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REMOVING ISOLATION FROM YOUNG PEOPLE WITH ME

No Isolation for ME

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With myalgic encephalomyelitis (ME), one of the most insidious consequences of this devastating and disabling disease that affects patients can be the isolation experienced.

This is especially true for younger patients and the consequences of this can extend far into adulthood and beyond and lead to unnecessary departure from society. Already, due to the consequences of a lack of a sensible and standardised pathway to care, patients are stigmatised and excluded from society. This need not be so and much could be done to avoid this by tackling this issue early on for young children affected by ME.

Earlier this year Invest in ME Research was contacted by a Norwegian company who were interested in demonstrating a product that was aimed at reducing the isolation experienced by many younger people who were unable to attend school, or were cut-off from social contact due to illness. Obviously, the charity immediately saw the parallels with ME and the possibility of raising awareness of one of the least publicised side effects of this disease on patients, and their families.

Our immediate reaction was how we can help use this to publicise awareness of the effects of ME on children. We then invited the company – **No Isolation** – to take a table at our 12th International ME Conference in London (IIMEC12) and offered to work further to support this campaign.

The charity felt this to be a worthwhile cause that could help alleviate some of the unnecessary suffering that careless or ignorant education systems inflict on sick children and their families.

The company's product - AV1 robot - helps children and youths with ME to continue to be connected to their peers at school despite not being present for all or some of the time due to illness.

The robot is now available in the UK and together, with No Isolation, we are hoping to set up trials.

Invest in ME Research will be contacting local education authorities to trial AV1.

Initially, a trial of three AV1 robots will be set up involving families who currently have a child with ME who is unable to attend school, or whose regular attendance is compromised by ME.

Children and youths with long-term illness such as ME do not need to be excluded from their friends' activities and progress and schools have a responsibility not to ignore them – something which can lead to long term discrimination.

The robot, called AV1, acts as the students' eyes, ears and voice in the classroom on days where they cannot be physically present. With AV1 the student controls the robot with an app on a tablet. When the student raises their hand, a light flashes on AV1's head. The robot can be turned 360 degrees, so the student can see the entire classroom and talk to other students. If the student does not feel like actively participating, they communicate it by turning on a blue light on AV1's head. AV1 is designed to withstand Childs play, and can join classmates in the playground or on after school visits.
AV1 is already helping ME-patients across Scandinavia, the Netherlands and UK.

Children and youths suffering from ME is the largest user group – a salient point and one that ought to be a red flag for any education system.

Research fellow Jorun Børsting and senior lecturer Alma Leora Culén at the Institute for Informatics, University of Oslo, are researching the technology needs of ME-patients. Having studied the use of AV1 among nine children and youths suffering from ME they see a big advantage in the fact that the robot is designed with ME-patients in mind. Børsting stresses that the robot cannot fully replace normal attendance at school or home teaching, but act as a supplement.

We invite support for this campaign to help younger children – in the hope and knowledge that it could lead to fewer problems in the future for young people affected by ME.

> *"Of the children I followed several had not attended school in a long time when they first received the robot. Some had been out of school for over six months. After they received AV1, all of them participated regularly, on their own terms - Jorun Børsting, Research fellow and senior lecturer Alma Leora Culén at the Institute for Informatics, University of Oslo."*

Invest in ME Research will receive no financial reward for this campaign. The charity does it in order to highlight and overcome a major consequence of becoming ill with ME.

We invite support for this initiative by assisting us with contact to local schools and education authorities.

> *The advantage in participating in class through a tablet is that they have full control over sound levels, light and movement. In a normal classroom they do not have the option to control sensory inputs in this way. Furthermore, they can participate exactly when they feel like it, taking into account that symptoms can fluctuate over the course of the illness, even from hour to hour*

Invest in ME Research is a major UK charity which campaigns for biomedical research into ME and for proper education of healthcare staff and support for ME patients. The charity has been instrumental in initiating a UK Centre of Excellence for ME and there are now five PhD student positions involved in researching ME.

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If you would like more information about this topic, please contact Invest in ME Research at **02380 643736** or email at info@investinme.org.

If you would like to be one of the families' trialling AV1 and would be prepared to report back during the trial and work with us, No Isolation and the school/school authority then we would be very keen to hear from you.