

# VOICES

THE NEWSLETTER OF PARTNERSHIP FOR CARING

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## Newspaper Series Spotlights Living with Dying in America

by Renie Rutchick, MSSS

Sandra North vividly recalls the night her mother died. After spending four years in a nursing home with advanced Alzheimer's Disease, her 89-year-old mother was rushed to a hospital because of difficulty breathing. In the emergency room, she was placed on a respirator. "She had tubes everywhere. I begged them to let her go in peace, but they wouldn't listen to me," says North. "When her heart stopped, a crash team rushed in to try to resuscitate her. In the process they broke her ribs. Finally they stopped trying and she died. The doctor said, 'We did all we could,' but she deserved a better end."

North has filled out a living will and appointed a healthcare proxy. Still, she worries that her death will be no better than her mother's. "How can I make sure things will be different?" she asks. As 80 million baby boomers prepare to care for aging parents, many are asking similar questions. So too are their parents.

These questions are the subject of *Finding Our Way: Living with Dying in America*, a 15-part newspaper series that will explore complex issues and endeavor to create a new culture in which we can be cared for as we near life's end. *Finding Our Way* is a collaborative national education effort coordinated by Partnership for Caring, Last Acts, The Center for Advanced Illness Coordinated Care/VA HealthCare Network Upstate New York at Albany, and the Center for Death Education and Bioethics at the University of Wisconsin.

Each article in the series will be written by a leading expert in the field of end-of-life care and will include compelling personal stories and state-of-the art information, tools and resources. Importantly, *Finding Our Way* considers matters far broader than our last hours or even our last days or weeks. *Finding Our Way* shows us that how we die is determined, in large part, by how we live with dying.

### Breaking New Ground

The *Finding Our Way* series begins the week of September 10. The 15-part series will be distributed by Knight-Ridder Tribune (KRT) News Service, one of the nation's leading distributors of news and feature articles, with more than 350

newspaper subscribers world-wide and a potential readership of 32 million. In a spirit of public service, KRT will increase potential readership by placing the series and related photos and art on a website where any newspaper can download and run it without cost, even those who are not KRT subscribers.

***Finding Our Way* shows us that how we die is determined, in large part, by how we live with dying.**

PfC Board Member Dan Tobin, MD, is the *Finding Our Way* Project Director and its chief architect. "More and more, we see death portrayed accurately and with sensitivity in TV

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## ONE VOICE

Karen Orloff Kaplan, ScD • President and CEO

Dear Friends,

It's a trend and we're listening! By phone, letter and email, many of you are getting in touch. In fact 8,000 of you completed the survey we sent out with the Winter 2000 issue of *VOICES*. It was a remarkable response and we're very grateful.

The vast majority of your communications have been enormously positive, particularly about PfC's new website ([www.partnershipforcaring.org](http://www.partnershipforcaring.org)) and recent editions of *VOICES*. Best of all, you have been full of wonderful suggestions about how we can help you — our Partners — to advocate more effectively in both your personal lives and for others.

The Spring issue's article, *Compassion Sabbath: Improving Ministry at Life's End*, drew uniformly positive reviews and requests for advice about how programs like it might be started in your own communities. A number of you asked to see more on issues of religion and spirituality as they affect people approaching the end of life. We will provide this information with pleasure.

Another issue high on your agenda is family caregiving. Several asked for more information about the caregiving many of us will provide as, increasingly, those close to us live with debilitating chronic and terminal illness. In response to your suggestions, you will find a new column, "Caregivers Corner," beginning in this issue of *VOICES* (see page 3). Let us know what you think about the column and, most important, what you'd like to see in it.

We're particularly excited by your response to the survey questions asking how you might get actively involved to improve end-of-life care and caring in your own communities. We asked how you'd like to raise your voices to spread the word about what improvements are needed. We asked if you would be willing to demand that changes be made so that care becomes readily available for you, those close to you, as well as others in your community. Just about all of you who completed the survey volunteered to raise your voices — contacting legislators, calling friends, hosting meetings and distributing information.

Surveys continue to come in. To enable more people the opportunity to get involved, we've put a copy of the survey on our website. In our next newsletter, we'll provide more details about the survey results. Even more important, during the next six months, we'll get back to those of you who responded with ideas for actions you might take and materials to help you to take these actions. Together, we'll raise our voices loudly — we'll make a difference.

Thanks to all of you who have added your voices to Partnership for Caring: America's Voices for the Dying. And, thanks to all of you who keep in touch. Please keep it up.

—Karen

## TAKE ACTION!

Help people across the nation become strong voices for dying people and their loved ones. How? One action step at a time!

### Promote *Finding Our Way*

This 15-week series offers a wonderful opportunity for our nation to learn about end-of-life issues and to affect change (see cover story). Make a difference and take one — or many — of these actions.

- **Launch** a letter writing campaign. Write your local newspaper to ask that they run the series. Tell why you think it's important for a comprehensive series on death and dying to appear in your paper. Let your paper know the series will be available without cost to all newspapers on the Knight-Ridder Tribune website beginning September 10. Ask family, friends and colleagues to write letters, too.
- **Contact** local radio and television stations. Tell them about the series and encourage them to run companion stories.
- **Share.** Do you have an end-of-life story? In your letters, offer to tell it to reporters.
- **Join** a local forum or steering committee to help plan community events associated with the series. Call PfC to learn how.
- **Engage** your friends and family in a discussion about the articles as they appear in your newspaper. Form an "articles club" or ask one of your community organizations to do so.
- **Let us know** you raised your voice. Drop a note, e-mail or call (see box below) to tell us your action steps.

### Nominate a Caregiver

- **Honor** a caregiver. *Caring* newsletter's Caregiver of the Year contest (see *Caregivers Corner*, page 3) offers a special opportunity to acknowledge a caregiver who performs these rewarding but stressful responsibilities. Pay tribute to someone you know — or to yourself — by making a nomination.



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## CAREGIVERS CORNER

*There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.*

—Former First Lady Rosalynn Carter

There are more than 25 million caregiving households in the United States. While caregiving for an adult family member or friend whose health status has deteriorated can be very rewarding, it is often stressful and hard work. In this column we acknowledge the rewards and difficulties and provide information about helpful resources as well as ways to advocate for better services for our nation's caregivers.

### Caregiver of the Year: Call for Nominations

Do you know a great caregiver or caregiving family? *Caregiving* newsletter's Caregiver of the Year contest honors five caregivers each year. Anyone caring for an aging relative, friend or neighbor is eligible. Nominations are accepted annually from June 1 to October 1. You can even nominate yourself!

To nominate a caregiver for this award, simply write an essay describing how the caregiver meets the following criteria:

- Caregiver's ability to complement caregiving responsibilities with his or her own needs and interests.
- Caregiver's problem-solving techniques.
- Caregiver's use of community services.
- Caregiver's community involvement.

Winners will receive a certificate, prizes and a subscription to *Caregiving* newsletter, which offers support, information and opportunities to share concerns with other caregivers and ask questions of experts. The winners and their stories will be featured in the December issue.

For more information about the Caregiver of the Year award or *Caregiving* newsletter, visit [www.Caregiving.com](http://www.Caregiving.com) or call Partnership for Caring (800) 989-9455.

### Stay Informed, Be an Advocate

A new website ([www.CaregiversCount.com](http://www.CaregiversCount.com)) was recently launched to educate, inform and empower family caregivers about activities in our nation's capitol that could affect them. [CaregiversCount.com](http://CaregiversCount.com) features articles that focus on the most recent developments and initiatives in Washington and provides suggestions on how to effectively advocate for or against positions and programs. It also offers links to other sites of interest to caregivers.

## Wit Screening a Huge Success

HBO Films, Partnership for Caring, and Last Acts held a screening and reception for the Mike Nichols film adaptation of the 1999 Pulitzer Prize winning drama *Wit*, which aired March 24 on HBO. Several members and representatives from more than 40 congressional offices attended. Other invited guests included Pfc partners who live in the metropolitan Washington, DC area and Last Acts partners.

The response was so strong, a second screening was arranged to enable more people to preview the film. The film's poignancy is beautifully expressed in the following letter to Pfc Chief Operating Officer Garey Eakes (see page 8).

March 22, 2001

Dear Garey,

I just wanted to thank you again for inviting me to the screening of *Wit*. As I have no political clout, I was obviously invited for personal reasons, and I appreciate your thinking of me.

I've been thinking about the movie all morning, and wanted to share my thoughts with you. When I saw the play it was before Dan was diagnosed, and while I found it powerful, moving, and thought-provoking, it really didn't affect me personally. Seeing the movie after having gone through the experience of watching someone I love die from cancer was a totally different experience.

The details in the movie were realistic and brought back lots of memories for me – Dan and I shared lots of popsicles and went through bottles of lotion. I can't remember ever seeing a movie that portrayed the process of dying so vividly and graphically – it was true. I was particularly struck by Vivian's comment about how fast the deterioration was at the end. Dan's death was like that.

While I did not have to deal personally with the issues that the movie brought up – the lack of sensitivity of the medical profession, the use of experimental treatments, the importance of research vs. the right to die with dignity – they should be of concern to all of us babyboomers as we start to deal with the deaths of our parents and start thinking about our own mortality. I feel immense gratitude that Dan was able to die at home, with no medical intervention other than pain medications, surrounded by the love and kindness of those close to him.

And I feel immense gratitude for you and your organization for bringing the end-of-life care issue to our consciousness.

Thanks, Garey.

*Robin Mass*

## Finding Our Way: Living with Dying in America

Look for these articles in the Knight-Ridder Tribune series to be published and distributed in newspapers this fall, beginning the week of September 10:

### Living with Dying in America

by Robert Milch, MD, and  
Donald Schumacher, PsyD

### It is Time to Talk:

#### Conversations Near the End of Life

by Dale Larson, PhD

### Widowhood

by Myra Christopher

### Palliative Care: Managing Pain and Other Symptoms

by Russell Portenoy, MD

### Planning for Care Near the End of Life

by Robert Bendiksen, PhD, and  
Bernard Hammes, PhD

### Culture and Diversity

by LaVera Crawley, MD

### Spirituality and Faith

by Martha Rutland-Wallis, PhD, and  
Hugh Maddry, MDiv, DRE

### Last Rites: Respecting a Life, Acknowledging a Death

by Thomas Lynch

### Caring for Aging Parents and Partners

by Karen Orloff Kaplan, ScD, and  
Ira Byock, MD

### Hospice: Comfort and Care

by Stephen Connor, PhD

### Nursing Homes & Long-Term Care

by Len Fishman, JD, and  
Muriel Gillick, PhD

### When a Child is Dying

by Joanne Hilden, MD, and  
Bruce Himmelstein, MD

### Unexpected Violence and Death

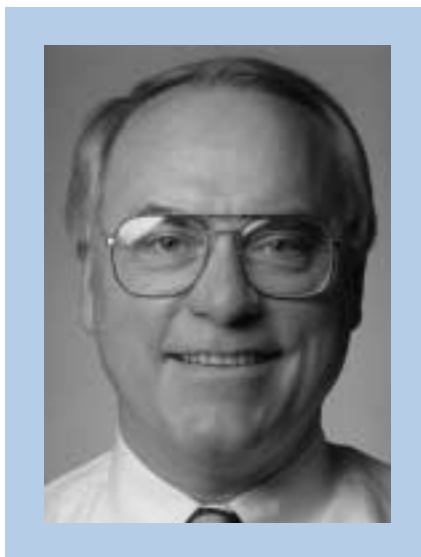
by Charles Corr, PhD

### Living with Loss

by Marcia Lattanzi-Licht, RN, MA

### A Vision for the Future

by Dan Tobin, MD



Mike Duggan, Director of KRT News Services, Special Sections and Syndication

read the series. If it is a success, I think it will lead to more attention to the subject by journalists in the future," he adds.

*Finding Our Way* focuses on a broad range of topics that impact the way people live and are cared for near the end of life (see sidebar). For example, Dale Larson, PhD, Chair of the Department of Counseling Psychology at Santa Clara University, writes about *It is Time to Talk: Conversations Near the End of Life*. "For people with serious illness, the medical treatments and quality of life that lie ahead are largely determined by conversations they have with healthcare providers and loved ones," says Larson. He discusses the types of conversations that are important, the barriers to having these often-difficult discussions and offers suggestions about ways to begin talking.

Another article considers the problems of *Widowhood*. "Widows and widowers are at greater risk of having significant health problems than are others," says Myra Christopher, President of the Midwest Bioethics Center and the article's author. She notes that bereaved spouses are often elderly men or women who have had the responsibility of being a primary caregiver. At the time of their loved one's death, they find themselves alone and often physically and emotionally exhausted. "It is also important to remember, however, that not all widows are old," adds Christopher. "In fact, there are a half million widows under age 45 in the US."

## Success Depends on Community Outreach

More than 350 community action coalitions nationwide are coordinating efforts to promote the series in their communities. "Although Knight-Ridder will make the series available to all newspapers across the country, each paper will make an independent decision about whether to run it. So, it is critical for consumers to write their local newspaper editors to let them know the issue is important to them and to ask that they run the series," says Garey Eakes, Pfc's Director of Public Affairs (see "Take Action," page 2).

"Widely read newspaper articles have had great impact in the past and have laid the groundwork for significant social change," says Karen Kaplan, Partnership for Caring's CEO. "We are honored to work with the very gifted writers on this project. And, we deeply appreciate the work of the community coalitions who will give life to these articles in their communities."

shows such as *ER* and *Gideon's Crossing* and this has a big impact on how the public views death. It seemed the timing was right to engage the public more directly in the wider issues and to provide the resources to help them gain control over their future," says Tobin who also directs The Center for Advanced Illness Coordinated Care/VA HealthCare Network Upstate New York at Albany.

"This series offers a great opportunity to address an issue that affects everyone but is not often discussed in the media," says Mike Duggan, Director of KRT News Service, Special Sections and Syndication. "I think our views on end-of-life issues are changing. My hope is to have as many people as possible

Building on the momentum of the highly successful community outreach associated with last year's PBS airing of *On Our Own Terms, Moyers On Dying* — which had an audience nearly 60% larger than the PBS prime-time average — the local coalitions hope to stimulate a similar response with *Finding Our Way*. For example, some of the coalitions are planning to:

- Urge local newspapers, TV and radio shows to develop local stories. Groups are offering to identify sources (both patients and experts), provide lists of local resources and even suggest potential advertisers.
- Involve local arts communities by staging art exhibits and special performances of the play *Wit* with 'talk back' discussions.
- Host community-wide discussion groups where residents can talk about the issues raised in the newspaper series.
- Encourage healthcare organizations to schedule "Grand Rounds" lectures on end-of-life care for professionals and informal brown-bag lunches where employees can discuss the series topics.

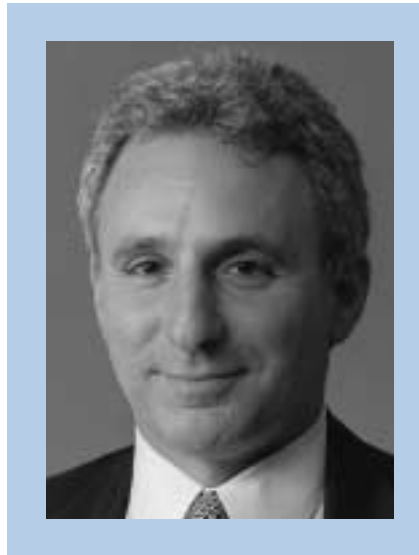
**"Transforming our fear into positive and proactive action will help us see the opportunities for growth and closure at life's end."**

to amaze me," says Donna Bales, President of the Association of Kansas Hospices and Project Director of the Living Initiative for End-of-Life Care (LIFE). "So many groups are coming together and the support they give one another really helps. The power of grass roots efforts is incredible."

## The Next Chapters

The newspaper series and all the community action that surrounds it will not end the story for *Finding Our Way*. In the fall of 2002 an expanded version of the 15 newspaper articles will be published in book form. The book will serve as a text for a variety of courses on end-of-life care and will be available to consumers in bookstores throughout the country.

At the same time, the *Finding Our Way: Living with Dying in America* website will be launched. The website will offer course content free-of-charge to universities and



*Don Tobin, MD, Finding Our Way: Living with Dying in America Project Director*

- Initiate community events, such as town meetings or mayoral proclamations to kick off the series and raise public awareness.

In Kansas, for instance, coalitions are planning a statewide, televised town hall meeting where people can call in questions to experts. They also will have an ongoing hotline available. Several are preparing discussion guides and materials for consumers about topics such as advanced care planning, pain management and palliative care that will be distributed in libraries, churches and senior centers. "The level of interest continues

## In the Legislature



On the federal level, the National Family Caregiver Support Act (H.R.782) was signed by President Bill Clinton at the end of the 106th Congress. This amendment to the Older Americans Act creates a national Family Caregiver Support Program that authorizes up to \$125 million a year in funding to states to provide systems of support services to family caregivers.

Also approved was H.R.5661, known as the Medicare, Medicaid and SCHIP Benefits Improvement and Protection Act of 2000. This amendment to the Social Security Act includes a five-percent increase in the base Medicare daily payment rates for hospice care.

The amendment also clarified the requirements for an individual to access hospice. While hospice eligibility determinations are supposed to be made by the treating physician, oversight groups known as fiscal intermediaries have been substituting other limiting criteria for the treating physician's independent clinical judgment. Section 322 of the statute states that a determination of an individual's eligibility for hospice due to terminal illness should be based on the physician's or medical director's clinical judgment regarding the normal course of an individual's illness. Hopefully, this will increase hospice usage.

In response to recent legislative changes and the adoption of rules under its "do-not-resuscitate" law, there have been revisions to Ohio healthcare advance directives. The changes to the Durable Power of Attorney for Health Care were minor. However, for those who are terminally ill or permanently unconscious, the amended Living Will now specifically authorizes the withholding of cardiopulmonary resuscitation (CPR) and the issuance of a do-not-resuscitate (DNR) order by healthcare providers. While current living wills are still valid, Partnership for Caring recommends that Ohio residents complete a new Living Will.

# PfC Convenes Summit on Healthcare Agency

**P**artnership for Caring recently convened a summit on healthcare agency, sponsored by The Fan Fox and Leslie R. Samuels Foundation. Sixty-seven nationally known clinicians and advocates joined to create a blueprint for future activities that will improve the ability of healthcare agents to carry out their difficult responsibilities. Samuels Foundation grantees also exhibited information about their current healthcare agency projects.



A few summit participants: Front (left-right): Tracy Miller, JD, VP, Quality and Regulatory Affairs, Greater New York Hospital Association; Joseph Fins, MD, Director of Medical Ethics, NYH-Cornell Medical Center; Arthur Levin, MPH, Director, Center for Medical Consumers; William Nelson, PhD, VA Medical Center National Ethics Center. Back (left-right): Garey Eakes, JD, PFC Chief Operating Officer; Bernard Hammes, PhD, Director of Medical Humanities, Gundersen Medical Center, LaCrosse, WI; Carl Coleman, JD, Associate Professor & Associate Director, Seton Hall Law School.

Participants discussed ways to ease the emotional stress that accompanies making difficult end-of-life decisions on behalf of another. They noted that many agents are not aware of the kinds of decisions they will be called upon to make, so they don't

have the information they need. Likewise, healthcare providers often are unaware of the agents' needs. And while laws grant agents decision-making authority, public policies need to build in more supports for that decision-making process.

The blueprint includes several areas for study and development. A few examples include developing a "job description" of the roles and responsibilities of all parties involved in the process, suggesting policy changes that recognize culturally diverse ways of making

end-of-life decisions, and developing a plan for a public health campaign about the appointment and effective use of healthcare agents. The blueprint will guide the Samuels Foundation in a second round of funding and provide direction to other efforts to change public policy, expand professional education and research, and engage the public in learning about the issues before a crisis occurs.



## IN THE VCR

**F**acing Death is a four-part video series that helps us look at important aspects of planning and care at life's end. Produced by Family Experience Productions, these award-winning videos are excellent resources for individuals and families as well as programs that train healthcare providers and volunteers.

### *Facing Death Part 1: Providing Physical, Emotional, and Spiritual Comfort to Loved Ones (33 minutes)*

This video presents a warm, candid, conversation-starting overview designed to help dying patients and their caregivers and loved ones know what to expect during the dying process and find ways to comfort one another. It presents inspiring and specific information about such issues as caring for patients, pain management, stages of dying, spiritual comfort, humor, disfigurement and counseling.

### *Facing Death Part 2: Practical Planning and Legal Issues (17 minutes)*

An exceptional nurse/attorney explains the legal instruments that can help dying people have their wishes honored and explores the legal issues confronting patients, caregivers and medical providers. Topics include wills, advance directives (living wills, durable powers of attorney for healthcare, and DNR orders) funeral arrangements and organ donation.

### *Facing Death Part 3: Understanding End-of-Life Patients Needs (15 minutes)*

This video helps people who are not dying understand the needs of those who are and begin talking about their own feelings. Patients facing death, caregivers, and healthcare professionals discuss a range of intense concerns and emotions, including honesty, denial, anger, hope and miracles (big and small), making preparations, and finding meaning.



Melissa Robbins (left), Samuels Foundation grantee, discusses results from her research, "Factors that Influence Health Care Agents' Ability to Fulfill Patient Wishes: The Health Care Agent's Perspective," with Molly Katz, Burness Communications.

**Facing Death Part 4: The Gift of Being There**  
(13 minutes)

This video is especially useful for people who have had little direct experience with a dying person. Patients, caregivers and hospice professionals discuss how important it is to a dying person to have family and friends “just be there” and not stay away. It also explores ways of being there for dying people who are alert as well as those who are comatose.

PfC is pleased to offer these videos for home and individual use for \$24.95 each, including shipping and handling. For institutional prices, which include public and group viewing rights, see the order form below.

**NEWSPAPER SERIES SPOTLIGHTS** *Continued from page 5*

the general public — including the ability to download live lectures from experts using new “web-casting” technology. An interactive course may be taken for credit or non-credit through university extension programs. Universities also will be able to integrate any of the content found on the website into their own courses.

“The combined aspects of the project — newspaper series, public outreach, book and website — will provide information and guidance to the consumer and patient, raise the bar for dignity and good medical care, and help us collectively face our cultural fear of dying,” says Tobin. “Transforming our fear into positive and proactive action will help us see the opportunities for growth and closure at life’s end.”

**ORDER FORM**

**Products**

*Advance Directives*. State-specific document with guidebook. Please specify state \_\_\_\_\_ \$5.00

*You and Your Choices: Advance Directives*. Helps readers complete advance directives. QA100 \$3.50

**PfC’s Award-Winning Question-and-Answer Booklets**

*Advance Directives and End-of-Life Decisions*. QA500 \$5.95

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*Cardiopulmonary Resuscitation, Do-Not-Resuscitate Orders and End-of-Life Decisions*. QA600 \$5.95

*Dying at Home*. QA300 \$5.95

*Healthcare Agents: Appointing One & Being One*. QA900 \$5.95

*Medical Treatments and Your Advance Directives*. Includes values questionnaire. QA400 \$5.95

*The Physician-Assisted Suicide Debate: Understanding the Issues*. QA800 \$5.95

**Videos**

*WHOSE Death Is It, Anyway?* An emotionally charged one-hour video that looks at the human side of end-of-life decision making V200 \$24.95

*Facing Death Part 1: Providing physical, emotional & spiritual comfort to loved ones*. 33 minutes. V220 \$24.95 (individuals), \$59.95 (institutions)

*Facing Death Part 2: Practical Planning & Legal Issues*. 17 minutes. V240 \$24.95 (individuals), \$59.95 (institutions)

*Facing Death Part 3: Understanding End-of-Life Patient Needs*. 15 minutes. V260 \$24.95 (individuals), \$59.95 (institutions)

*Facing Death Part 4: The Gift of Being There*. 15 minutes. V280 \$24.95 (individuals), \$59.95 (institutions)

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# PfC Names Chief Operating Officer

We are pleased to introduce M. Garey Eakes, JD, who joined Partnership for Caring in January as our Chief Operating Officer and Director of Public Affairs. He will be responsible for the day-to-day management of PfC operations and our communications efforts. This support allows CEO Karen Kaplan to spend more of her time advancing the PfC mission. "I hope that many of our Partners have an opportunity to get to know Garey and find out what an enormous asset he is for PfC and its mission!" says Kaplan.

Eakes brings a wealth of knowledge, experience and a strong public policy orientation to PfC. An elder law attorney for 16 years, he has been a forceful and effective advocate for older people and those facing long-term illness, disability and incapacity.

He was co-counsel for Michelle Finn in the Hugh Finn case from the initial trial through the Virginia Supreme Court

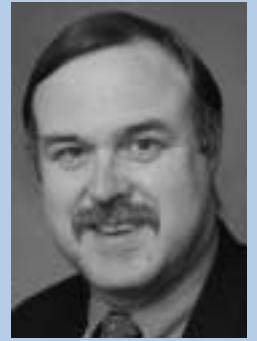
appeals. This case drew national attention when the governor of Virginia intervened to prevent the removal of Finn's feeding tube. Hugh Finn was in a persistent vegetative state from a severe brain injury sustained in an automobile accident. Both the state Circuit Court and Virginia's Supreme Court rejected the governor's petition and the feeding tube was removed. A bill was later passed by the state legislature to partially compensate Mrs. Finn for her expenses due to the action taken by the government to prevent withdrawal of her husband's life support.

As a frequent writer and lecturer, Eakes has been a guest on numerous radio programs and has been seen as a legal expert on *Court TV*, *CSPAN*, *CNN's Burden of Proof*, and the *CBS Evening News*.

Eakes was a founding member of the National Academy of Elder Law Attorneys (NAELA) and served as

President and Chair of its Board of Directors. He has been honored as a NAELA Fellow. In Virginia, Eakes formed a statewide coalition of Alzheimer's advocates and served on the Board of the Alzheimer's Association, Northern Virginia Chapter. He also served for the past two years on the Partnership for Caring Board.

"I had a long-held desire to move from one-on-one representation to a position where I could fully devote my energies to effect change for many. Partnership for Caring is the opportunity to work where my heart is," says Eakes. "I look forward to developing deeper public involvement in raising expectations for care at life's end."



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