

## Your Rheum Newsletter October 2020

### **What we've been up to**

Since our last newsletter in May, the Your Rheum group has been busy trying to keep young people actively involved in shaping research during a global pandemic. Due to the ongoing lockdown restrictions across the country, we have been unable to facilitate face-to-face meetings and have instead, been hosting virtual zoom meetings! Our first meeting was just an initial introduction, as many of the young people had never “met” Frances, and to see if zoom was a viable option for future use. It thankfully was and we have had 3 meetings so far, which have been a huge success, with an average turnout of 8 young people from across the UK per meeting! The meetings usually last around an hour and a half. We designate time for 1-2 research projects (30 mins each) and also time for discussion. It is honestly fantastic to hear all your thoughts and feelings regarding the various research proposals. Our most recent meeting was centred on the “vocational readiness of young people with a long term health condition” and it was fundamental in identifying the key people and areas that researchers need to focus on in order to improve things in the future! We also started with a fun activity where, using Mentimeter, we asked the young people to write down “What did the 10 year old YOU want to be when they grew up?” and the results were unexpected, but also lovely to see:

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What did the 10 yr old You want to be when  
they grew up?

Mentimeter

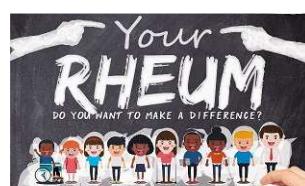
astronaut teacher  
archaeologist  
marine biologist  
**fashion designer**  
policewoman a tennis player  
race car driver  
chef

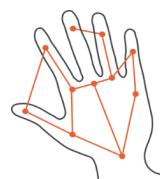


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### **Get involved**

Our next zoom meeting is provisionally planned for early November so get in touch if you would like to join us. All you have to be is between 11 and 24 years old, living with a rheumatic condition and be interested in voicing your opinion to help shape future research projects. If you would like to join the next meeting, email: [your.rheum@manchester.ac.uk](mailto:your.rheum@manchester.ac.uk) and one of our lovely team will send you the zoom invite once a date is set! If you would be interested in joining the group, please send us an email ([your.rheum@manchester.ac.uk](mailto:your.rheum@manchester.ac.uk)) and one of our team will send over the membership documents! We would be particularly interested to hear from you if you would like to help in creating 2 short videos to help with recruitment to Your Rheum and to explain to young people what research is. More of this particular activity in future newsletters.





## *The LUNA Project*

One of our lovely Your Rheum members, Beth, has co-founded this exciting new charity and is currently a trustee and provided this piece for this month's newsletter:

The LUNA (Learning to Understand Needs and Abilities) Project is a small charity that aims to improve the awareness of young people living with long term health conditions and the support that they receive, particularly from peers. It stemmed from the realisation that many young people struggled to talk to their friends about their health or that often they felt that peers didn't understand. The group is run entirely by young people, with people participating and volunteering from across the country, many with personal connections to the issues that the LUNA Project deals with.

To try and raise awareness and support young people the LUNA Project runs a number of projects. The LUNA Project runs workshops in schools and youth groups with all ages, which involve interactive tasks that are designed to promote empathy, communication and introduce children to the topic of disability in young people. We also run a blog and create resources with current projects including

- The 'Me and My Friends to You and Yours' series in which different young people explain how their condition affects them physically and emotionally and what friends can do to help, often with a friends perspective running alongside. We currently have over twenty entries in this project and are always looking for more contributions.
- Resources around transition between services and managing appointments how to communicate effectively with your doctor. This is a new project for which we are actively looking for both young people and health professionals to get involved with.
- Online learning resources. In response to COVID-19 making visitors in schools challenging we have begun to create 'online learning' tasks for a variety of ages that hopefully address some of the same topics as in our workshops. These have only been limitedly reviewed unlike our face to face workshops so any feedback would greatly appreciated.

You can find out more and access online learning materials and other resources at <http://www.thelunaproject.org.uk/> . If you are a young person and wish to get involved you can email: [thelunaprojectuk@gmail.com](mailto:thelunaprojectuk@gmail.com)

## *Keep up to date*

To keep up with our activities, read our blog posts and to find out about new opportunities, go to <https://yourrheum.org/> or follow us on twitter @yourrheum

