Ohio. She has taken over all the library work.

"I would, therefore, like to suggest that readers of REHABILITATION GAZETTE, which seems to be the last polio link, submit names of doctors they might know in their home towns who can easily relate medical problems (perhaps heart strain, low blood pressure, too much or too little exercise, etc.) to polio problems."
—Larry Schneider

REHABILITATION GAZETTE
(1979)



"...dreams are coming true...the international conference, for which Gini was a catalyst, to analyze the problems of aging polios and share the experiences of respirator-users and the medical teams from their former polio centers with medical team components of the present era."

"We have long dreamed of a tour but it did not become a reality until the spring of 1980 when Gini was awarded a fellowship by the World Rehabilitation Fund. The fellowship, International Exchange of Experts in Rehabilitation, funded a one-month study of independent living in Denmark and England.

"...added another month on our own...and visited six more countries—France, Belgium, Switzerland, Sweden, Scotland, and Ireland."

REHABILITATION GAZETTE
(1980)

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"This conference may prove," says Dr. [Allen] Goldberg, "to be a turning point for many involved people, policies and programs. From the conception—a dream of Gini's—it demonstrated that when people work together, by a process of mutual respect and sharing, ANYTHING worthwhile can be accomplished. A spirit of being together, needing each other, led to a cooperation which overcame every barrier: funding, accommodations, transportation, required services, etc.

"The most important thing I learned is that polio survivors are leaders. They must organize and take action to help themselves and others with disability."

REHABILITATION GAZETTE
(1981)

"A month after the conference, Joe and I spent a weekend 'retreat' with the board of directors, looking back and planning for the future.

"Together, we created exciting plans to perpetuate and expand the GAZETTE, which for 25 years has been the hub of that network.

"To reflect our plans for the next 25 years, we changed the name to:

"GAZETTE INTERNATIONAL NETWORKING INSTITUTE (G.I.N.I.)"

"...specifically, arrange for the publication of the PHYSICIAN'S HANDBOOK ON POLIO which the GAZETTE is correlating with Dr. Armin Fischer at Rancho Los Amigos Hospital"

REHABILITATION GAZETTE
(1982)

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"During the past year, we expanded the G.I.N.I. Board of Directors and hired Judith Raymond as our first salaried executive director. Judith is a long-time volunteer with the GAZETTE, and her experience as a former director of an Ohio public library fits well with G.I.N.I.'s objectives."

"We mourn the loss of the *Rehabilitation Gazette's* co-editor, the Gazette family's big-hearted 'Papa Joe,' and Gini's beloved husband of forty-seven years."

REHABILITATION GAZETTE
(1985)



"Gini Laurie was one of several experts in rehabilitation from the United States, England, Australia, Canada, and Hong Kong invited to participate in the First International Conference on Rehabilitation of the Handicapped in the People's Republic of China. The conference was held at the Great Wall Sheraton Hotel in Beijing in January 1986.

"After Beijing, Laurie met in Tokyo with disabled Japanese leaders including Dr. Masao Nagai, Director, Department of

Psychiatry, the National Rehabilitation Center. For the last 10 years, Nagai, who is quadriplegic, has directed the translation of the REHABILITATION GAZETTE into Japanese. Nagai arranged Laurie's visits to independent living centers in Tokyo and Kyoto."

REHABILITATION GAZETTE
(1986, No. 1)

福

"Dr. Danforth, secretary for the St. Louis Award Committee, said Gini, the mother of the independent living movement, was being honored '...as an historian, researcher, and advocate for the right of persons with disabilities to live independently; for her vision in creating a world-wide network of people and information with the power to dignify and motivate the lives of countless individuals ...and her tireless efforts to call forth the unique potential of every human being.'"

REHABILITATION GAZETTE
(1986, No. 2)

福

"A warm welcome to new staff member Joan Headley, who joined G.I.N.I. on August 17, 1987, as director of G.I.N.I.'s International Polio Network."

"Each minority group in the United States, as it has gained self-awareness as a group, has found itself needing to look in two directions. While concentrating on future strategies and breaking new ground, it is also forced to trace its own historical roots and to claim its existence through time. The disability movement is no different. It has a history but the validity of its involvement in past events too often lacks documentation. The heroes are seldom recognized as such and too often forgotten."
—Mary Jane Owen

REHABILITATION GAZETTE
(1987, No. 1)

"Our future, as we now see it, will build on the two defining characteristics of G.I.N.I.: we have always been and will continue to be a network of real people helping each other, and we have always done that best when we share vital, practical information." —Jack Quigley

REHABILITATION GAZETTE
(1987, No. 2)

福

"To celebrate its 30th anniversary the *Rehabilitation Gazette* presents this extraordinary collection of life experiences written by individuals with a disability.

"Because of these life experiences in the *Rehabilitation Gazette*, thousands of individuals with a disability have attained independent living through rehabilitation."

Rehabilitation into Independent Living - REHABILITATION GAZETTE (1988)

A Memory of Gini

A woman stands alone,
White of hair and past weeping,
Poplar straight amongst a herd of wheels.
She woos them with a whistle.
Like startled deer in a forest clearing
They still,
Heads turn as one,
They pirouette to her call.

DR. HUGH NEWTON-JOHN,
AUSTRALIA

A Celebration for Gini

Gini Laurie was the honored guest Saturday evening, June 3, 1989, at the Fifth International Polio & Independent Living Conference, St. Louis, Missouri. Conference attendees were sad about the state of Gini's health but found consolation in her unflinching ability to live life to its fullest and with dignity.

Former G.I.N.I. Board President, Mickie McGraw, Cleveland, Ohio, and current Board President, Jack Quigley, St. Louis, Missouri, eloquently spoke on behalf of the thousands of individuals whose lives have been touched by Gini Laurie and her work.

Wind Beneath My Wings

In trying to find the right words to speak to you about G.I.N.I. and its past and future—I've really struggled with how to best share what I feel. I suspect that one of the reasons I've been asked to do this is because I've been around for such a long time. I guess it follows that my mature years may provide a unique perspective.

It is true that I've been a part of G.I.N.I. at all of my own and its various stages of development. As with so many of you, we have more or less grown up together!

When the "Toomeyville Gazette" was born in the mid-50's, I was one of the Cleveland City Hospital Toomey Pavilion graduates, who eagerly looked forward to news of my fellow alumni. As the years passed and the GAZETTE's circulation grew to include people with other disabilities in other states, I consistently but firmly refused the Editor's efforts to get me actively involved.

I was a teenager; I was dealing with my own feelings about being "different"; and I def-

initely did not want to be identified with an organization for and about disabled people! It made me feel more disabled.

But we all know who that editor was and we've been on the other side of her "gentle determination." Gini Laurie slowly helped me piece it together. She nurtured and encouraged me; she believed in me before I believed in myself; and one day I found myself INVOLVED. To this day, I am amazed at how she can make you feel like it was all your idea in the first place! The most recent proof of that is my appearance here tonight.

The simple truth is that Gini has an uncanny ability to ask people to do only what she knows they can, even if they don't know it themselves at the time.

I became editor for the GAZETTE's "Market Place"—helping people with disabilities barter, buy, and sell everything from wheelchair elevators to mouth and foot painted cards. I participated in the first International Handicapped Artist's Exhibit held in Chagrin Falls,

Ohio, and the subsequent Exhibits sponsored by Kenny Rehabilitation Institute in Minnesota.

Later I was art editor for the newly named *Rehabilitation Gazette*. I designed its logo and covers and created the GAZETTE's first Christmas card. I met and interacted with many wonderful people and gained confidence in myself as a "real" person. During that time I entered and graduated from the Cleveland Institute of Art and got my first job through a contact made while working for the GAZETTE.

Throughout my adolescence and young adult life Gini and the GAZETTE taught and prodded me to be me—not so much through words but by action and example. I carry their gifts with me and use them daily in my personal and professional life.

Eventually, I became a member of the GAZETTE's Board of Trustees and helped conceptualize and establish GAZETTE International Networking Institute—also known as Big Gini!

From that local, mimeographed newsletter for less than 100 post-polio survivors, G.I.N.I. has grown into a multifaceted organization by and for all people with disabilities.

Through its publications, conferences, and information service, G.I.N.I. challenges and unites us as advocates and activists for the rights and dignity of people with disabilities throughout the world. This Fifth International Conference—and its spirit of sharing—demonstrates the depth and breadth of G.I.N.I.'s impact on our lives.

But my story is only important because it illustrates so clearly what G.I.N.I., the organization, and Gini, the person, have meant to so many people. It truly reflects G.I.N.I.'s past and future because it is a story that could be retold in hundreds of ways by hundreds of other people in this room and around the world.

Nephesh — Breath and Spirit

This night, as some of you know, contains within it a rare and wonderful privilege. Gini Laurie's life and work among us are coming to a magnificent close, and we are sharing in it. Tonight we all share a common gratitude that the God of Life, and her very personal God, sustains her into this moment together of triumphant celebration.

It is hard but strangely comfortable to relate to her reclining, physically weakened, working for breath, and at the same time to see her in the mind's eye energetically striding about, gathering us together for

G.I.N.I. is an organization, but that organization is a person—Gini Laurie—and a family—each one of us.

Gini's voice continues to ring loud and clear—there is much work to be done to insure that all people can live and work and play independently and with dignity. Equally loud and clear is the message that we must be individually and collectively responsible to see that this work is done because no one else is going to do it.

Without us G.I.N.I. will not continue—each of us has a voice and the unique resources to support and actualize G.I.N.I.'s goals—which in reality are our goals!

Gini Laurie's life has been lived in celebration of the human spirit and its potential. I believe Gazette International Networking Institute can and must continue that celebration.

the next, and then the next plenary session of these biennial Conferences.

She has joined us in yet another way, as she has been joining us for fully forty years. She has entered our lives with mind and heart since her first volunteer hour in a Cleveland hospital. Gradually that mind and heart expanded until they embraced the lives and experiences of literally thousands of us around the world.

My own life was profoundly changed by four issues of the GAZETTE I was handed in a rehab hospital bed twenty-five

I'd like to close with a song that touched me. It is the essence of what Gini and the GAZETTE are to me—the "Wind Beneath My Wings." Though some of my close friends know I have a not-so-secret desire to sing on Broadway, I'll spare you that and instead just share [some of] the song's lyrics. It was sung by Bette Midler in the movie "Beaches." Perhaps some of you have heard it.

"...You were content to let me shine, You always walked a step behind.

"Did you ever know that you're my hero? You're everything I would like to be.

"I can fly higher than an eagle. You are the wind beneath my wings."

Fifth International Polio & Independent Living Conference (1989) —Mickie McGraw

years ago, long before I ever knew her. And I know many of you have had similar experiences.

While others were despairing, she was seeing possibilities. While others were saying something couldn't be done, she was saying let's try. While others were waiting for expert professional opinion, she was finding expert personal experience among those whose lives were on the line. While others have spent their time planning grand schemes and magnificent national organizations in their heads or on paper, she was working at

trading information and connecting people in a living, breathing, human organism that defied easy categorization—maybe that's why she referred to it simply as "her friends."

That organism has given birth, in its own mysterious way, to other manifestations of the urge toward full life among those of us who are disabled—the bigger, more public structures and organizations, the products and programs—that we almost take for granted today.

There is a Hebrew word, "nephesh," that is used in the

Old Testament to describe what God breathes into the human beings He had created. It means two things. It means both Breath and Spirit depending on where and how it is used. Gini, you have offered both to us for many years. You early became an expert on breathing, and then how to do it at home and out in the open, when it didn't come easily. And in doing so you found Spirit within us to which you added a courageous, tireless, happy Spirit of your own. Together those gifts have given us Life, and we are grateful to you for all of it.

In this moment together, as all the years and words and friends and experiences come together in powerful focus, we would give back to you the fullest measure of that "nephesh"—both Breath and life-giving Spirit—for the limitless future toward which you now are moving.

My friends, our friend Gini Laurie.

Fifth International Polio & Independent Living Conference (1989) —Jack Quigley

Gini Laurie died of cancer on June 28, 1989 at her "Gazette House." The burial service at Bellefontaine Cemetery in St. Louis was private.

On July 1 Rev. Patrick O'Laughlin celebrated memorial mass at the St. Louis Cathedral, 4431 Lindell Boulevard. Rev.

James Michler concelebrated the mass.

Mr. Tanner Chrisler read from Isaiah 25:6,7,9; Romans 14:7-9,10-12; and Matthew 25:31-46.

Rosemary Boedicker, Terry Lynch, Betty Morris, and Helen Zak, ladies who lovingly assisted

Gini during her illness, were Eucharistic Ministers.

Rev. O'Laughlin spoke for us all when he said, "...we thank God for the great gift, the blessing Gini was to all of us."



To Friends of Gini and G.I.N.I.

We wish to thank the G.I.N.I. friends who sent condolences upon the death of our sister. The reminiscent letters provided lasting memories and the thank you letters provided comfort.

Mrs. Herbert (Mickie) Cammerer, Dayton, Ohio

Mr. Jack Wilson, St. Louis, Missouri

To Contributors to the Gini Laurie Endowment

Your response to the Gini Laurie Endowment has been most gratifying.

The G.I.N.I. Board of Directors wants to thank all of the many generous contributors to the Endowment. You have contributed significantly to Gini's on-going work, which continues to expand in scope and volume.

The entire fund is prudently invested, and the interest it is generating is currently being reinvested. Only the income

generated by the fund will be used, as needed, to support current operations. We are hopeful that the Endowment will continue to grow. Contributions are tax-deductible.

We of the Board and staff are very excited about the future of G.I.N.I. We hope you will continue to feel proud of all of our publications and identify with our on-going people-to-people effort. Thanks very much to all.

Jack Quigley, President, G.I.N.I. Board of Directors



FRIENDS AROUND THE WORLD

At three months of age, in 1910, I had poliomyelitis. Eighty years later I look back, and with prayer I have truly lived.

All my life I have edged open heavy oak doors of cathedrals. I had to get inside to pray. Denomination made little difference, Protestant, Catholic, or Jewish. The route covers four continents. In my travels I have pried open the heavy doors of Notre Dame, Chartres, Saint Mark's, Saint Paul's, Coventry, and Canterbury.

I now have had a part in opening the doors of the National Cathedral, Washington, DC, for all individuals with a disability.

My gift is new doors at the top of the ramp on the north side. In the original style, the new heavy oak doors are motorized. The inner doors were not replaced but motorized.

"I am as happy as the four men in Luke, Chapter 5, who went up on the roof and let the paralyzed man down with his bed through the tiles."

Y'vonne Greatwood, 1515 Great Falls Street, Apt. 403, McLean, VA 22101 U.S.A. Y'vonne has secured a design patent for her crutch pads and is looking for a company that will produce and distribute them.

Y'vonne Greatwood and the late Rt. Rev. John T. Walker, Bishop of Washington.

"Inclusion Body Myositis (IBM) is a rare, progressive disease of distal and proximal muscle groups resulting in weakness and atrophy of the muscles. It is non-familial and is resistant to cortico-steroid therapy and other immunosuppressive therapies. It is often painless, but some individuals may suffer from intense pain. Progress of the disease varies.... Cause is unknown. Diagnosis is confirmed by muscle biopsy.

"I am active in trying to form a support group for this rare disease. The purpose of this support group will be to exchange information, provide emotional support, increase awareness of the disease in the

medical community, and stimulate research."

Jerome J. Pietrowski, 6300 W. Touhy Avenue, Niles, MI 60648 U.S.A.

"My niece in Jacksonville, FL, is 38 years old and has a rare brain disorder diagnosed as paraneoplastic cerebella degeneration. I would like to know if there is anyone else who has this disorder so she can communicate with them. I feel that if she knew there was someone else to share frustrations and small success with, perhaps it would help her cope."

Lois Schultz
501 Andrus Road
Downers Grove, IL 60516
U.S.A.



"Spent this year gradually getting people together to start a polio support group and also trying to mobilize paramedics...."

Patricia Rock
174 Daniels
Welwyn Garden City
Herts AL7 1QW
United Kingdom

"During the recent First Pacific Northwest Regional Polio Conference, in Richmond, B.C., I met with polio survivors who had had paralysis of the throat and/or face.... We had several concerns. How do we maintain the function we have? How do we keep from deteriorating? We also had several things in common. We all have swallowing problems, choke easily, grind our teeth, and have varying degrees of hassles with other people's attitudes. I would appreciate receiving comments."

Sieglinde Stieda
2790 West 21st Street
Vancouver, B.C. V6L 1K4
Canada

"Progress has been slow and it's taking longer than I had hoped, but even without our published directory the Travelin' Talk network is finally starting to work."

"...very rare and special people who are willing to have their names and telephone published for travelers to call in a time of need...."

To become a member of Travelin' Talk, an information network providing assistance to travelers with a disability, contact: Rick Crowder
Travelin' Talk, P.O. Box 3534
Clarksville, TN 37043 U.S.A.

Porta-Lung is available, in Europe, through Uwe Frehse, Westendstr. 93, D-8000 Munchen 2, West Germany.

G.I.N.I. has received several notes from Zhang Li, Beijing Children's Welfare Institution, No. 52 Quing He, Beijing, China, a special guest at the Fifth International Polio & Independent Living Conference in June 1989. "I think of Mrs. Laurie's laughing countenance and speech, Mrs. Laurie's deep influence on my heart. With her help I was able to attend the Conference. I personally met people with disabilities from other countries and saw the beautiful city of St. Louis. I shall never forget."

"...closed head injury...in 1983. I was in a coma for five weeks. I have limited mobility and strength.... I have some long term and short term memory loss. I would like a U.S. pen pal."

Dominic Musso
1215 Seneca Drive
Dothan, AL 36301 U.S.A.

"I am 39 years of age and had polio at the age of six and would like to correspond with others."

Calvin Green
Cedar Grove
Mandeville P.O.
Jamaica, West Indies

"My cousin is very much interested in meeting people [polio survivors] thru writing. Her name and address are Miss Digna Albarillo, 56 Malvar Street, Project 4, QC, Metro Manila, Philippines, 3008."



"I am very sorry I could not attend your conference because my father suffered a heart attack. I had hoped to meet other polio survivors throughout the world. Perhaps some would like to write to me. I have a senior position in a publishing house."

Rajesh Rawal
8/182 Sunder Nagar
Naranpura Char Rasta
Ahmedabad 380 013
India

Six Point Plan

The Six Point Plan is a section of the Omnibus Budget Reconciliation Act of 1987 (Public Law 100-203). The law which became effective January 1, 1989, outlines the new payment system for the purchase or rental of DME (durable medical equipment).

Equipment is classified into six categories and the "capped rental items" category has caused major problems for individuals with a disability covered by Medicare.

Before the passage of the Six Point Plan, lump sum purchase of DME was allowed, and the user retained ownership of the equipment.

Under the present law, in most cases, expensive DME (in excess of \$150, which includes power wheelchairs, chest cuirass with pump, commodes, and walkers) is classified as "capped rental items." The rental agreement is for a maximum of 15 months with Medicare paying the vendor a monthly rent calculated as "10% of the average submitted purchase prices on assigned claims for new equipment between July 1 and December 31, 1986, updated to account for inflation."

The total rental payments cannot exceed 150% of the original DME cost. After the 15th month, the vendor retains ownership and the client continues to use the equipment. The vendor may only bill for maintenance six months after the initial 15 months.

The above regulations have had a definite financial impact on

vendors. Consequently, vendors are refusing services to Medicare recipients. Medicare consumers are left with no means of access to repairs or new DME.

Dianna Poggetto at the Center for Independent Living (CIL) in Berkeley, CA, chairs the CIL Medicare Committee which has proposed an amendment to the Six Point Plan.

"Our solution to this problem is to retain the option of either lump sum payment or rental."

The option to rent is acceptable for consumers who only need equipment for a short time.

For long-term DME users (i.e., individuals with a disability), the lump sum payment is the only sensible procedure. The lump sum payment will financially allow vendors to provide the services that keep DME functional. In addition, the user will own the equipment which is very important to an individual with a disability when traveling or relocating.

We ask readers of the *Rehabilitation Gazette* who have been affected by the Six Point Plan to send details of your experience to G.I.N.I., 4502 Maryland Avenue, St. Louis, MO 63108. The collective experiences and concerns will be forwarded to Dianna Poggetto, CIL, 2539 Telegraph Avenue, Berkeley, CA 94704 (415/841-4776).

We strongly encourage you and your groups to secure a packet of information from Dianna and become involved in changing these regulations.

Americans with Disabilities Act

The Americans with Disabilities Act was overwhelmingly passed by the Senate in September 1989.

During the months of January and February, the Act is being considered by four House committees (Education & Labor; Public Works & Transportation; Judiciary; Energy & Commerce). It is still necessary to contact your representatives and ask that they support the ADA without any further weakening amendments. Mail your personal letter (they do not receive many personal letters) of support to Hon. (Name), U.S. House of Representatives, Washington, D.C. 20515.

Over 1 million ADA postcards have been printed. Quantities of 200 or more are available by contacting ADA Regional Contact Persons. Call G.I.N.I. at 314/361-0475 for the names and phone numbers of these contact people.

Upcoming Events

Conference on Polio Eradication and Post-Polio Physical Rehabilitation, January 30-February 1, 1990. Frederick Maynard, M.D., Sunny Roller, M.A., and a team of specialists from the University of Michigan will be sharing their expertise with the physicians in South India courtesy of Rotary. For more information contact Dr. S. Jones, Home for Handicapped (Polio) Children, LMS Compound, Trivandrum 695033, Kerala, India.

1990 International Art Show by Disabled Artists—27th Year. The deadline for artwork is February 28, 1990. Contact Art Show, Sister Kenny Institute, 800 E. 28th St. at Chicago Avenue, Minneapolis, MN 55407 U.S.A. (612-863-4482) for more information.

World Health Day (Our Planet, Our Health: Think Globally, Act Locally), April 7, 1990. For a free planning kit, contact the American Association for World Health, 2001 S Street, NW, Suite 530, Washington, DC 20009 U.S.A.

Abilities Expo '90 (Convention Center, Los Angeles, CA), April 6-8, 1990. For more information about a show of products and services for individuals with a disability, seniors, professionals, educators, and dealers, contact RCW Productions, Inc., 1106 2nd Street, Suite 118, Encinitas, CA 92024 U.S.A. (619/944-1122).

The Ventilator: Psychosocial and Medical Aspects; Muscular Dystrophy, Amyotrophic Lateral Sclerosis, and Other Diseases: The Patient, The Family, The Staff, and The Community; The Present and The Future, April 26-28, 1990. This symposium is coordinated by The Foundation of Thanatology and will be held at the New York State Psychiatric Institute in New York City. For information contact Dr. Austin H. Kutscher, Columbia-Presbyterian Medical Center, 630 West 168th Street, New York, NY 10032 U.S.A.

The 1990 Independent Living Conference, May 12-15, 1990. This conference, held at the Hyatt Regency Bethesda, MD, is co-sponsored by the Research and Training Center on Independent Living at the University of Kansas and the National Council on Independent Living (NCIL). Contact Susan Elkins, 3111 Haworth-BCR, University of Kansas, Lawrence, KS 66045 U.S.A. (913/864-4095).

Post-Polio International Conference: Poliomyelitis-A Forgotten Disease and its Late Effects, May 23-25, 1990. Contact Frances Brown, 6203 Fegenbush Lane, Louisville, KY 40228 U.S.A. (502/239-9792) or Lee King, Heart & Lung Jewish Hospital, Louisville, KY (502/587-4044).

Polio Support Group Leaders' Workshop, June 8-10, 1990. Contact Joan Headley, International Polio Network, 4502 Maryland Avenue, St. Louis, MO 63108 U.S.A. (314/361-0475).

Abilities Expo '90 (Cervantes Convention Center, St. Louis, MO), October 5-7, 1990. Contact RCW Productions at address above.

NJ Conference on the Late Effects of Polio, October 13, 1990. Contact Raritan Valley Post-Polio Support Group, RD 1 Peapack Road, Far Hills, NJ 07931 U.S.A.

Sixth International Polio & Independent Living Conference, June 5-8, 1991. Contact Joan Headley, G.I.N.I., 4502 Maryland Avenue, St. Louis, MO 63108 U.S.A.

FIFTH INTERNATIONAL POLIO & INDEPENDENT LIVING CONFERENCE

MAY 31 - JUNE 4th, 1989

Sheraton-St. Louis Hotel • St. Louis, Missouri

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<p><u>Tape #2</u> - What Really Limits Us? Elevating Everyone's Expectations 2-Tape Session Date: 5-31-89 Time: 1:30 p.m. - 4:45 p.m.</p>	_____	_____
<p><u>Tape #3</u> - International Progress Reports: Networking and Research 2-Tape Session Date: 6-1-89 Time: 8:30 a.m. - 11:45 a.m.</p>	_____	_____
<p><u>Tape #4</u> - Prescription for Fatigue, Underventilation, and Weakness 2-Tape Session Date: 6-1-89 Time: 1:30 - 4:45 p.m.</p>	_____	_____
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<p><u>Tape #6</u> - Psychological Adjustment: Several Points of View Including Yours 1-Tape Session Date: 6-2-89 Time: 1:30 p.m. - 3:30 p.m.</p>	_____	_____
<p><u>Tape #7</u> - Ethical Theory, Medical Care, & Life and Death Decisions 1-Tape Session Date: 6-3-89 Time: 8:30 a.m. - 9:30 a.m.</p>	_____	_____
<p><u>Tape #8</u> - Mutual Decision-Making In Life & Death Situations 1-Tape Session Date: 6-3-89 Time: 10:00 a.m. - 11:45 p.m.</p>	_____	_____
<h3>Home Mechanical Ventilation Workshop</h3>		
<p><u>Tape #9</u> - Ventilation Problems & Solution of Anesthesia, Tracheostomies, Sleep and Swallowing-Related to Polio, S.C.I. 1-Tape Session Date: 6-3-89 Time: 1:30 p.m. - 3:00 p.m.</p>	_____	_____
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<u>Tape #12</u> - Travel With Ventilators 1-Tape Session		
Date: 6-3-89 Time: 3:00 p.m. - 4:00 p.m.	_____	_____
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Date: 6-3-89 Time: 3:00 p.m. - 4:00 p.m.	_____	_____
<u>Tape #14</u> - Demonstrations of New Face Masks, Cpaps and Glossopharyngeal (Frog) Breathing) 1-Tape Session		
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Gazette International Networking Institute



STATEMENT OF PURPOSE

The Gazette International Networking Institute is an organization of people with disabilities, their families, friends, and supportive health care professionals. It is dedicated to supporting the independent living, self-direction, dignity and personal achievement of people with disabilities everywhere. G.I.N.I. also communicates with the general public. It seeks the alteration of current social and economic patterns toward the full participation of people with disabilities in every aspect of the broader community.

G.I.N.I. will continue its historic efforts related to polio and its late effects. Building on this history, it will also continue to collaborate with people with other physical disabilities in support of their needs and goals.

G.I.N.I. is international in scope and collaborative in style. G.I.N.I. operates in two modes: **information gathering and dissemination, and connecting people with people.**

G.I.N.I. is a compiler and source of information:

- It reviews and evaluates information.
- It regularly publishes substantive newsletters and journals.
- It maintains an historic, yet up-to-date library and resource center.
- It provides detailed responses to specific inquiries on request.

G.I.N.I. is a network of people:

- It actively resources polio and other support groups in the United States and around the world.
- It encourages and supports local, community-based organizations dedicated to education in disability issues and improvement in the delivery of health care services for people with disabilities.
- It organizes periodic international conferences bringing together people with disabilities, leaders in the disability rights movement, health care and rehabilitation professionals, and interested friends to interact, to learn from each other, and to define up-to-date disability related issues.

Glimpses of G.I.N.I. Friends ...

