

# COBMS Newsletter

## COBMS wins inaugural PPI Ignite Award for Patient Involvement



Last week, PPI Ignite (you can learn more about them in an article later in the newsletter) let us know this trial is an example of excellence in Patient Involvement.

On their web page, you can read more about what we have done in this study to include the Patient Voice. The MS Society of Ireland was consulted at the start of this trial on its suitability for people living with MS. This involvement ensured patients are on the Trial Steering Committee (the Board of Directors), there is a Patient Advisory Panel available for any queries the management of the trial has on how the study is conducted, and there is an assistant Researcher who has MS. People who have this disease are part of every decision, ensuring everything done in the trial is suitable for the Participants.

An example of how this involvement has led to changes, is how the therapy is delivered, which was substantial due to the Pandemic. We used the excellent experience of the MS Society in how they transitioned from face-to-face physiotherapy sessions to a completely online version. This method was then amended by the Patient Advisory Panel to make it more suitable for this study.

1

### TRIAL STATUS

The study has started the treatment phase. This will continue for several months

2

### LEARN MORE

If you want to know more about the COVID-19 vaccine click [here](#)

3

### INTERESTING FACT

Robert is hosting a Progressive MS webinar series with MS Ireland. Register [here](#)

Learn more about clinical trials



IPPOSI have developed a website which will teach you more about what is meant by a 'clinical trial' [here](#). It has content suitable for all ages.

### PPI Ignite Seminar



On April 28 PPI Ignite is hosting the 6th National Public & Patient Involvement in Research conference (Register [here](#))

## Interview - Robert Joyce

### Patient Representative on the Trial

Robert is a Research Assistant in the COB-MS study. He has Secondary Progressive Multiple Sclerosis and shares his experience with the team to improve the quality of the research.

#### Where are you from?

I was born in Galway.

#### What is your specialty, and why did you choose it?

My early life focus was small businesses, either owning them or helping others achieve their goals. Now my MS and other illnesses have changed my focus, highlighting Patient Advocacy.

#### Is there something you do which nobody would realise?

Sometimes I like to draw, creating something from nothing.

#### What is your favourite book/film?

The Lord of the Rings has been a favourite since I first read the books as a teenager. I've read the books and watched the movies several times, and it still makes an impact.



Is there something you would love to do/see, and why?

Just like my colleague Fionnuala, I really love travel - experiencing new cultures,

and ways of living. I would love to visit Asia and experience these ancient civilisations, plus I love the food.

## PPI Ignite

NUIG is leading Patient Involvement in Ireland

**“With NUI Galway as lead, the PPI Ignite network is being established to put the public and the patient at the centre of health and social care research”**

NUI Galway is to lead a new network of universities to champion public and patient involvement in health and social care research.

## COB-MS PRESENTS 5 POSITIVE OUTCOMES OF PPI

Recently Dr Sinéad Hynes (the Principal Investigator of the COM-MS Trial) and Robert Joyce (Assistant Researcher living with MS) presented to the Public Health and Health Service Research seminar series on the positive aspects of Patient Involvement

The video of the presentation can be viewed [here](#). It is about 30 minutes long. It shares how recruitment was improved, how materials can be better designed to suit people with MS and how an overall emphasis on Collaboration is having direct, positive effects on the study.

The Health Research Board, in conjunction with the Irish Research Council, announced the development of the new Public and Patient Involvement (PPI) Ignite Network across seven universities and 10 partner organisations, some of which represent patients.

With NUI Galway as lead, the PPI Ignite network is being established to put the public and the patient at the centre of health and social care research.

It aims to ensure that the next generation of graduates is familiar with Public and Patient Involvement (PPI) and know how to incorporate it into their research.

In the partnership, patients and members of the public will have the opportunity to work with research teams to decide what issues are important to focus on and how best to carry out research.

A key goal will be to ensure that the voices of marginalised and disadvantaged groups are heard.

The new network is being headed up by Professor Sean Dinneen, of the School of Medicine at NUI Galway, and Edel Murphy, who is based in the Institute for Lifecourse and Society in the University.

“The National PPI Network is a great opportunity for Irish universities to work together to re-imagine what health and social care research is all about and to involve our local communities as genuine partners in the research effort,” Professor Dinneen said.

“Rather than adding a tokenistic patient voice to our research we have to take time to form, nurture and engage with a diverse group of individuals from our local community who can provide an authentic public and patient perspective on our research.”

An online hub is to be set up with the aim of connecting patients and members of the public who are interested in being involved

## **The COB-MS Team**

### **Principal Investigator**

Dr Sinéad Hynes

### **Post Doctoral Researcher**

Dr Christopher Dwyer

### **Assistant Researchers**

Eimear Bane

Robert Joyce

Anusha Moses

Fionnuala Rogers

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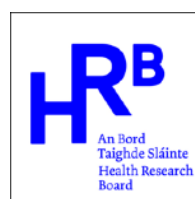
**Address:** Áras Moyola  
NUIG, Galway, Co. Galway

with research communities who are seeking PPI partners.

The network will also deliver training in PPI to researchers, the public, patients, community organisations, policy-makers and research funders.

Members of the public and patients with an interest in finding out more about Public and Patient Involvement can contact [ppi@nuigalway.ie](mailto:ppi@nuigalway.ie)

### **Sponsor**



### **Collaborators**

