

**This document is to support Branches and Groups following the announcement of the death of Rob Burrow CBE**

The profile that former Leeds Rhinos rugby player Rob Burrow CBE has, because of his playing career and the way he chose to live his life with MND in the media spotlight, means that there is likely to be a lot of interest.

Please treat this information sensitively.

**SUPPORT FOR YOU**

| Who   | Contact details   |
|---|---|
| Your regional contacts including your Area Support Coordinator, Regional Fundraiser and Head of Regional Care |   |
| Volunteering team   | Call: 01604 611681<br>Email: <a href="mailto:volunteering@mndassociation.org">volunteering@mndassociation.org</a>     |
| MND Connect   | Call: 0808 802 6262<br>Email: <a href="mailto:mndconnect@mndassociation.org">mndconnect@mndassociation.org</a>        |
| MND Association Communications team   | Call: 01604 611687<br>Email: <a href="mailto:communications@mndassociation.org">communications@mndassociation.org</a> |

**ROB BURROW'S TIMELINE FROM DIAGNOSIS**

This information is to help you answer questions from your members or the community

**December 2019:** Rob announces his MND diagnosis.

**October 2020:** Weekend of the Challenge Cup Final and transmission of Rob's story 'My Year With MND' on BBC. Fans and supporters donate £70,000 to the MND Association.

**December 2020:** Rob's former captain Kevin Sinfield completes 7 in 7. His show of support and friendship for Rob made headline news and helped him raise an incredible £2.6 million.

**July 2021:** Rob becomes a patron of the MND Association

**September 2021:** Rob joins the United To End MND campaign, delivering a letter to Downing Street urging the Government to invest £50m in targeted MND research.

**November 2021:** Kevin completes Extra Mile challenge in honour of Rob. Raises over £2 million for MND Association and Leeds Hospitals Charity

**April 2022:** Rob Burrow receives MBE at Windsor Castle Investiture

**October 2022:** The second Rob Burrow documentary 'Living with MND' is shown by the BBC

**November 2022:** Rob greets his former team mate Kev Sinfield at Headingley during his Ultra 7 in 7 Challenge which raises £2.3 million

**May 2023:** Rob completes the inaugural Rob Burrow Leeds Marathon having been pushed round the 26.2 mile course in his wheelchair by Kevin Sinfield

**Jan 2024:** Rob awarded a CBE in 2024 New Year's Honours list

#### SOCIAL MEDIA ACTIVITY

Please refer to the guidance sheet 'branch and group media guidance death of a high-profile supporter patron or person with MND' available to help you use social media appropriately when a high-profile supporter, patron or person with MND dies.

#### SUGGESTED ANSWERS TO POTENTIAL QUESTIONS

**Q.** I am upset by the news of Rob Burrow's death. What support can you give me?

- Provide the contact details of MND Connect

If you feel that the individual may benefit from external services:

- Samaritans: call 116 123 for free 24 hours a day
- MIND: Infoline – 0300 123 3393

**Q.** Where can I donate in memory of Rob Burrow?

- Please refer to the MND Association's social media accounts and our website for the appropriate links for you to donate in line with Rob and his family's wishes.

Please follow the MND Association's lead around donations – we won't be asking people to donate but will follow the lead taken by Rob's family and the Leeds Rhinos.

**Q.** I've seen pictures and videos of Rob and I am concerned that I have MND. How can you help me?

Refer them to:

- MND Connect
- Our website

**Q.** The media have been in touch with me asking for a comment. What can I say?

- Please pass on the contact details of the Communications team (as above) and ask them to get in touch with us directly. We will manage all media requests to ensure they are appropriate and so we can keep a record.

**Q.** How can I volunteer my time to support the MND Association?

- Please visit our website to find out more [www.mndassociation.org](http://www.mndassociation.org)

Communications Team  
MND Association  
June 2024