

The logo for the iNO Registry, featuring the text "iNO Registry" in white on a dark blue rounded square background.

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Dear Colleague,

I am writing to you as a Steering Committee member of the Inhaled Nitric Oxide Registry to invite you to join this project. The Registry was established originally as a pilot project in 2006, and formally launched in September 2009. Anonymised data is submitted online using a web-based data form and held securely in a central data repository in Sweden managed by MedSciNet, an internet database provider who also runs other similar projects such as the Swedish PNQ National Perinatal Quality Registry and a variety of high profile international randomized controlled trials.

The aim of the Registry is to collate data about patient demographics, indications for treatment, delivery and administration of iNO, thresholds for treatment, concomitant treatments, potential adverse effects of therapy and clinical outcomes. Specifically, these data will allow:

- Promotion of consistent, high standard, clinical management amongst clinicians using iNO.
- Monitoring the range of indications for which iNO is used in routine clinical practice which may itself inform regulatory bodies about prioritising areas for drug licensing.
- Identifying adverse events associated with iNO therapy (a post-marketing surveillance role).
- Generation of research hypotheses that can be tested formally in the context of properly designed clinical trials.
- Support of future clinical trials of iNO therapy by, for example, informing discussions about sample size calculation.
- To monitor trends of iNO usage in relation to other cardiorespiratory therapies such as extracorporeal membrane oxygenation.

To date information has been collected from over 880 children treated with iNO from 24 neonatal and paediatric intensive care units in 11 countries.

Data from the pilot phase of the Registry has been presented at various international scientific meetings (ESPR, WPICC) and an original paper was accepted for publication (Acta Pædiatrica 2010: 99, pp. 854–860). We have demonstrated that this type of information can be collected and reported successfully, and believe that it has the potential to add to the body of observational research on iNO therapy.

I hope that you will consider joining the Registry (it is free to join and submit data). At present the Registry is funded through charitable funds but we plan to secure independent (non-commercial) EU funding in the future.

For more information please contact the iNO Database Administrator, Julie Wray, at iNORegistry@lwh.nhs.uk or visit our website at <http://www.medscinet.net/iNO> for more information on the Registry.

We look forward to welcoming you to the Registry.

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