

Patients, carers and healthcare professionals celebrate inaugural World HMV (Home Mechanical Ventilation) Day, encouraging NHS Trusts and patients to embrace the opportunity of rediscovered independence and enhanced quality of life

17th May 2023: The HMViP (Home Mechanical Ventilation in Partnership) Group is celebrating the first ever World HMV (Home Mechanical Ventilation) Day on **20<sup>th</sup> May 2023**. The group aims to raise awareness, share knowledge and improve education amongst clinicians and HMV users to help them continue to support and represent patients, their families and carers.

World HMV Day and the HMViP website are dedicated to the memory of Ronnie Ward, who was a participant in the HOT-HMV trial<sup>1</sup>. Ronnie, a former naval serviceman, was diagnosed with COPD in 2014. Using HMV reduced his risk of being hospitalised and enabled him to enjoy several additional years at home in Sussex with his family.

Ronnie's wife, Julie, said: "I can't stress strongly enough what it meant for us as a family and for Ronnie to have this additional time."

HMV can benefit patients with conditions that damage the lungs, such as COPD and those that restrict the movement of air in and out of the body, including obesity, curvature of the spine (also known as Kyphoscoliosis), and neuromuscular conditions such as Motor Neurone Disease and Duchene Muscular Dystrophy. The HMViP Group is encouraging patients with these conditions to visit the HMViP website (<a href="www.hmvip.co.uk">www.hmvip.co.uk</a>) to find out more about HMV, how it works, and the benefits others have experienced as a result of their treatment.

HMViP is calling on NHS Trusts to consider improving HMV access for patients with chronic respiratory failure, given that it is a cost-effective intervention that can reduce hospitalisation risk and improve symptoms and quality of life in certain patient groups<sup>2</sup>. UK and international guidance now recommend that HMV be offered to appropriate patients with COPD.<sup>3</sup>

<sup>&</sup>lt;sup>1</sup> https://eri.ersjournals.com/content/52/suppl 62/PA1679

<sup>&</sup>lt;sup>2</sup> <u>https://thorax.bmj.com/content/78/5/523</u> Murphy et al, Cost-effectiveness of home non-invasive ventilation in patients with persistent hypercapnia after an acute exacerbation of COPD in the UK

<sup>&</sup>lt;sup>3</sup> https://hmvip.co.uk/research-and-evidence

Alison Armstrong, Chair of the HMViP Group and Nurse Consultant in the North-East Assisted Ventilation Service, Newcastle-upon-Tyne Hospitals NHS Foundation Trust comments:

"We want those patients who would benefit from using HMV to be aware of the advantages of this treatment, including maintaining their independence and improving their quality of life. These patients, their families and carers deal with the impact of their underlying conditions on a daily basis; we want to celebrate them and represent their needs on World HMV day. We want to do this by sharing our common interest in HMV with as wide an audience as possible."

## **Patient Story**

lan Flatt lives between York and Harrogate in Yorkshire with his young family. He was diagnosed with motor neurone disease (MND) in 2019. The condition affects the way that lan's neurones communicate, and it is particularly pronounced in his respiratory system, which means he can have difficulty breathing. A referral to the respiratory team at St. James's hospital in Leeds followed his diagnosis, where he was issued with a home ventilator.

Rachael, lan's wife and carer says, "I noticed a difference in lan straight away. Although to begin with lan only used the machine for 4 hours a night, it made him more comfortable and he got a better night's sleep. The children were a bit uncertain, so we decided that we'd give it a name and now the ventilator is called Vespa which seemed to help them accept it."

lan now uses Vespa for about 16 hours a day but has additional lightweight portable machine which hooks onto his chair, so he doesn't have to stay indoors. This has reintroduced more normality to their lives and it has meant that lan can enjoy doing what he loves most: being outside. Last year he climbed Snowdon with Vespa, this year he is planning to run the Rob Burrows' Leeds marathon and do some challenging endurance walks.

To watch or read Ian and Rachael's full account go to: <u>lan's and Rachael's story</u>

The HMViP Group is made up of a multi-disciplinary team, representing HMV centres across the UK, with a wealth of knowledge and practical experience in this field. It includes respiratory consultants, clinical nurse specialists, clinical academics, specialist respiratory physiotherapists, as well as patients and carers.

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For further information and access to spokespeople and patient stories, please contact:

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**About HMV** 

HMV (Home Mechanical Ventilation) provides a way of supporting a patient's breathing outside of a hospital setting. The intention of the treatment is to improve quality of life, relieve symptoms, reduce risk of hospitalisation and improve survival rates.

HMV is delivered via a machine, attached to a hose, connected to a firm-fitting mask, covering the nose and/or mouth or via a tube in the neck (tracheostomy). Machines deliver a steady stream of air, either at set pressures or variable pressures, to deliver a pre-decided volume, or a combination of both.

## **About HMViP Group**

Our mission is to create fair and equitable access to a care agenda led by patients. We shall champion evidence-based approaches for HMV to encourage adoption in centres not currently providing this service. Furthermore, we shall support and represent patients and their family carers with improved patient education, to empower patients to obtain the correct (and best) treatment.

## https://hmvip.co.uk/

## **HMViP Group members:**

- Alison Armstrong, Consultant Nurse, Newcastle upon Tyne NHS Foundation Trust. (Chair)
- Katy Buchan, Home NIV Lead/Senior Respiratory Physiotherapist, Bristol University Hospitals Bristol and Weston NHS Foundation Trust (Committee).
- Lisa Emmett, Specialist Respiratory Physiotherapist, Leeds Teaching Hospitals NHS Trust (Committee)
- Patrick Murphy, Clinical Lead, Lane Fox Respiratory Unit, Guy's and St Thomas' Foundation Trust
- Louise Rose, Professor of Critical Care Nursing and Research Division Head, Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, King's College London.
- Ben Messer, Consultant, Newcastle upon Tyne Hospitals NHS Foundation Trust
- Rebecca D'Cruz, Consultant, Lane Fox Unit, Guy's and St Thomas's NHS Foundation
   Trust
- Naveed Mustfa, Consultant, Royal Stoke University Hospital
- Joanna Shakespeare, Consultant Clinical Scientist, University Hospitals Coventry and Warwickshire
- Alex Long, Clinical Lead Physiotherapist, St Bartholomew's Hospital, London
- Chris Stevenson, Former GP and Patient
- Fleur Perry, member of Pathfinders Neuromuscular Alliance and patient
- Julie Ward, Nursey Nurse and Former Carer
- Gillian Gibbons, Secretariat