

Appendix A: Cure SMA Teen Video Contest Guidelines

Cure SMA is hosting a video contest to raise SMA awareness and provide the opportunity for teens and young adults (aged 12 to 21) to share their experiences. We want you to participate!!

The purpose of this contest is to raise awareness about the impact that SMA has on teens and young adults, and the strategies you use to help navigate your day to day life. Your voice is crucial. Your video will help to increase awareness of the disease. We hope that your peers can learn from you!

Who can enter?

- You must have a diagnosis of Spinal Muscular Atrophy (SMA)
- You must be 12 to 21 years old
- You must live in the United States
- You may work individually or as a group (up to 3 individuals), but one person must apply and represent on behalf of the group. This individual must have a prior diagnosis of SMA
- Parents and adults can be advisors, but we respectfully request the teen/young adult be the primary driver
- Parental permission is required for contestants under 18 years old
- Immediate family and staff of Cure SMA are ineligible to submit

How to enter?

- We want to know more about all of the creative techniques you utilize to remain an active teenager or young adult. Create a short (3 min or less) video that highlights the following:
 1. How does SMA impact your goals as a teenager/young adult as you deal with the issues that others your age face including (but not limited to):
 - a. School/Work
 - b. Friendships
 - c. Independence
 - d. Dating

In addition to item #1 above, all videos must also include one or more of the following topics.

2. What care/treatment options are the most effective for you as you manage your symptoms? (physical therapy, hydrotherapy, massage therapy, breathing assistance, nutrition etc.) Please refrain from mentioning any drug name or clinical trial; videos including this information will be disqualified from the contest.
3. Even with the most well thought out plan, life gets in the way! What challenges do you face along the way and how do you manage?
4. In addition to treatment, do you have additional strategies that contribute to your daily joy/improved quality of life? (dog companion, helper, devices, treatments, etc.)

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- Upon completion, please submit your video, via email, to CREATE EMAIL ADDRESS. All videos will be reviewed prior to Cure SMA staff posting the content to the Cure SMA's YouTube® account. Participants under the age of 18 years of age must have parental consent. A signed consent form along with a copy of identification is required with each submission; those over the age of 18 must also consent and provide a copy of identification. Please contact Mary Curry at mary.curry@curesma.org or 847.264.1189. Notification of acceptance will be provided via email along with a direct link to the uploaded content.
- Individuals or groups may submit more than one video as long as each video covers different topics. Please see above for the list of subject areas.
- Winners will be chosen based on total "Likes" obtained by each video; every "Like" equals one vote. All participants are encouraged to share their video with friends and family members to increase the total number of votes received. Only videos submitted to Cure SMA and uploaded to Cure SMA's YouTube® account will be considered.
- Make sure you read and approve the terms and conditions. Easy!!

Exclusion criteria

- All entrants 18 years of age and older are required to submit a signed consent and photo ID via email to Mary Curry at mary.curry@curesma.org; entrants under the age of 18 year of age are required to obtain permission from all parents and/or legal guardians as well as a copy of a photo ID. Those that do not comply are excluded from participation.
- All videos will be reviewed for content prior to Cure SMA's acceptance of video entry. All videos that do not feature the required subjects will be disqualified. Any videos that mention any drug name or clinical trial will be disqualified. The participant will be notified via email if disqualified.

Timeline is as follows:

Submission Period: October 15, 2018 to November 20, 2018

Cure SMA Video Upload Date: November 28, 2018

Time Period to Market Your Film: November 28, 2018 to December 9, 2018

Announcement of Finalists and Grand Prize Winner: December 21, 2018

Prizes:

Winners will be chosen based on the total "Likes" obtained on their video between November 28, 2018 at 12:00 am CST to December 9, 2018 11:59 pm CST.

Prizes will be awarded as follows:

1st Place: Amazon Gift Card for \$150

2nd Place: Amazon Gift Card for \$125

3rd Place: Amazon Gift Card for \$100

Winners will be notified by e-mail.

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Terms and Conditions

For optimal video upload guidelines visit the [YouTube®](#) website.

Participants of Cure SMA's Video Contest agree to YouTube's® [Community Guidelines](https://www.YouTube.com/yt/about/policies/#community-guidelines) (<https://www.YouTube.com/yt/about/policies/#community-guidelines>) and [Terms of Service](https://www.YouTube.com/static?gl=US&template=terms) (<https://www.YouTube.com/static?gl=US&template=terms>). YouTube® is not a sponsor of your contest and all participants are required to release YouTube® from any and all liability related to this contest.

Entrants may only submit their own original works.

All submitted videos are subject to approval and may not be accepted if they are found to be offensive or in violation of copyright. This includes the use of copyrighted music, digital, movie, or printed works. See "Acceptable Site Use" in ACS Terms of Use.

Cure SMA reserves the right to use submitted videos on the Cure SMA website and in other promotions, including but not limited to the Cure SMA channel on YouTube®, Cure SMA's SMARt Moves microsite, and the Cure SMA publications. Cure SMA and the organization's industry partners are release from any and all liability related to this contest.

Any personal information supplied by you to Cure SMA will be subject to Cure SMA's privacy policy posted at <http://www.curesma.org/privacy-policy.html>. By entering the Contest, the Entrant/Parent/Legal Guardian grants Cure SMA permission to share your E-mail address and any other personally identifiable information with You Tube or with any co-sponsor solely for the purpose of administration and prize fulfillment. Cure SMA will not sell, rent, transfer or otherwise disclose your personal data to any third party other than as described above herein or in the privacy policy.

Please contact Mary Curry at mary.curry@curesma.org or 847.264.1189 with any questions.

Appendix B: Cure SMA Teen Video Link and Results



Congratulations to the Winners of Cure SMA's Video Contest!

January 15th, 2019|[Community Awareness](#), [Front Page News](#)

Cure SMA recently hosted a video contest to raise SMA awareness and provide the opportunity for teens and young adults (aged 12 to 21) to share their experiences. The purpose of this contest is to raise awareness about the impact that SMA has on teens and young adults, and the strategies used to help navigate day to day life.

Special thanks to everyone who participated in our contest and helped to make it a success! Thank you for sharing your journey. We continue to learn from each of your stories.

Although the contest has ended, please continue to view and share all of the contest entries on [Cure SMA's YouTube Channel](#) at https://www.youtube.com/watch?v=u9baqO4Ino8&list=PLQVcp9RApBmz3QN_CBFXGIUAWeoTLmKMn&index=2

Congratulations to all the participants and thank you to all that voted!