



NurOwn Social Media Campaign

First: Big thank you to the NurOwn Working Group for their incredible work on this project.

Vision: From now until September 27, I AM ALS and the ALS community will use the template social media posts below to encourage people to submit written testimony for the NurOwn AdComm and support I AM ALS' statement on NurOwn.

<https://iamals.org/action/nuown-sign-on/>

Action: Read through the social media posts below and copy and post the ones' you like onto your social media feed. There's no need to post them all at one time. In fact, it might be more effective to post them on different days and at different times of the day.

On page 5 of this toolkit you will find the One More Point social media post template. Unlike the other tweets, you need to personalize this one to your situation or the situation of your loved one(s).

.@US_FDA @FDACBER Instruct the AdComm that qualitative data is as important to consider as quantitative data. Consider the totality of evidence and recommend #NurOwn for approval! #NurOwnNow

<https://iamals.org/updates/guide-to-submitting-written-testimony-to-the-fda-about-nuown/>

.@US_FDA @FDACBER Please continue your pattern of regulatory flexibility with #ALS therapies so more people can live longer with ALS while we work towards a cure. #NurOwn #NurOwnNow

<https://iamals.org/action/nuown-sign-on/>

.@US_FDA @FDACBER Please show the same regulatory flexibility with #NurOwn that you did with Relyvrio and Tofersen #NurOwnNow

<https://iamals.org/action/nuown-sign-on/>





.@US_FDA @FDACBER Too many people have died waiting for regulatory review of #NurOwn for #ALS. A fair and transparent discussion of all the data is extraordinarily important to the ALS community. #NurOwnNow
<https://iamals.org/action/nuown-sign-on/>

.@US_FDA @FDACBER #ALS is a 100% fatal disease. Please act swiftly for promising #ALS therapies and approve #NurOwn #NurOwnNow
<https://iamals.org/action/nuown-sign-on/>

.@US_FDA @FDACBER #ALS impacts people of all ages. Lives are cut too short. Children lose parents. Parents lose children. Please approve #NurOwn #NurOwnNow <https://iamals.org/action/nuown-sign-on/>

We need you! Tell @US_FDA @FDACBER why you think they should recommend #NurOwn #NurOwnNow
<https://iamals.org/updates/guide-to-submitting-written-testimony-to-the-fda-about-nuown/>

"When the FDA receives a new drug application to treat advanced cancers or other diseases like #ALS that progresses rapidly, the agency can approve it quickly..." - Former FDA Comm. Janet Woodcock. Well, @FDACBER & @US_FDA, approve #NurOwn quickly. #NurOwnNow
<https://iamals.org/action/nuown-sign-on/>

.@US_FDA @FDACBER Please consider the totality of evidence and patient-reported impact on functionality and approve #NurOwnNow #NurOwn
<https://iamals.org/action/nuown-sign-on/>

.@US_FDA @FDACBER At 25 you should have a long life ahead of you filled with potential and possibility. For a young person living with #ALS, that is not reality. Please approve #NurOwnNow #NurOwn
<https://iamals.org/action/nuown-sign-on/>





.@US_FDA @FDACBER Give people a chance to be alive when the next ALS therapy comes through. #NurOwnNow #NurOwn

<https://iamals.org/action/nurown-sign-on/>

.@US_FDA @FDACBER "Please approve #NurOwn. It's hope for an otherwise hopeless disease." - daughter of a person living with #ALS. #NurOwnNow

<https://iamals.org/updates/guide-to-submitting-written-testimony-to-the-fda-about-nurown/>

.@US_FDA @FDACBER The ALS community wants their lived experience recognized. Help them by asking the AdComm to consider the totality of evidence #NurOwnNow #NurOwn

<https://iamals.org/updates/guide-to-submitting-written-testimony-to-the-fda-about-nurown/>

Tell the AdComm that 1 point on the #ALS-FRS scale is the difference between choking sometimes & choking continuously #NurOwnNow #NurOwn

<https://iamals.org/updates/guide-to-submitting-written-testimony-to-the-fda-about-nurown/>

Tell the AdComm that 1 point on the #ALS-FRS scale is the difference between cleaning your genitals yourself or having someone else do it. #NurOwnNow #NurOwn

<https://iamals.org/updates/guide-to-submitting-written-testimony-to-the-fda-about-nurown/>

If you have a connection to #ALS, tell AdComm members how important their review of the totality of evidence is by submitting your comment before Sept 20, 2023, using these guidelines:

<https://iamals.org/updates/guide-to-submitting-written-testimony-to-the-fda-about-nurown/>

#NurOwnNow #NurOwn

#ALS advocates and champions - tell AdComm members that Nurown works. Submit your comment before Sept 20, 2023. Here is a guide:





<https://iamals.org/updates/guide-to-submitting-written-testimony-to-the-fda-about-nurown/>

#NurOwnNow #NurOwn

You can make a difference in the movement to end #ALS by telling AdComm members how important it is to approve #NurOwn. Here is a guide:

<https://iamals.org/updates/guide-to-submitting-written-testimony-to-the-fda-about-nurown/> #NurOwnNow

#ALS is a 100% fatal disease that causes increased paralysis over time and usually progresses rapidly. Ultimately, people living with ALS lose the ability to eat, talk, breathe, or move on their own. We need #NurOwn #NurOwnNow Please sign this letter <https://iamals.org/action/nurown-sign-on-letter/>

Most people with #ALS typically live only 2 to 5 years after diagnosis. The ALS community has waited years for #NurOwn. We need it now. #NurOwnNow <https://iamals.org/action/nurown-sign-on-letter/>

Each treatment helps move #ALS further from a fatal disease to becoming a chronic disease. The importance of this cannot be understated and its time is now. #NurOwnNow #NurOwn <https://iamals.org/action/nurown-sign-on-letter/>

Each new #ALS therapy approval gives those living with ALS more longevity and better quality of life. Now is the time for #NurOwn #NurOwnNow Please sign this letter <https://iamals.org/action/nurown-sign-on-letter/>





One Point Matters

Template:

.@FDACBER With ALS, #OnePointMatters! If I had one more point in my ALSFRS-R score, I could XXXXXXXX instead of XXXXXX. Consider the totality of evidence and recommend #NurOwn for approval! #NurOwn #NurOwnNow 🌻
<https://iamals.org/action/nuown-sign-on/>

Directions:

Replace the template phrase “I could XXXXXXXX instead of XXXXXXXX” with any of the below, or with your own example. Adding a picture or video would make the post more effective.

Example:

.@FDACBER With ALS, #OnePointMatters ! If I had one more point in the ALSFRS-R score, I could still feed myself instead of needing someone else to feed me. Please approve #NurOwn ! Please allow all those with ALS to have a fighting chance. #NurOwnNow

Some examples:

- I could swallow my own saliva and not choke hourly (be at risk of suffocating to death hourly) if my caregiver did not catch my choking signal.
- I could cut my own food instead of having someone else cut my food.
- I could use the bathroom myself instead of having someone help me.
- I could brush my own teeth instead of having someone do it.
- I could get dressed on my own instead of needing someone to button my buttons, zip my zippers and tie my shoes.
- I could pull my covers up when it's cold instead of just staying cold.
- I could walk up the stairs to my bedroom instead of crawling up the stairs.
- I could wash myself instead of having someone wash me.
- I could walk on my own with a walker instead of needing to sit in a wheelchair.
- I could breathe on my own instead of having to wear a bi-pap.





- I could hold my grandson in my arms.
- I could use the joystick on my power chair to get around instead of having someone have to control my chair for me.
- I could speak so people could easily understand me.
- I could eat whatever I wanted and not worry about choking.
- I could swallow my food easily and not need a feeding tube.
- I could talk to my daughter on the phone and have her understand what I'm saying.



We are a patient-led community revolutionizing how to cure disease