

The Morris ALS Principles: A Multi-stakeholder Framework for Patient-Driven Research

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Background:

ALS is a devastating and fatal neurodegenerative disease. In the more than 150 years since it was first described, there are still no cures or treatments that stop or reverse progression. One of the goals of I AM ALS is to remove barriers to treatments and improve ALS care and research from a multi-stakeholder perspective.

Despite their expertise and contributions, people living with and impacted by ALS are still blocked from attending scientific forums sponsored by organizations that are supposed to be serving the community and organizations still limit their participation and ignore their concerns. As such, ALS advocates turned to the HIV community to learn from how they demanded -- and received -- seats at decision-making tables. Inspired by the Denver Principles, a landmark document drafted by HIV/AIDS activists in 1983, ALS advocates sought to create the first guidance document to outline people living with ALS' expectations regarding their inclusion in matters directly affecting them. The Morris Principles serve as a social contract solidifying the necessary involvement of people living with ALS.

Objective:

The group created this directive outlining a series of rights and responsibilities for ALS organizations and stakeholders to follow. The principles demonstrate how including people living with ALS in decision making processes is not just the right thing to do, but necessary to effectively serve and advocate for the community and find treatments and cures.

Methods:

ALS advocates met weekly via Zoom and corresponded via email from March 5, 2021 to May 21, 2021 to define and refine a manifesto in an iterative process inspired by the Delphi consensus method.

Results:

Advocates identified five priority areas:

- protecting “intellectual, physical and financial dignity”
- global stewardship of “our disease and respected partners in the science of treatments and cures”
- acting as trusted peers with clinicians, researchers and policy makers
- fighting for “equity in decision-making”
- leading to end ALS

Specific guidance was developed for targeted audiences: healthcare professionals; the scientific and ALS research community; ALS policy community, legislators and regulators; and ALS nonprofits. This guidance document came to be named the Morris ALS Principles, as it was inspired by ALS advocate Sandy Morris.

I AM ALS posted the Morris ALS Principles on its [website](https://iamals.org/updates/the-morris-als-principles/) with the ability for people to download a copy: (<https://iamals.org/updates/the-morris-als-principles/>). I AM ALS and community members then distributed the principles to ALS nonprofits, clinicians, researchers, ALS Congressional caucus members and other stakeholders. As of October 19, 2021, 874 people have visited the Morris ALS Principles webpage 967 times.

The Morris ALS Principles authors recommend the invocation of the principles in all interactions with stakeholders. The principal developers encourage all stakeholders to use the document when developing programs or initiatives.

ALS advocates will work with and publicly cite offenders and applaud upholders of the Morris ALS Principles, as well as proactively collaborate with organizations to confirm they are in adherence with the principles.

Discussion

The full impact of the Morris ALS Principles has not yet occurred. Currently the team is forming a process to announce organizations in compliance and violation of the Morris ALS Principles.

The first steps of creating community principles is powerful in that it gives ALS advocates a powerful tool and ALS organizations guidance on how to act ethically and effectively.

Conclusion

The Morris ALS Principles provide a multi-stakeholder advocacy framework to create a more ethical and effective ALS landscape. We recommend all stakeholders who work in the ALS space review, use and enforce these principles.

This remains a living document that is maintained in the spirit of continuous improvement.