Funeral service federal legislative and regulatory update

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- Thank you
- Introduction
- What does a funeral service lobbyist do?
- NFDA Advocacy
- The federal legislative/regulatory process
- Details on key federal legislation
- Details on key federal regulations
- Let's talk – your questions/comments

What does a funeral service lobbyist do?

Advocacy ... to change "what is" into "what should be"

- **Advocate**: Educator, cheerleader, sales, diplomat, negotiator, historian, parliamentarian, researcher, liaison
- **Analyze**: policy, situations, people
- **Passionate**: never personal, honest, determined, relentless, thick skinned, able to build relationships
- **Adaptable**: able to change direction and tactics, no script or rules, or schedules

NFDA Advocacy

NFDA Advocacy leads the profession by providing expert guidance on funeral service-related **legislative** and **regulatory** issues to the federal government: Congress and federal agencies

- **Regulatory issues:** (Agencies including FTC, EPA, VA, DoD, DoL, DoJ, CDC, HHS, DHS, etc…sometimes Congress)
- **Legislative issues:** (Congress, outside stakeholders including)
  - **Veteran's funeral and burial issues** (VA, Congress, VSOs, survivor groups)
  - **Mass fatality planning and response** (DoD, DHS, HHS, CDC, Governors, etc.)
  - **Environmental Health & Safety issues** (EPA, NASEM, ACC)
  - **Small Business issues** (Congress, business coalitions, tax coalitions)

The federal legislative/regulatory process

- Federal legislation and regulation are intricately intertwined.

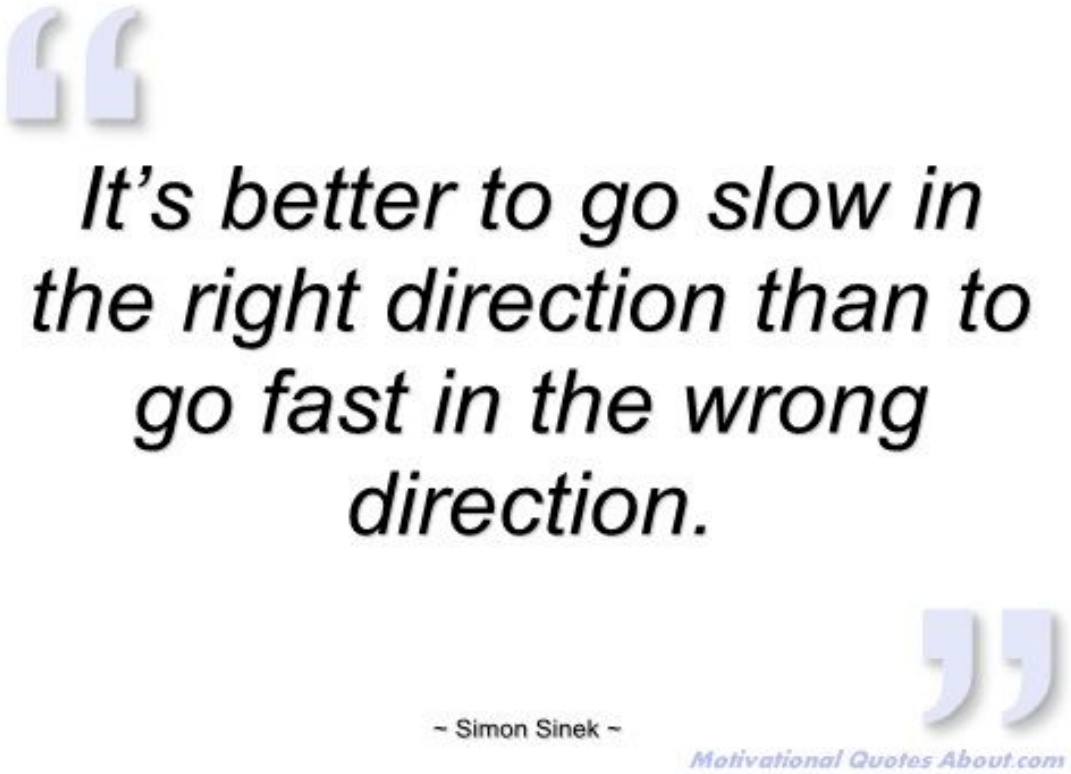
- NFDA initiates and advocates for funeral service legislation with Congress

- Expert guidance can be formal in the form of written Comments or testimony, or oral testimony or can be done out of the public eye.

- When legislation is signed into law, NFDA works in the regulatory phase to help interpret/implement Congressional intent.

- Laws are usually passed with a grace period before enactment to allow agencies to develop regulations.

The federal legislative/regulatory process



- Congress maintains oversight of the agencies and will often engage in oversight activities, particularly if Congress and the Administration are held by different parties.
- Congressional oversight is another way for NFDA to engage in the process.
- This Congress is engaging in a lot of oversight hearings to ensure the agencies are not overstepping their legal authority or creating burdensome regulations.
- Things in Washington move very slowly…until they don't!

The federal legislative process

- Problem/opportunities
- Leadership approval, research, and drafting language
- Bill introduction (but not always legislation!)
- Committee (jurisdiction)
- Subcommittee
- Hearing (sub and full)
- Mark-up (sub and full)
- Votes (sub, full comm, floor)
- Reconciliation (with other chamber)
- POTUS (veto or signed – enactment)
- Regulatory phase

The world of Body Brokers

Sunset Mesa - Colorado

- Colorado Funeral Home Body Brokering Scheme, Part 1 - The Perfect Scam Podcast by AARP
- Sunset Mesa - Criminal Podcast
- Exclusive: FBI Raids Colorado Body Broker Following Reuters Report
- Montrose Funeral Home Owner Who Allegedly Sold Hundreds of Bodies Without Families' Consent is Federally Indicted
- Date Set for Trial in Case of Funeral Home Selling Body Parts
- Second Plea in U.S. Funeral Home Scheme to Sell Body Parts
- Koch's Sentence Date Continued in Fraud Case Centered on Sale of Bodies
- Families Demand Accountability in Sunset Mesa Body Scheme Case as Koch Pleads to Mail Fraud
- Former Colorado Funeral Home Owner Sentenced to 20 yrs for Selling Body Parts
- 'Somebody Murdered my Dead Husband': Victims of Colo. Funeral Home that Doubled as Body Broker Begin to Heal

The Body Trade: Cashing in on the Donated Dead

Harvard Medical School

- Harvard Tells Horrified Husband His Wife's Remains May Have Been Sold in a Body Part Trafficking Operation by a Former Morgue Manager
- Ex-mortuary Worker Indicted for Selling Stolen Body Parts for $11k to a Man She Met on Facebook (New York Post)
- Niece Who Gave Aunt's Body to Harvard Medical School for Science Research Reveals Her Disgust After Morgue Manager is Accused of Selling Hundreds of Corpses

The Stories of Other Families

- Owner of Twin Cities Tattoo Parlor Admits to Trafficking in Body Parts
- Grisly Scene: FBI Finds Stolen Human Remains 'Decorated' Around Mount Washington Man's Home
- Her Remains Were Dumped in Arizona. Now her Family is Calling for Regulation of the Body Donation Industry

Actual headlines

- Outrage as live autopsy is carried out on WW2 veteran
- Harvard tells horrified husband his wife's remains may have been sold in a body part trafficking operation by a former
- Morgue manager: The body parts industry is booming with heads going for $3k, spines for $1,200
- 'The person becomes a commodity': funeral directors seek law to regulate 'body brokers'

Meet Amanda

"HER REMAINS WERE DUMPED IN ARIZONA"

NOW HER FAMILY IS CALLING FOR REGULATION OF THE BODY DONATION INDUSTRY.

After his daughter, Amanda West, died from cancer in Seattle in 2019, David Griffin learned that donated bodies do not always end up where the donors intended.

NFDA Advocacy - CDRI

The Consensual Donation & Research Integrity (CDRI) Act

S. 2191: Sens. Chris Murphy (D-CT) & Thom Tillis (R-NC)

H.R. 4275: Reps. Gus Bilirakis (R-FL) & Lizzie Fletcher (D-TX)

- Registration
- Inspection
- Chain of custody
- Labeling and packaging
- Disposition
- Violations

NFDA Advocacy - HSA

Health Savings Account funds for final expenses

- Health Savings Accounts (HSAs) were created in 2003 so that individuals covered by high-deductible health plans could receive tax-preferred treatment of money saved for medical expenses.

- If the law allowed funeral expenses to be deemed a qualified expense for which HSA funds could be used, the beneficiary of an HSA could use the proceeds from a decedent's HSA to pay for the funeral on a tax-free basis

The federal regulatory process

The Administrative Procedure Act (APA), applies to all agencies of the federal government and provides the general procedures for various types of rulemaking.

The APA governs the process by which Federal agencies propose and establish new regulations.

Once an agency decides that a regulatory action is necessary or appropriate, it develops and typically publishes a proposed rule in the *Federal Register*, soliciting comments from the public on the regulatory proposal.

After the agency considers this public feedback and makes changes where appropriate, it then publishes a final rule in the *Federal Register* with a specific date upon which the rule becomes effective and enforceable.

In issuing a final rule, the agency must describe and respond to the public comments it received.

Pre Rule-Stage

Origins of a rule:

An agency cannot issue a Rule unless granted authority to do so by law.

Before the rulemaking process, an agency evaluates possible alternative solutions to a rulemaking and determines whether the benefits of the regulation justify the costs.

Agencies will typically submit an "Advanced Notice of Proposed Rulemaking" (ANPR) to the Federal Register

This notice allows the public the opportunity to comment on whether or not a rulemaking should be initiated.

If an agency believes a rulemaking is warranted, the agency then proposes their findings to Congress or to the President in order to receive authority to issue a regulation.

A “Unified Agenda” is published semiannually in order to declare significant regulatory activities that agencies expect to take in the coming year and to inform the public about both pending and completed regulatory actions.

Proposed Rule Stage

Notice of Proposed Rulemaking:

- After an agency researches the issues and determines whether a new Rule is necessary, it often proposes a regulation, also known as a Notice of Proposed Rulemaking (NPRM). Typically these proposals are published in the Federal Register (FR) and made publicly available in print and on-line at http://www.federalregister.gov so that they are readily accessible to the public.
- Public comment period
- During this phase of the rulemaking process, agencies accept public comments via Regulations.gov. Some agencies also accept comments by mail, fax, or email. In a typical case, an agency will allow 60 days for public comment. However, in some cases they provide either shorter or longer comment periods. An agency may receive no comments or as many as thousands of comments or more.

Docket:

- The rulemaking docket (known as a Docket Folder) contains all of an agency's relevant rulemaking materials (e.g., NPRM, hearing Notices, extensions of comment period, and Final Rule), supporting documents (e.g., economic and environmental analyses), studies and other references, all public comments, and other relevant documents.
- The public dockets for agency rulemakings can be found at Regulations.gov. You can access any electronic docket on this site by searching with a unique identifier such as the docket number or ID, Regulation Identifier Number (RIN), or even a keyword.

Final Rule Stage

Post-comment period:

After the comment period closes, the agency reviews all comments received and conducts a comment analysis. Then agencies decide whether to proceed with the rulemaking process or issue a new or modified proposal. In some cases they withdraw the proposal.

Preparing a Final Rule:

Any Final Rule must include preamble and Rule text. The preamble includes a response to the significant, relevant issues raised in public comments and a statement providing the basis and the purpose of the Rule.

Typically, agencies respond to all public comments in the preamble of the Final Rule or a withdrawn proposal.

Published Final Rule:

No Final Rule becomes effective in less than 30 days of its publication in the FR, unless it grants an exemption, relieves a restriction, or for "good cause," which includes such things as emergencies.

A copy of any published Final Rule can be found on this site in the rulemaking docket, along with the relevant regulatory materials (e.g., Supporting and Related Materials, Public Submissions).

NFDA Advocacy - EPA

- Embalming fluids first contained chemicals, like mercury and arsenic, which were very dangerous to embalmers
- Formaldehyde (formalin) replaced these heavy metals and has been the main preservative in embalming fluids since the early 1900s
- Other preservatives, like Glutaraldehyde, are sometimes used by some chemical suppliers
  - Safety Data Sheets (SDSs) frequently indicate that formaldehyde is present in some concentration in those embalming fluids

NFDA Advocacy - EPA

Examples of Cases Where Formaldehyde Use is Essential

- Veterans - The current wait time for a burial of a U.S. Veteran in Arlington National Cemetery and some other national cemeteries is up to and over nine (9) months.
- Immigrants - Repatriation of human remains to other states and internationally so that the deceased can be buried at "home" and with family.
- Certain religious and ethnic services – Those that require delayed funeral services to allow time for family and friends to arrive, clergy to arrive, religious services to take place, or by tradition.
- Trauma, Autopsy, and Anatomical Donation – Cases that have a delay between death and embalming due to medical investigations, accidents, etc.
- Restorative art - Requires firm, dry tissues. Only formaldehyde can provide the best foundations for this procedure. This allows the family "closure" and to view their loved ones following trauma and disease.

NFDA Advocacy - EPA

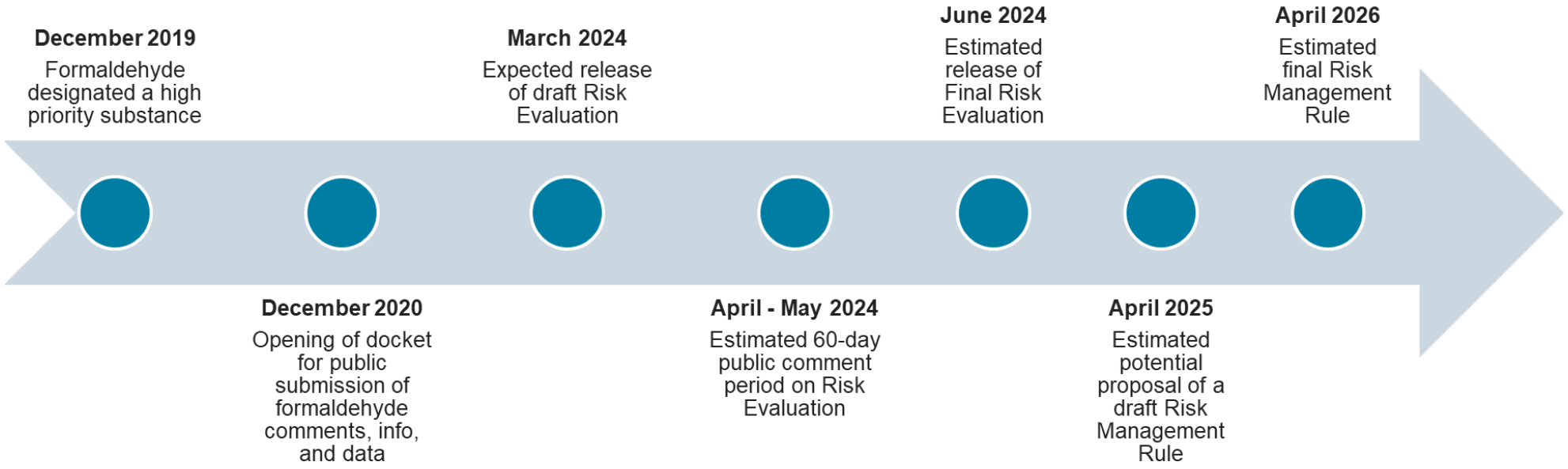
The Toxic Substance Control Act (TSCA)

TSCA requires the EPA to periodically conduct risk assessments to determine whether particular uses of chemicals present an unreasonable risk to human health ***or*** the environment.

This may lead to a federal determination that the health risk to embalmers and others is too high AND could result in the EPA taking action, including:

- establishing very low exposure standards
- enacting management restrictions
- setting standards that NFDA's members must meet in order to embalm with formaldehyde
- issuing violation notices and penalties should funeral directors not comply

NFDA Advocacy - EPA



How will the EPA assess formaldehyde risk?

- EPA will rely on published scientific literature to assess exposure to formaldehyde for funeral service
- EPA will compare exposure estimates to “safe” levels they determine
  - Not yet clear what those “safe” levels will be
- Comparisons used to determine potential risk to workers

Historical Literature Published on Formaldehyde Exposure During Embalming

- At the time of our study, the highest quality data on exposure to formaldehyde involved exposures prior to the 1990s and may not reflect current practices due to:
  - Improvement on formaldehyde handling practices.
  - Changes in technology, products, or practices related to embalming.
  - Reduction in number of embalmings over time.
- The overall literature reports a wide-range of task-length exposure concentrations.
  - Observed Range: **0.03 to 20.89 ppm**

The leadership dilemma for NFDA

#1 Priority:

health and safety of embalmers and others in funeral service

#2 Priority:

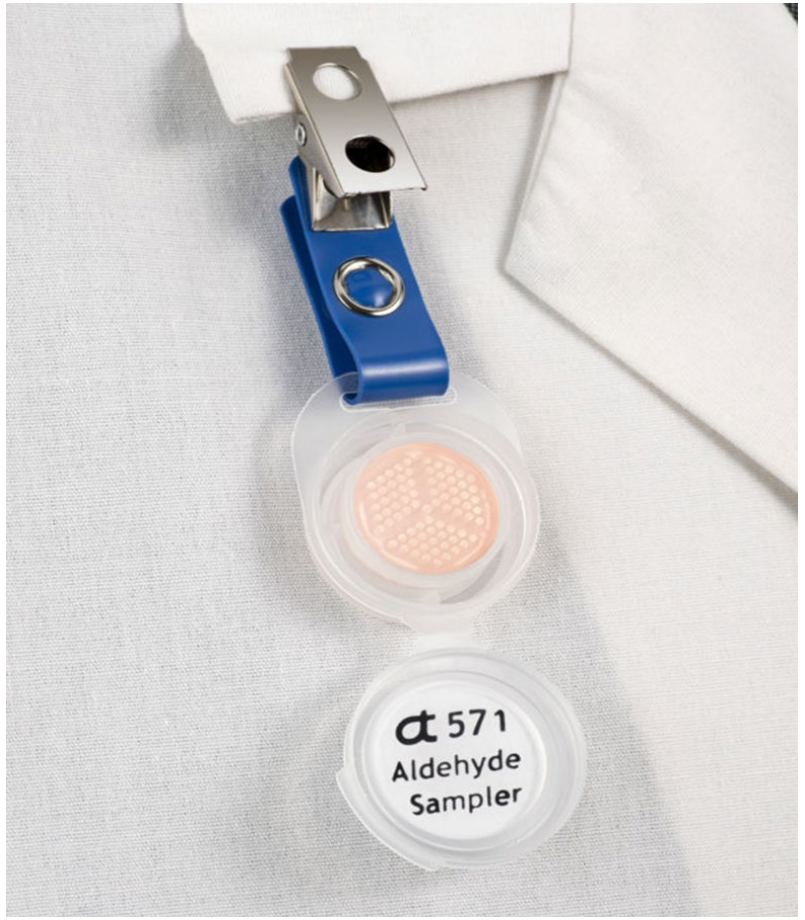
data

NFDA Formaldehyde Exposure Study

- NFDA staff worked with a scientific consulting firm to do an exposure study on formaldehyde in embalming

- NFDA submitted comments and the study results to the EPA.

- NFDA's study was accepted for publication in the July 2022 issue of the peer-reviewed ***Journal of Occupational of Environmental Hygiene*.**



NFDA study details

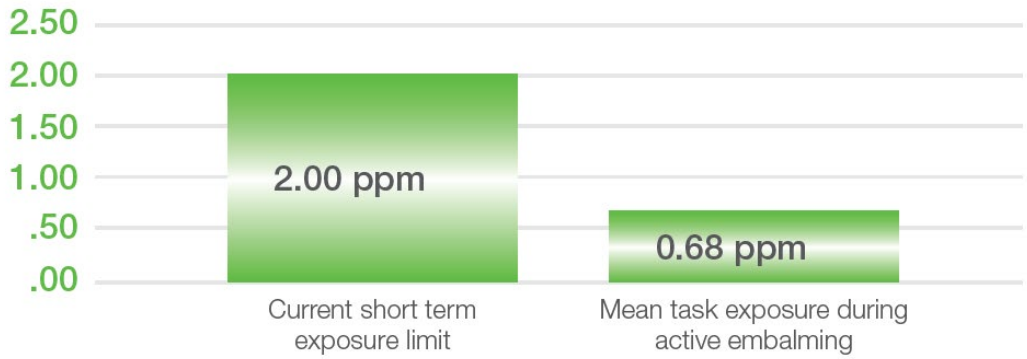
Funeral homes volunteered to have industrial hygienists come and conduct research in their embalming rooms

Recorded physical characteristics (e.g., room size, chemicals used, active ingredient concentration, room ventilation rate) and formaldehyde air samples

PPE and ventilation were used during embalmings per OSHA requirements

NFDA study conclusions

- Formaldehyde exposures have declined from those reported in published literature (outside of Allen, et al. 2022)
    - Reduction in task-level (i.e., during active embalming) exposure to formaldehyde reflected in our current data
    - Changes in exposure pattern (frequency of embalming– key to understanding long-term worker exposure)
- NFDA Study (Allen, et al. 2022) represents the most appropriate data for understanding current exposures to formaldehyde in funeral service profession



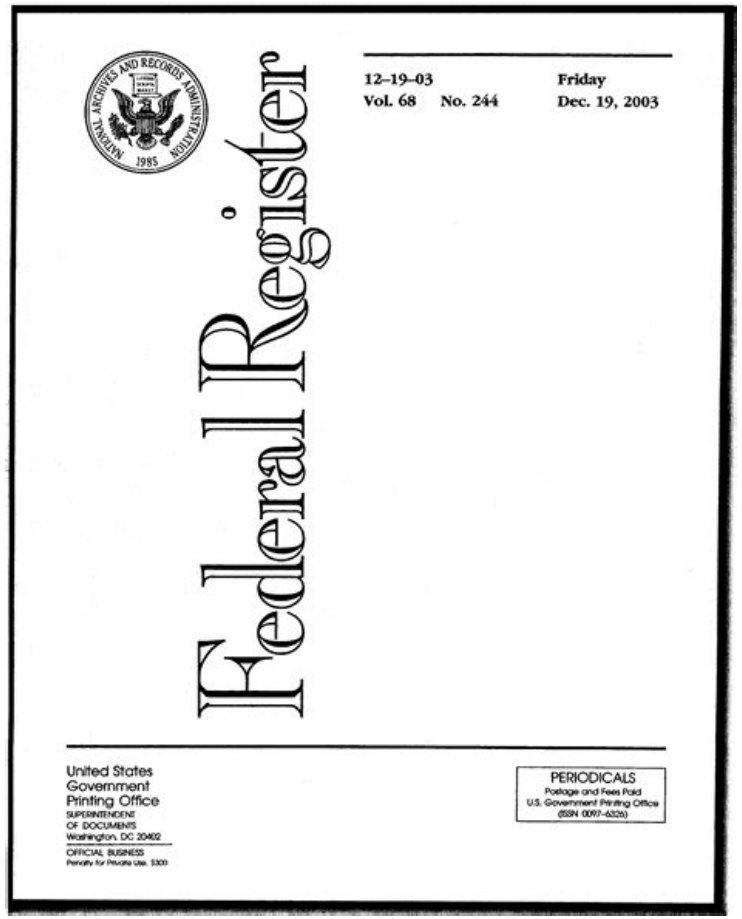
NFDA Advocacy - FTC

- The Funeral Rule (16 CFR 453) went into effect in 1984 and was revised in 1994

- The Rule requires funeral providers give itemized price information & other disclosures
    - It mandates providing consumers with a General Price List, Casket Price List, and Outer Burial Container Price List

- The Rule also prohibits funeral providers from:
    - misrepresenting legal, crematory, and cemetery requirements;
    - embalming for a fee without permission;
    - requiring consumers to buy certain goods or services; and,
    - engaging in other deceptive or unfair practices.
- Penalties for violations are up to $50,120 per violation.

NFDA Advocacy - FTC



In October 2022, the Federal Trade Commission ("FTC") issued an Advance Notice of Proposed Rulemaking (ANPR) for the Funeral Rule ("the Rule"), the federal regulation that governs funeral homes. The ANPR addressed seven different areas for which the FTC is considering expanding the Rule:

- Online and Electric Price Disclosures
- Crematory Fees and Additional Costs
- Reduced Basic Fee Services
- Alternative Forms of Disposition
- Embalming Disclosure
- Price List Readability
- Impact on People in Underserved Communities

NFDA Advocacy - FTC

NFDA has long asserted that there is no need to expand the Rule. The data clearly shows that:

- consumers do not price shop for funeral goods and services, especially not online;
- price is not a primary determining factor for funeral consumers; and,
- the Rule has not delivered its intended benefits and instead, has resulted in confusion for funeral providers and consumers, and increased costs while stifling price competition and innovation.

How can you make a difference?

Get involved/grassroots:

- NFDA website to learn about our issues
- Contact Congress
- Key Contacts
- Share issues with NFDA
- Educate others
- Join NFDA at our annual Advocacy Summit in Washington, DC: March 20-22, 2024

Let's talk – your questions/comments

Thank You For Listening

- What Would You Like To Discuss?
- What Questions Do You Have?

- Reach out to me at: lwitter@nfda.org