



# OMAS

## WEBSITES GUIDE



### [OMSLIFEFOUNDATION.ORG](https://OMSLIFEFOUNDATION.ORG)

OMAS Resource documents  
OMAS publications  
OMAS Caregiver Conference Presentations  
Registry information  
Social media information



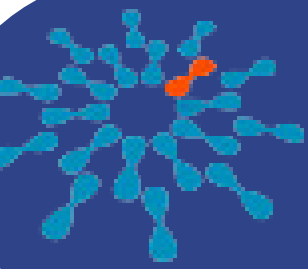
### [OMS.IAMRARE.ORG](https://OMS.IAMRARE.ORG)

Patient reported registry of OMAS data. Series of surveys developed for research and clinical use.



### [DANCINGEYES.ORG.UK/](https://DANCINGEYES.ORG.UK/)

Providing support and information to families of children with DES. Based in United Kingdom



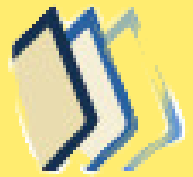
### [RAREDISEASES.ORG](https://RAREDISEASES.ORG)

National Organization for Rare Disorders (NORD) site with specific details and an animated video on OMAS



### [WIKIBOOKS.ORG/WIKI/OMS\\_MANUAL](https://WIKIBOOKS.ORG/WIKI/OMS_MANUAL)

A collection of resource information including publications, government & private agencies, statistics, and other data.



### [NEUROLOGY.ORG/DOI/10.1212/NXI.0000000000001153](https://NEUROLOGY.ORG/DOI/10.1212/NXI.0000000000001153)

OMAS consensus statement on diagnosis and treatment of OMAS. Details on treatment from 18 leading OMAS specialists.



### [PRINCIPLEDRESOURCES.COM](https://PRINCIPLEDRESOURCES.COM)

Powering data driven strategies for non-profit organizations.



### [RAREAWARENESSRADIO.ORG](https://RAREAWARENESSRADIO.ORG)

Podcasts highlighting rare diseases featuring patients, doctors, and organizations involved in rare diseases. Sponsored by OMSLife





# OMAS

## SOCIAL MEDIA GUIDE



### [FACEBOOK.COM/GROUPS/OMSLIFE](https://www.facebook.com/groups/OMSLIFE)

OMAS caregiver and patient group. This group is a closed group. Providing platform for questions and feedback on OMAS issues.



### [FACEBOOK.COM/OMSLIFEINFORMATION](https://www.facebook.com/OMSLIFEINFORMATION)

OMAS page for public consumption. Providing information on OMAS to friends, family, and anyone interested in learning.



### [FACEBOOK.COM/GROUPS/ESPANOLOMSLIFE](https://www.facebook.com/groups/ESPANOLOMSLIFE)

Para Español – Busque “OMSLife” en Facebook para encontrar la página de OMSLife en Español / Síndrome Kinsbourne



### [FACEBOOK.COM/DESSTFUNDRAISING/](https://www.facebook.com/DESSTFUNDRAISING/)

The facebook page for the Dancing Eyes Syndrome Support Trust, a foundation for OMAS based in the United Kingdom.



### [INSTAGRAM.COM/OMSLIFEAWARENESS/](https://www.instagram.com/OMSLIFEAWARENESS/)

The instagram page for the OMSLife foundation. Follow to connect with the community and learn more about OMAS.



### [LINKEDIN.COM/COMPANY/OMSLIFE-FOUNDATION-INC/](https://www.linkedin.com/company/OMSLIFE-FOUNDATION-INC/)

The LinkedIn page for the OMSLife Foundation, a foundation dedicated to raising awareness of Opsoclonus Myoclonus Syndrome, maintaining a support network for caregivers, and funding research for a cure



### [LINKEDIN.COM/COMPANY/PRINCIPLED-RESEARCH-RESOURCES-L3C/](https://www.linkedin.com/company/principled-research-resources-l3c/)

The LinkedIn page for Principled Research Resources, L3C, a company that provides data analytics & research expertise to non-profit patient advocacy groups



### [LINKEDIN.COM/SHOWCASE/RARE-AWARENESS-RADIO/](https://www.linkedin.com/showcase/rare-awareness-radio/)

The LinkedIn page for Rare Awareness Radio, a podcast dedicated to shedding light on underrepresented diseases and the efforts of non-profit foundations working tirelessly to support those affected

