THE TIMES | Monday December 26 2022

News

Hope at last for baby who can't breathe while asleep

Hugo Daniel

Stephanie Roberts and James Oakley with Casper, whose condition is so rare there are fewer than 100 cases in Britain

Keep Me Breathing

End Goal for 2028 (but with implementable improvements along the way):

A totally implantable biofeedback diaphragm pacer system that will be capable of sensing the patient's ventilatory needs and automatically adjust ventilatory demands of the patient. [1.]

Fusing Science and Entrepreneusrship

1. DIAPHRAGMATIC PACING IN INFANTS AND CHILDREN WITH CONGENITAL CENTRAL HYPOVENTILATION SYNDROME. ANTHONY C. CHIN , DONALD B. SHAUL , PALLAVI P. PATWARI , THOMAS G. KEENS , ANNA S. KENNY , AND DEBRA E. WEESE-MAYER

KEEPMEBREATHING.COM

KMB - Why We live and Breathe CCHS Every. Single. Day

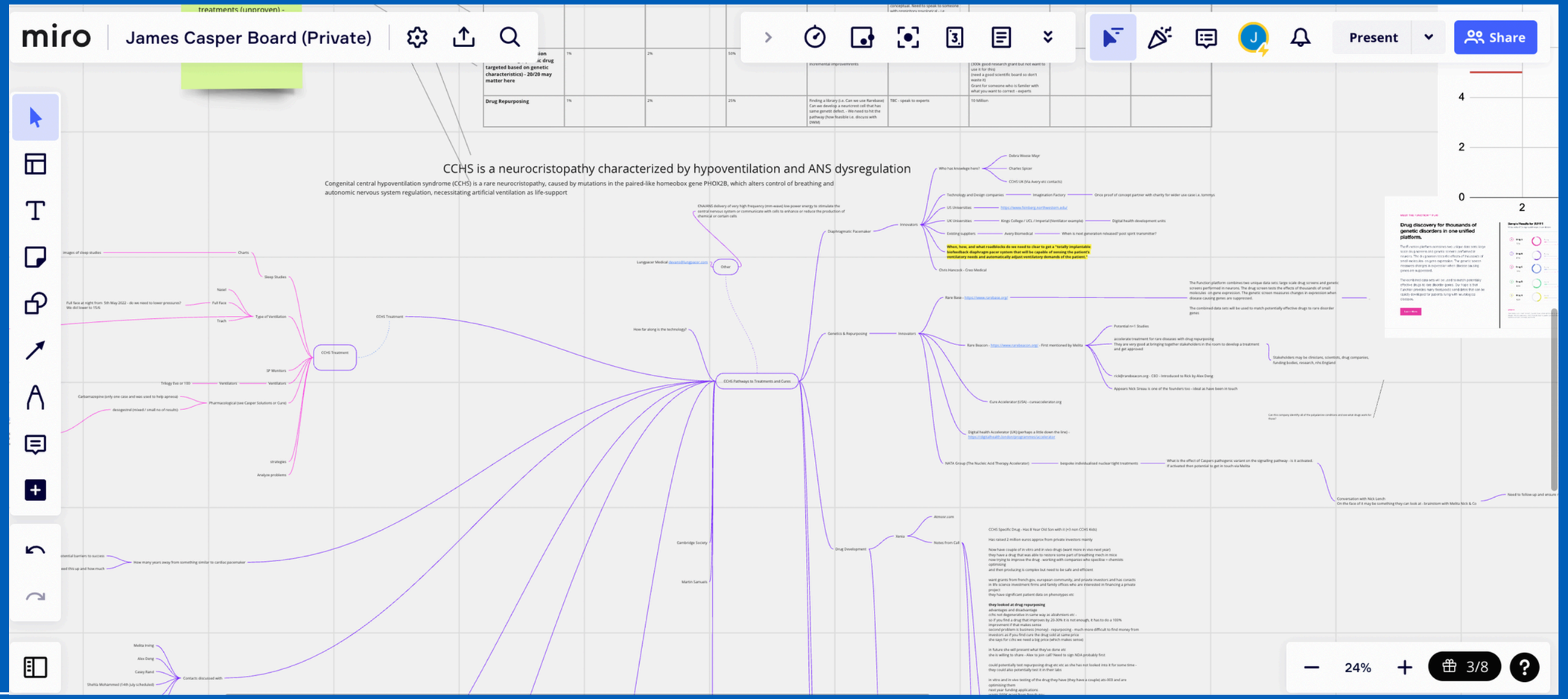
On 2nd December 2021, Casper Oakley Roberts was born. On the 1st September 2022, 273 days and 5 hospitals later he finally came home.

We were told in June 2021 to prepare to go home and have Casper on a ventilator for the rest of his

We requested a meeting with a geneticist who thought he was there to explain the diagnosis ... but actually we wanted to know how to cure a disease that has no cure!

He helped us set in motion everything we've done to this day

5 Month Journey to see where we could make the difference in under 5 years with our resources



April 2024

How hard is it to build a treatment that gives people with a very rare disease, a normal life. For them and their families.

Pretty Damm Hard.

But...

Is it as difficult as achieving a precise landing with a spacecraft on a comet 310 Million miles away?

“Rosetta is one of the most challenging missions ever undertaken so far. No-one before attempted a similar mission, unique for its scientific implications as well as for its complex and spectacular interplanetary space maneuvres.”

Professor David Southwood, European Space Agency’s Director of Science

As difficult as developing a treatment for a disease at least twice as rare as CCHS?

Complete mitigation, Complete Symptom Control, Complete Prevention of Disease Progression

1 in every 250,000-1 million babies are born with alkaptonuria (Black Bone Disease)

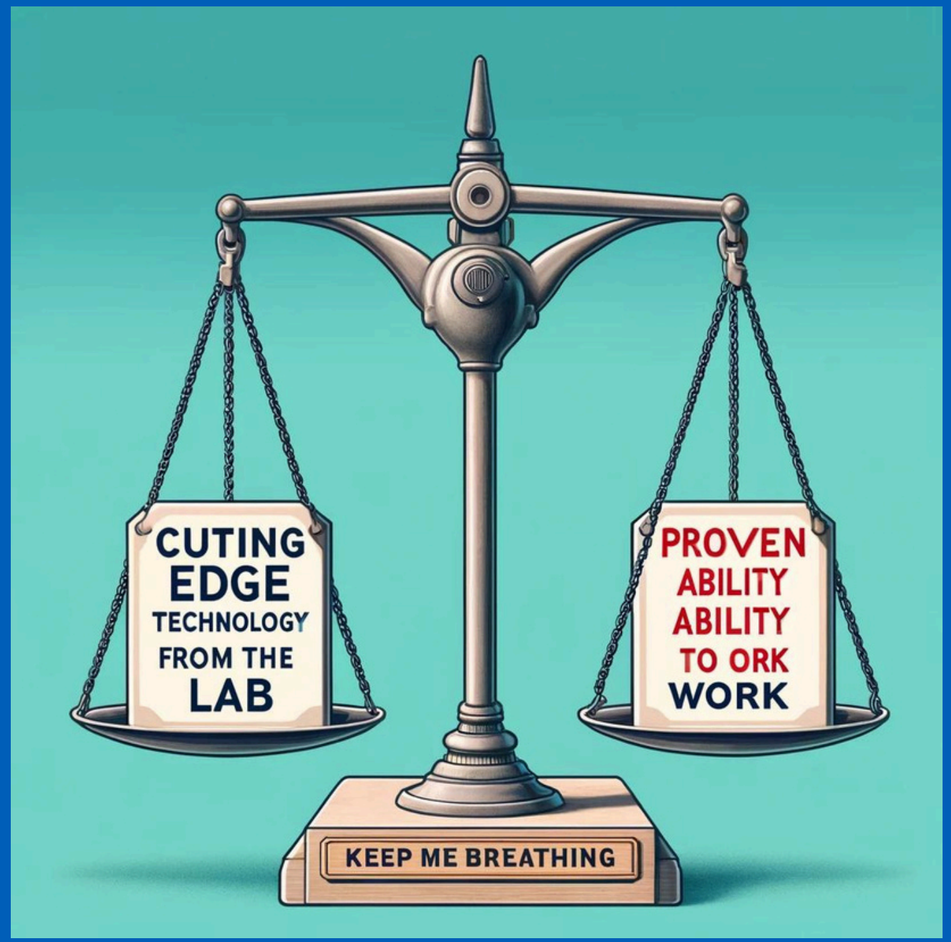
We’re not sure of the answer yet but we have the right people on the team to challenge us. And quickly (by Rare Disease Standards!)

+

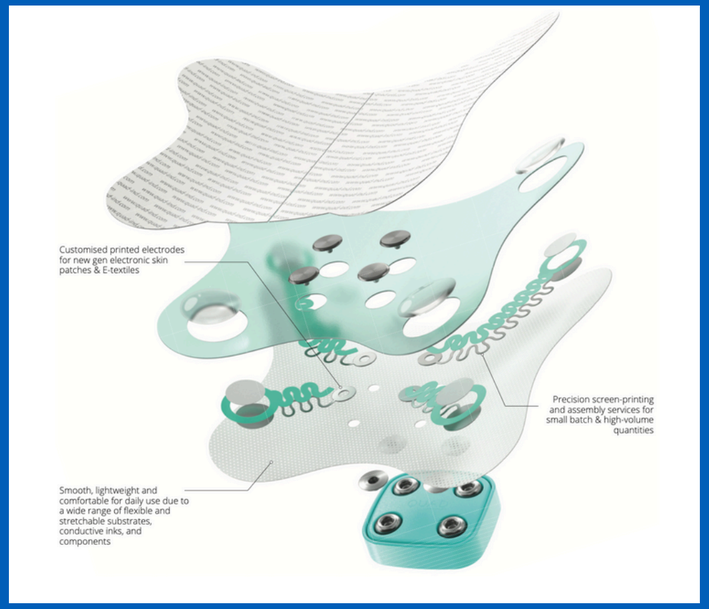
CCHS NETWORK

FAMILY • FOUNDATION • SCIENCE

Striking the right balance



Striking the right balance



Our newest development: Hydrogel-free electrode patch

Quad Industries develops customised carbon enhanced adhesive electrodes that make an excellent alternative for hydrogel-based wearable patches.

There are plural benefits using this hydrogel-free technology platform:

- The patch's inability to dry out enhances its shelf life and opens up more options for packaging and storage.
- Our straightforward manufacturing process offers cost-effective patch customization.
- The stick-to-skin patches are AAMI EC12 compliant, and all materials are approved in 510(k) and CE marked finished good medical devices.

Due to its low impedance, signal quality remains uncompromised when compared to hydrogel patches.

Our wearable sensors, medically certified for use in various applications like sleep apnea, ECG monitoring, anesthesia monitoring, and stimulation, open the door to new possibilities. Developers exploring hydrogel solutions at first glance should also consider the numerous advantages of the hydrogel-free electrode.

Building a constortium

Germany

(UK)

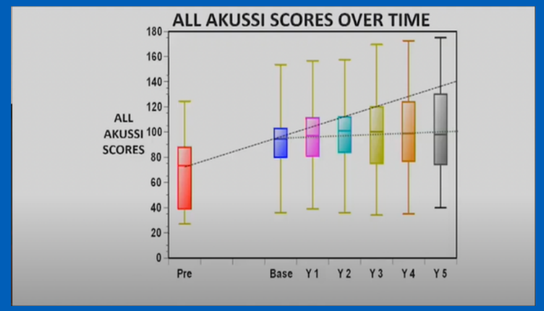
Materials and technology

Building relationships with Clinical professionals and sites

(UK)

(EU)

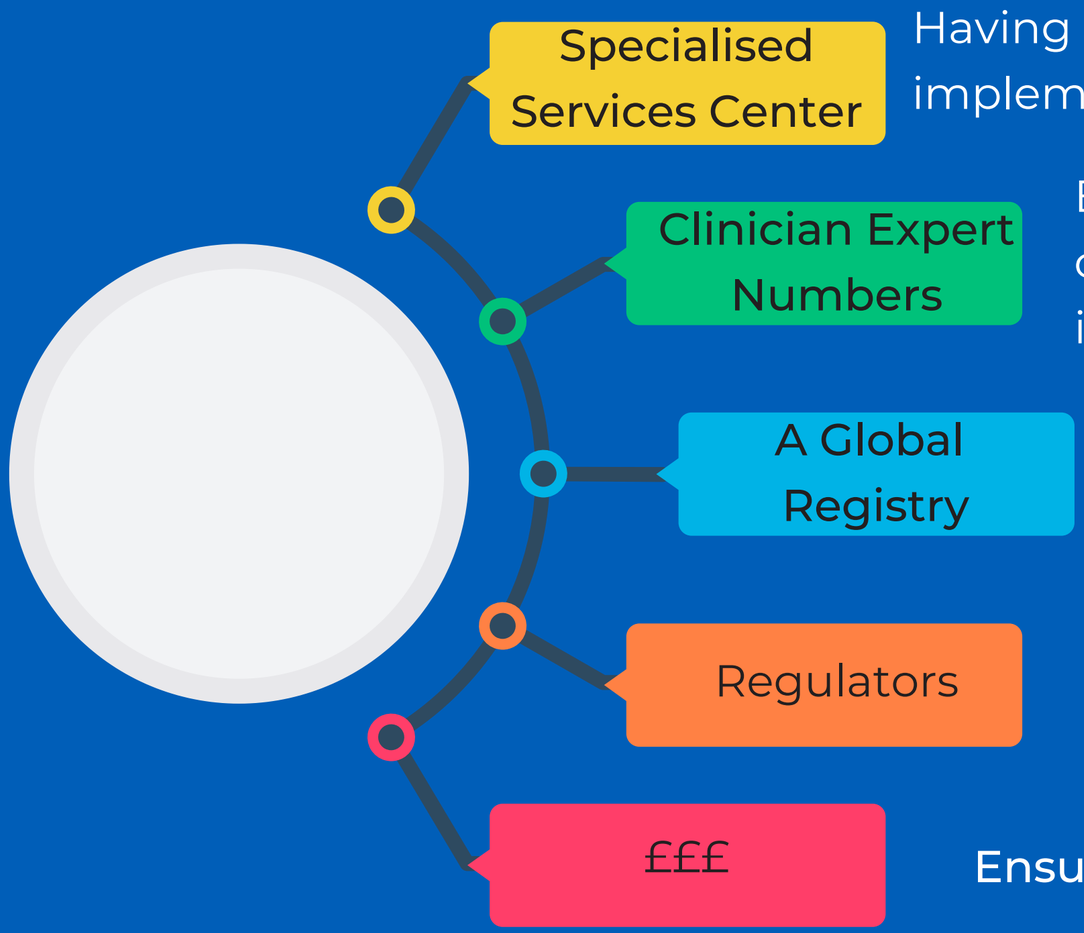
Regulatory and monitoring



Analysis - and Global Study in a Box (defined sensors, cloud interface, patient monitoring)

We need global Cooperation!

Potential Roadblocks



Having an expert Multi Disciplinary team capable of implementing and managing transitioning patients

Ensuring legacy of CCHS clinicians, clinicians with the confidence and expertise to implement advances in treatment

Collaboration, data pooling, anonymised surveillance of different mutation types

Time, cost -MDSAP QMS that meets UK, EU and FDA

Ensuring we have access

Why are we confident of achieving something game changing by 2028

We are building while trying to foresee, and fix in advance, the major roadblocks

Listening to the CCHS Experts and Experts who have delivered life changing solutions for patients

Technology, R&D

Proven operators with a track record of innovation and clearance of class 2B & Class 3 devices in UK, EU & US

Regulatory

Having an experienced regulatory and quality management team who have worked with UK, EU, FDA

Service Center and Clinicians

Building strong relationships with clinicians and hospitals. Benefits i.e. fewer hospital hours, Improved patient pathways ▸ QALY (Quality Adjusted Life Years)

Next Steps on The Breathing Pacemaker

- Device Development
- Bench Testing
- Accelerated Aging
- Specialised services centre planning & funding
- Treatment data center
- Pre-clinical studies

"I have been leading a team of 6 Cambridge researchers to provide Strategic and Technical Consultancy advice to this amazing charity, Keep Me Breathing...

The technology already exists. It's tying in different innovations from other diseases and bringing that to CCHS and then developing a technology that's directly applicable to that disease"

Akaash Kumar, Biochemical Engineer, The Times Newspaper

Thank you

Keep Me Breathing

Thank you’s - Too many

KEEPMEBREATHING.COM

A Registered Charity Run Like A Tech Start Up

Fusing Science and Entrepreneusrship