Person writing press release	Insert date
Internal approval	Insert date
External Approval	Insert date

THE CHARITY OF YEAR:

[Name of Company] names The Mikaere Foundation as it's Charity of the Year

[Place image of company logo or team]

The Mikaere Foundation has been selected as [Insert name of company]'s Charity of the Year for [insert year] by its staff and the organisation aims to raise [£X] throughout the partnership. The Mikaere Foundation is a charity which supports children with Nonketotic Hyperglycinemia (NKH) – a terminal neurometabolic disorder.

The company, which [insert summary of the organisation], has committed all of its annual fundraising efforts to help the charity. Employees hope to [fundraise, increase awareness etc] throughout [insert year] in a bid to raise vital funds to help support more families with this devastating diagnosis.

The Mikaere Foundation supports families who have a child with Nonketotic Hyperglycinemia (NKH). Because NKH is terminal, every day is precious. The Mikaere Foundation helps fund research into effective treatments and provides support and information to families, carers and the medical professionals who support them.

Melanie Gedye, Chair of the Mikaere Foundation, says: "We are absolutely delighted to have been selected as [insert name of company]'s Charity of the Year for [insert year]. The partnership will have a huge impact for the Mikaere Foundation, enabling us to support more families who have a child living with NKH, a terminal disease. We have already received a great response from employees willing to fundraise for us, and we can't wait for the partnership to start. All the money raised from this partnership will help us support families living with NKH, and to fund much needed research

into such a heartbreaking disorder. We hope to give kids with NKH the opportunity to live longer, fuller lives."

The Mikaere Foundation is a national charity providing expert support to families, when they need it, to help them navigate a life with Nonketotic Hyperglycinemia (NKH). It relies almost entirely on voluntary donations to support children with NKH.

- Ends -

PHOTO NOTES:

Photo 1 (L-R): [Insert name(s) of people in the above image from left to right, where it was taken and what they're doing]

NOTES TO EDITORS:

About Nonketotic Hyperglycinemia (NKH)

- NKH) is a rare and terminal neurometabolic disorder that affects the glycine cleavage system.
- Children with NKH are unable to process the amino acid glycine, which (among other things) is a neurotransmitter, and this causes significant brain damage and quite severe disability.
- One in three children diagnosed with NKH are not expected to see their first birthday, and of those that do, the average age of death is thought to be around 4-8 years old.
- Typical symptoms for a child with severe NKH include seizures, dystonia, global developmental delay (where children are unable to talk, walk, stand or sit without support), feeding by tube, Cortical Vision Impairment (CVI) and neuromuscular issues (such as scoliosis and hip subluxation).

About The Mikaere Foundation

- The Mikaere Foundation is a registered charity that supports children and families living with Nonketotic Hyperglycinemia (NKH).
- When a child is diagnosed with NKH, family life is turned upside down and becomes more precious than ever. The Mikaere Foundation works with the main metabolic referral centres to provide information and support to help parents navigate this traumatic time.
- The charity also funds research into NKH effective treatments, as well as advancing the education and awareness of the public and those in medical professions.

- The Mikaere Foundation relies almost entirely on voluntary donations and through the generosity of its supporters helped fund several research studies in Research, pushing the boundaries of NKH knowledge, and has supported a number of families raising a child with NKH.
- The Mikaere Foundation's vision is that one day, a diagnosis with NKH will be treatable, and will no longer cause profound disability or pain.
- For more information, please visit www.mikaerefoundation.org.

For more press information or opportunities please contact:

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