

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



**the
mikaere
foundation**

type

business/school] to hold [type of event] for The Mikaere Foundation to support children with terminal disorder NKH.

**[Location and
of**

[Place image here - ideally with The Mikaere Foundation logo visible]

The [insert group/business/school name], from [insert location] is holding a [insert type of event] on [insert date] to help raise funds for The Mikaere Foundation, a charity which supports children with Nonketotic Hyperglycinemia (NKH) – a terminal neurometabolic disorder.

The event invites [locals/friends/family/customers] to enjoy a fun-filled day including [insert example activities/agenda]. With help from supporters, the [insert group/business/school name] is hoping to raise [£X] through [insert raffle/ticket sales etc].

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 Gedy, Chair of the Mikaere Foundation, says: “We are very grateful that [insert school/business name] is holding such a fantastic event to help us fund our vital support to families with NKH. It’s going to be a great [night/day]. Money raised from the event will help us support families, 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:

Sam Hulance

Mikaere Foundation Trustee

Email: sam@mikaerefoundation.org