



CALL TO ACTION:

Now is the time for all interested SMA families to join The FAST Movement by calling their local newspapers and TV stations to raise public awareness that there is a successful treatment for SMA and all patients need access!

As members have notified The Fast Movement of media opportunities, we acknowledge the extreme frustration of SMA families. We would like to stress the importance of not creating a negative environment regarding progress of moving drugs toward the approval process. Please represent The FAST Movement with factual information and work together to spread awareness that SMA patients urgently need access to this successful treatment.

Suggestions for media outreach from FAST supporters on the critical need for ISIS-SMNrx to receive FDA approval and be accessible to all SMA patients.

Who We Are:

The FAST Movement is a group of SMA families that are waiting and hoping for a treatment for their loved ones. We want the FDA and pharmaceutical companies to know that lives depend on their ability to get safe and effective drugs to patients as quickly as possible. SMA is the most lethal genetic disease in babies and children under 2. It is one of the 7,000 rare diseases affecting 35 million Americans. 1 in every 40 people are carriers of SMA, and 1 in 6,000 babies born will be diagnosed with SMA. There are avenues established by the FDA to speed up the drug approval process for rare and terminal diseases. All parties must be determined not to take one single day more than absolutely necessary to get these drugs to SMA patients.

Main Message:

- ISIS and Biogen Pharmaceutical Companies are treating SMA patients in phase 3 clinical trials, with a drug called SMNrx. Per FDA standards, SMNrx has shown overwhelmingly positive safety and effectiveness in SMA patients. Hundreds of doses have been administered to SMA patients, and the life-saving and functional improvements experienced and measured in patients are beyond the hopes and expectations of researchers, physicians, patients, caregivers, and pharmaceutical companies. With no approved treatment, currently, more than 35,000 lives are depending on them.
- Drugs to treat deadly progressive diseases like SMA can present unique challenges to pharmaceutical companies and the FDA. The FAST Movement realizes that industry leaders must be willing to acknowledge that the phenomenal results of SMNrx are not typical for new drugs and require creative and determined minds to get market approval without delay.
- There is no doubt that SMNrx is a safe and life saving treatment for SMA, but each day that it is unavailable to patients allows more irreversible disease progression and for many children, death.