2019 Consumer Voice Leadership Award Winners



Based on your nominations, Consumer Voice recognizes people who have demonstrated an exceptional commitment to improving the lives of long-term care consumers. Awards will be presented at our 43rd Annual Conference, November 4, 2019 at the Crystal Gateway Marriott in Arlington, Virginia from 7:00 pm to 9:00 pm in the Grand Ballroom.

JANET TULLOCH MEMORIAL ADVOCACY AWARD: George Barnes

This award was established in 2000 after the death of Janet Tulloch, a nursing home resident, author, committed advocate and long-time member of the Consumer Voice's Board of Directors. It honors a citizen advocate, family caregiver, or long-term care consumer (e.g. resident of a nursing home or assisted living facility or an individual receiving home and community-based services) who has worked directly with and for consumers to improve the lives of long-term care consumers.



George Barnes is a long-term care resident of a Texas nursing home who has routinely advocated for his and other residents' rights. A carpenter by trade, Mr. Barnes has found a family among the residents and staff at his home – a family that he says is at the center of his advocacy work. Mr. Barnes' recent advocacy journey began when he was wrongly evicted from his nursing home and sent to a mental health facility. Even after the mental health facility found that he did not meet commitment criteria, he was not allowed back and was sent to another nursing home, over an hour away from his friends and home. With the help of the Office of the State Long-Term Care Ombudsman, Mr. Barnes won his appeal of this improper discharge, yet the facility still refused to honor the state's order to readmit him. For nine long months, Mr. Barnes fought to be admitted back to the place he called home – a home filled with his

family of residents and staff members. His hard work and dedication paid off, as he was not only allowed to return, but his case also resulted in major changes statewide in Texas. Because of his advocacy work, the state regulatory agency has now instructed all state surveyors to require Texas nursing homes to enforce hearing officers' orders to readmit wrongfully discharged residents. A bill based on his case has also made significant progress in the State legislature. After having such a big impact, Mr. Barnes says he is happy to be back at his home and wants to commend the Ombudsmen and nursing home staff for all the hard work they've done.

HOWARD HINDS MEMORIAL AWARD: Anthony Szczygiel

The Howard Hinds Award was established in 2005 in memory of the late Howard Hinds, a Tennessee District Long-Term Care Ombudsman. Howard was a true champion for residents and for the Ombudsman program as well as a passionate advocate on national issues. The award honors an individual who has effectively advocated for long-term consumers on the local level.



Tony Szczygiel is a SUNY Buffalo Law School Professor Emeritus. Tony taught at the Law School from 1982 through 2015. He earned his Juris Doctor from Boalt Hall, UC Berkeley School of Law, in 1975. From 1977 through 1981 he worked in a Legal Services Corporation funded program providing representation to migrant and seasonal farmworkers. Tony's Law School teaching and research centered on Elder Law and Health Law. Tony has made over 300 presentations for the New York State and local County Bar Associations, as well as other advocates and consumers. He has served as a Board member for various local not-for-profit organizations, including Canopy of Neighbors, a "Village"

dedicated to helping seniors age in community. Tony supervised law students and worked on long-term care issues in the Law School's Legal Services for the Elderly Clinic that he started in 1983 and operated until 2014. The Clinic worked closely with Legal Services for the Elderly, Disabled or Disadvantaged, now named the Center for Elder Law and Justice (CELJ). One major focus of this clinical work was administrative appeals of Medicare and Medicaid determinations, with state and federal court litigation following where appropriate. Tony continues to volunteer with the Center for Elder Law & Justice. After his retirement, Tony became a certified volunteer with the New York State's Region 15 Long-Term Care Ombudsman Program where he is working on systems advocacy projects.

CERNORIA JOHNSON MEMORIAL ADVOCACY AWARD: Martha Deaver

Cernoria McGowan Johnson (1909-1990) set up the national program of Nursing Home Ombudsmen in 1974. The award in her honor is presented to someone whose work has had national impact or is a model for national excellence and who exemplifies accomplishment in his or her chosen field.



Martha Deaver has been doing advocacy work since the 1980's. For the past 20 years, she has served as the President of the Arkansas Advocates for Nursing Home Residents. In 2010, Martha was honored with the FBI Director's Community Leadership Award. She also received the 2016 Arkansas Trial Lawyers Advocacy Leadership Award. In 2014, Martha worked with Jeff Lowenstein with the Center for Public Integrity. In 2006, Martha worked with Trudy Lieberman and Consumer Reports, and her story was featured in the *Ladies' Home Journal*. In 2005, Martha also received the Consumer Voice Janet Tulloch Memorial Award. For the past 15 years, Martha chaired the Annual National Residents' Rights

rally. After finding only annual surveys were posted, Martha worked with GOA culminating in complaint surveys being added to the CMS Nursing Home Compare website. She also served three terms on the Governor's Long-Term Care Advisory Board. Martha serves on two committees focusing on long-term care needs for our Veterans and serves on the Professional Advisory Council for Alzheimer's Arkansas.

JANET WELLS PUBLIC POLICY LEADERSHIP AWARD: Toby Edelman

The Consumer Voice's Policy Leadership Award recognizes an individual who has provided exemplary leadership in the public policy field in advancing quality of care and quality of life for residents receiving long-term care services.



Toby S. Edelman has been representing older people in long-term care facilities since 1977. As a Senior Policy Attorney with the Center for Medicare Advocacy since January 2000, Ms. Edelman provides training, research, policy analysis, consultation, and litigation support relating to nursing homes and other long-term care facilities. Under two grants from the Commonwealth Fund, she evaluated the federal nursing home survey and enforcement system and its impact on state activities and provided technical assistance to states on effective enforcement practices. In cooperation with the Centers for Medicare & Medicaid Services, she recently completed a Commonwealth Fund project to evaluate seven states' deficiency citations for misuse of antipsychotic drugs. Since September 1999, she has written a monthly newsletter on nursing home

enforcement issues. Ms. Edelman was the lead attorney for a statewide class of nursing facility residents who successfully challenged the state of California's refusal to implement the federal Nursing Home Reform Law (Valdivia v. California Department of Health Services, Civ. No. S-90-1226 EJG (E.D. Calif. 1993). As a beneficiary representative, Ms. Edelman has testified before Congress and served on federal task forces, technical expert panels, and working groups on nursing home issues. Ms. Edelman received a B.A., Magna cum Laude, from Barnard College (1968), an Ed.M. from the Harvard Graduate School of Education (1969), and a J.D. from the Georgetown University Law Center (1974). Ms. Edelman is a member of the Washington, DC Bar.

TOBY S. EDELMAN LEGAL JUSTICE AWARD: Kelly Bagby

This award was created in 2009 to honor those who, working through or with the legal system, go to extraordinary lengths to achieve justice for long-term care consumers. It is named in honor of Toby Edelman of the Center for Medicare Advocacy, whose work for more than 30 years has influenced and shaped long-term care law, policy and enforcement.



Kelly Bagby is the Vice President at AARP Foundation Litigation (AFL) managing the office's work related to health, hunger, housing and human services. Kelly specializes in civil rights, disability rights, health law, and other public interest areas, with an emphasis on litigation. She has been a part of AFL's Team since 2008. She has litigated a range of discrimination and public interest cases in federal and state courts for the past two and a half decades. Kelly has served as class counsel in several cases enforcing Title II of the Americans with Disabilities Act to allow people to age in place in the community rather than be forced to have their long-term services provided in nursing facilities. *Darling v. Douglas (Cota v. Maxwell-Jolly)*, 688

F. Supp. 2d 980 (N.D. Cal. 2010); *Brown v. District of Columbia* (Case No. 10-02250). Kelly was co-counsel in several cases in California, Delaware and Tennessee in which nursing facility residents were administered psychotropic medications without any informed consent. She and her colleagues are currently litigating a high-profile case in which a vulnerable nursing facility resident was illegally evicted from the facility where she had lived with her husband for five years and dumped into a hospital without due process.

PUBLIC SERVICE AWARD: Jordan Rau

The Consumer Voice Public Service Award recognizes an individual or organization whose work has profoundly expanded coverage and public understanding of long-term care issues.



Jordan Rau is a senior correspondent for Kaiser Health News (KHN). His stories have been published by *The New York Times, The Washington Post, NPR, USA Today, The Philadelphia Inquirer, Chicago Tribune* and other media outlets. He previously reported for *The Los Angeles Times, Newsday,* the *Concord (NH) Monitor* and two newspapers in Vermont. He is a graduate of Wesleyan University. He joined KHN at its founding in 2009. KHN is a nonprofit news service covering health issues. It is an editorially independent program of the Kaiser Family Foundation, which is not affiliated with Kaiser Permanente.

ELMA HOLDER FOUNDER'S AWARD: Arlene Germain

Established in 2002 as a lifetime achievement award to honor a person whose life work exemplifies leadership in the field of long-term care reform, the award is also a tribute to Elma Holder, the Consumer Voice's founder and friend. Elma's personal commitment, integrity, and vision shaped the organization and quality of care and life in long-term care.



Arlene Germain is Co-founder and President of the Massachusetts Advocates for Nursing Home Reform (MANHR www.manhr.org). MANHR, founded in 2000 by grassroots volunteers, is the only statewide consumer group advocating for improvements in the care, dignity and quality of life for MA nursing home residents. Arlene first learned the importance of strong advocacy when her mother entered a nursing home over 20 years ago. Since then, Arlene has been involved in the care of many loved ones in Massachusetts long-term care facilities. When she assumed MANHR leadership in 2004, Arlene ran the organization on evenings and weekends while she was controller of a prestigious venture capital firm. She retired from accounting in 2011 and then devoted herself full-time to MANHR, on a continued volunteer

basis. Over the past 15 years, Arlene greatly expanded the scope of MANHR's advocacy. MANHR initially networked and mentored family-run councils in nursing homes. Under Arlene's tenure, MANHR's impact grew to include advocating for public policies and promoting best care practices to improve the care and lives of nursing home residents. MANHR now represents nursing home residents in coalitions, committees, and statewide initiatives; is an active advocate in MA Attorney General quarterly meetings; and provides research to state officials and the media. Arlene currently serves on Consumer Voice's Leadership Council, previously was on their Board 2005-07, and has been a member since 1997. In 2013, she was honored to receive the Consumer Voice's Janet Tulloch Award for her dedication to nursing home resident advocacy. Arlene's care experiences with her loved ones and the many injustices to residents are the driving force behind her passionate advocacy efforts.